Shonali Choudhury
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Mellissa Withers *Editors*

Global Perspectives on Women's Sexual and Reproductive Health Across the Lifecourse

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Foreword

This volume comes at an opportune time, bringing together the right mix of issues and perspectives that, if given proper attention, could truly make a difference to the sexual and reproductive health of women across the globe. The countries of the world are at very different stages in their efforts to improve women's sexual and reproductive health. Some have decades of experience, while others are only just beginning to put the mechanisms in place to strengthen such efforts. That said, similar challenges have long existed in resource-rich and resource-poor countries alike. The extent to which the health services that are made available are actually responsive to what women need is of course of paramount concern. There is also a host of distinct but related challenges posed to women of all ages, and in all parts of the world, ranging from inhospitable legal environments to family and community structures which conspire to ensure that true sexual and reproductive health—a state of complete physical, mental, and social well-being—is still not fully attainable. As is made clear in this volume, these challenges must all be addressed. To that end, in all places even incremental changes in policy, processes, and systems can lead to big-picture changes with positive and lasting effects. This is as true in places with a long history of doing the right thing as in places where such efforts are only just beginning. In this context, it is worth remembering that all nations have made legal and political commitments to protect the health of all people, including their sexual and reproductive health, through the application of human right norms and standards.

A particular feature of a human rights orientation is the explicit attention it requires to the participation of affected people and/or communities. A rights-based approach to sexual and reproductive health has to enable all people, especially those from vulnerable and disadvantaged groups, to exercise their rights to information and services free of discrimination, coercion, and violence. Who is vulnerable or disadvantaged clearly will vary between countries and within countries, but explicitly bringing human rights norms and standards into research and into programming can assure not only that human rights concerns are explicitly assessed and addressed but that better health outcomes are achieved. Human rights may be brought into both programming and monitoring of sexual and reproductive health efforts with a wide range of primary concerns: to improve the delivery of services; to reduce inequalities in access and use of services by certain populations; to identify any violations that may be occurring because of program design and/or implementation; to directly impact health outcomes; or to orient a program to bring attention to broader human rights issues that may impact the populations being addressed by the program. Human rights norms and standards have implications for programming, for monitoring mechanisms employed, for data collection, for disaggregation—the list goes on. There are today many large- and small-scale processes occurring within countries and at the global level to engage and monitor human rights within the context of sexual and reproductive health programming, but they remain inadequately documented, reported, funded, or replicated. Even with the best of intent, health information systems and other relevant mechanisms are largely inadequate to report data from population subgroups—let alone describe the extent to which human rights formed part of how an intervention was put in place or implemented, or whether the extent to which human rights were promoted or violated in the intervention contributed to the health outcomes of concern or to human rights realization more generally.

Whether the action taken is big or small, the strength, capacity, and commitment of governments are of prime importance, including their convening and coordinating role to engage national stakeholders. The engagement of civil society is key as well, not only to name the issues of concern but also for the capacity and ability to organize. Although the strength of civil society varies greatly between countries, civil society institutions are critical to attaining visibility and a platform from which to engage in everything from advocacy to the delivery of services in ways that speak most clearly to the women who need them. Getting the right interventions right, including getting the right combination of people actively engaged and energized, is central to supporting the sexual and reproductive health of women everywhere and throughout their lives. A purposeful mix of key stakeholders is important for continuity, visibility, and building relationships, and ultimately useful for simultaneously engaging bottom-up and top-down approaches—as each type of stakeholder has access to and credibility in different national, regional, and international spaces.

In recent years, although it remains insufficient, support for the sexual and reproductive health and rights of women across the globe has been unprecedented. This book is of crucial importance, sharing the work of academic and practice-oriented experts who are advancing theory, empirical research, and interventions for and with women around the globe. It is my strong belief that what exists must be supported and sustained, but with a watchful eye towards global, regional, and national political realities. The fact that the subject of women's sexual and reproductive health is in and of itself deeply political—and politicized—affects how such work is best advanced. Even in the best of times and with the most sensitive and appropriate approaches, setbacks are inevitable as political momentum shifts. Of particular concern to women's sexual and reproductive health in all parts of the world, however, are the retrogressive shifts in the larger global political economy occurring in the last few years. The recent election in the United States of America only adds to this concern, bringing into question the survival of relevant US government-funded family planning programs in the USA and outside. As the implications for the continuing support of national governments to women's sexual and reproductive health are unknown, so too are the potential impacts—not only for the institutions engaged in relevant service delivery and advocacy, but also for the lives of women and girls more generally.

There is a very real concern that the field of sexual and reproductive health, as tenuous as gains have been, will substantively regress, something as true within the borders of the USA as outside. More constrained national spaces, let alone the larger geopolitical space, may lead (either deliberately or inadvertently) to reductionist approaches to sexual and reproductive health. Truly important issues, many of which are discussed in this book, will be dropped or de-emphasized, alongside a loss of attention and support for ensuring the sexual and reproductive health of the most difficult to reach and most marginalized populations in each of our societies. There is a very real risk that sexual and reproductive health will be reduced to simply ensuring that X many millions of women and girls use contraceptives, without a strong focus on free and informed choice and all of the various aspects of our sexual and reproductive health and rights that are necessary not only for services to work but for us to fully live our lives. We may end up back where we were decades ago with target-driven programs that will reduce choice and restrict rights—with almost no attention to understanding *the specifics of the populations who most need contraception and other sexual and reproductive services* nor *what it takes to support people's ability to use them*. Contraceptive services are clearly necessary but not sufficient to reduce the unmet need for family planning and for sexual and reproductive health services more broadly. As stated in 1994 by the governments of the world in the International Conference on Population and Development Program of Action, and recognized in research and policy and programmatic efforts many times since, contraception is most effectively delivered as a key element of a package of mutually reinforcing sexual and reproductive health services which includes attention to human rights.

We need vigilance to ensure that political winds do not take us backwards into something vague, undefined, and ultimately harmful to women's lives. It is precisely at the intersection of human rights and the public health evidence brought together here, and with the support of key stakeholders, that we can build the inclusive and collaborative intellectual and political leadership needed to ensure that the sexual and reproductive health of women of all ages will be fulfilled without discrimination.

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Preface

Global Perspectives on Women's Sexual and Reproductive Health Across the Lifecourse was conceived by Shonali M. Choudhury, Ph.D., a women's health scholar and advocate. Shonali believed passionately in women's rights, and she championed research and practice that centers the experiences of marginalized women. When she conceptualized this compiled volume of work, Shonali was a faculty member in the School of Nursing and Health Studies at the University of Miami. She had already completed a qualitative study of establishment-based female sex workers in Tijuana, Mexico, and was beginning new collaborations in Miami to better understand Latina women and HIV. She envisioned this book as a way of bringing together diverse, global perspectives on current issues in sexual and reproductive health. She felt strongly that the book should give voice to women whose perspectives and experiences are often discounted or ignored: young women, old women, those who seek abortion, and survivors of violence, among others. Shonali also wanted to highlight the work of new investigators, who are rising in the field of sexual and reproductive health and have new insights to share.

At the age of 31, Shonali was diagnosed with a brain tumor. Over the next three years, Shonali would work, struggle, and resist. With the unparalleled support of her parents, Parimal Choudhury and Barbara Southard Choudhury, she worked through surgeries, chemotherapy, and radiation—teaching, writing, planning projects, designing data collection, dictating manuscript edits. Shonali continued to pour herself into her work as she was fighting for her own survival because she saw women all over the globe, of all ages, engaging in their own fights for survival and she wanted to tell their stories and better their lives.

The three of us—Shonali, Jennifer, and Mellissa—first met as graduate students in Public Health at the University of California, Los Angeles. Our experiences in the Department of Community Health Sciences shaped our shared values and goals, and helped us to forge warm personal and professional ties. So when Shonali's health was declining and it became clear that adding co-editors would ensure that the book would come to fruition, she turned to us. The book was still in its initial stages of planning, with several chapters solicited, and some edited, but no publisher. Motivated by friendship, intersecting professional interests, and the weight of

Shonali's legacy, Jennifer and Mellissa have brought the book to its completion. We share Shonali's passion and hope. We believe that the interventions and research presented here can help to shape the next generation of advocates, healthcare providers, and researchers striving to improve quality and equity in women's sexual and reproductive health.

The Importance of the Lifecourse Perspective in Sexual and Reproductive Health

This book emphasizes a lifecourse perspective in understanding women's sexual and reproductive health. This perspective takes into account critical periods in a woman's development and recognizes that experiences are shaped by the wider social, economic, and cultural contexts in which they take place. It also emphasizes that present experiences are shaped by the past and will, in turn, affect future experiences. While this perspective stresses the importance of all ages and stages of life, it allows us to consider the long-term consequences of both biological and sociocultural experiences that take place early in women's lives. For example, several chapters in this book highlight the pervasiveness of gender-based violence and demonstrate that victimization of girls and women often begins very early. Because gender norms and beliefs are so deeply rooted in many societies, many forms of violence against women can be perceived as normal or even sanctioned by society, thereby going unrecognized. This book brings attention to the multitude of harmful gender norms and vulnerabilities that affect women at different stages in their lives, including early marriage, unwanted or mistimed pregnancies, sexually transmitted infections, economic disempowerment, and physical and sexual abuse. It also recognizes the ways in which women in a variety of contexts resist, survive, and overcome.

As shown in this book, gender inequities affect girls and women at every stage of their lives, placing them at a disadvantage to boys and men, and often influencing their life trajectories. Although women may experience heightened vulnerability for exploitation or violence during key milestones in their lives, such as sexual debut, marriage, or pregnancy, we should not examine each milestone in isolation. Rather, we wish to acknowledge the importance of considering the intersection of biological, sociocultural, and behavioral factors that influence women's health status and how these may accumulate over a woman's lifetime, shaping health outcomes over the long term.

In taking a lifecourse perspective, we also reject the emphasis that is often placed on women (and women's health research) solely in terms of reproductive capabilities. This limited perspective minimizes the experiences of older women, as well as women who choose not to have children. In addition to looking at women at all stages of life, in this book we examine a range of sexual and reproductive health experiences, not only marriage, contraception, and childbearing, but also sexual pleasure and sexual partnerships, health issues not directly related to reproduction.

Finally, in this book we hope to highlight the opportunities to improve women's sexual and reproductive health and to achieve socioeconomic and racial/ethnic equity at various points in women's life courses. We should aspire to the best possible health outcomes at every age and must examine how to best support women to achieve this. Improving sexual and reproductive health for all women will require a close examination of the opportunities and challenges for change across the lifecourse—for individual women and for the institutions with which women interact beginning even prior to their birth.

Women's achievement of optimal sexual and reproductive health rests on the realization of a wide range of human rights. Women must have the freedom and autonomy to make decisions throughout their lives, whether choosing a marital partner, determining if and when to have children, or deciding to work outside the home. Women across the world are denied the ability to exercise these rights on a daily basis. We subscribe to the notion of sexual and reproductive rights as fundamental to women's health, well-being, and participation in society. Ensuring women's sexual and reproductive rights across the lifecourse must be at the forefront of our efforts to improve the health of women across the globe.

Organization of This Volume

The book is organized into five parts, each with its own substantive focus. The book begins with a part on childhood and emerging adulthood. The chapter by Anita Raj and colleagues lays a foundation for understanding the risks and challenges of child marriage for girls and women. Next, Marie Brault and colleagues examine the role of individual agency in delaying marriage and first pregnancy in India. Eunice Muthengi and Karen Austrian present an integrated, multisectoral model to prevent child marriage and early childbearing in Kenya. The last chapter in this part, by Brittany Chambers and Jennifer Toller Erausquin, focuses on the US setting and the stigma surrounding teenage motherhood.

The second part of the book focuses on childbearing, with three chapters touching on different topics. The chapter by Kara Francisco and Morgan Sanchez examines the perceived autonomy of black women in the USA in choosing vaginal births after previous cesarean sections. The chapter by Charlotte Warren and colleagues relates the experiences of women living with obstetric fistula in Kenya. Finally, Aparajita Gogoi and colleagues explore access to and quality of maternal health care in India through an innovative mobile phone program.

The third part explores reproductive control: fertility, contraception, and abortion. Mellissa Withers and colleagues examine cultural influences on fertility preferences in Bali, Indonesia. Then, the chapter by Deborah Mindry and colleagues presents strategies to promote safer contraception among HIV-positive women in sub-Saharan Africa. The final two chapters of this part relate to abortion: Natalie Whaley and Jenn Brandt examine abortion in the USA through the lens of media (both mainstream and social media); Michele Eggers presents experiences of women in Chile, a context in which abortion is criminalized.

The next part focuses on violence against women and its role in sexual and reproductive health. In the first chapter in this part, Shonali Choudhury and colleagues use in-depth life history interviews to examine the intersections of individual agency, experiences of violence, and HIV risk among female sex workers in Tijuana, Mexico. Next, Jamila Stockman and Kristin K. Gundersen provide evidence for a continuum of sexual violence among Black women in the USA. Abigail Hatcher and colleagues present a conceptual framework for addressing intimate partner violence in pregnancy, used in the South African context. Then, Jennifer McCleary-Sills and colleagues examine the evidence surrounding violence against an understudied population: older women. In the last chapter of this part, Lillian Artz and colleagues present a criminal justice perspective on women's exposure to sexual violence across the lifecourse in South Africa.

The final part of the book addresses topics beyond reproduction. Elizabeth Reed and colleagues start off this part with a discussion of the promise of cash incentives for improving sexual and reproductive health, with a focus on HIV/STI prevention. Jennifer Toller Erausquin discusses HIV knowledge and behaviors across relationship types for women in the Dominican Republic and Haiti, indicating a potential need for better-targeted interventions. Next, Lwendo Moonzwe Davis presents evidence from a mixed-methods study conducted in Zambia to understand links between women's intimate relationships and their sexual and reproductive health. The next chapter in this part by Laura Pascoe examines the understanding and experience of sexual pleasure among heterosexual women of various racial, ethnic, socioeconomic, and religious backgrounds in Cape Town, South Africa. The following chapter by Megan Huchko describes the development of a promising cervical cancer prevention project in East Africa. Finally, Engida Yisma and Stephanie Ly examine the conceptualization of menopause across cultures.

Although our aim is to present a wide range of challenges relating to global women's sexual and reproductive health, this book does not provide a comprehensive analysis of all issues. A multitude of important topics were left out, including sex-selective practices that have led to gender ratio imbalances, and the importance of male engagement in sexual and reproductive health. In addition, several key populations were not included in the chapters selected for this book, including lesbian, bisexual, and transgender women; non-cisgender persons; indigenous women; and women in the Middle East. Although these topics and populations were beyond the scope of this book, we do not wish to diminish their importance. Meeting the needs of all women is a critical part of the advancement of sexual and reproductive health globally.

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Part I
Childhood and Emerging Adulthood

Chapter 1
Girl Child Marriage: A Persistent Global Women's Health and Human Rights Violation

Anita Raj, Emma Jackson, and Serena Dunham

Introduction

Child marriage, i.e., the formal marriage or informal union of an individual before they are age 18, affects approximately 900 million people worldwide (UNICEF, 2014). Although it can occur for both boys and girls, 82% of those married as minors are female (UNICEF 2014). While there has been a global decline in the practice over the past 30 years, this decline has been inadequate, particularly in South Asia and sub-Saharan Africa, where prevalence of child marriage remains above 30% (UNICEF 2014). The practice has been recognized as a global human rights violation under Article 16 of the 1948 United Nations Declarations of Human Rights, which states:

> "Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage during and its dissolution. Marriage shall be entered into only with free and full consent of the intending spouses. The family is natural and fundamental group unit of society and is entitled to protection by society (UN, 1948)."

However, despite long-standing global recognition of child marriage as a harmful practice, elimination of the practice has proven difficult. Internationally accepted standards for what constitutes the age of a child continue to vary by nation, and resistance against long-standing traditional practices, particularly in contexts of rural poverty and low rates of education, can be viewed as culturally insensitive or disrespectful. Nonetheless, due to substantial documentation of the disproportionate burden of child marriage on girls relative to boys (UNICEF, 2014) and the extensive evidence of the public health impact of child marriage, particularly on maternal and

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child health (Raj, 2010), global consensus on child marriage as a harmful practice has been achieved. In September 2015, the United Nations and its member states unanimously adopted the Sustainable Development Goals (SDG), an intergovernmental set of 17 aspirational goals toward health, peace, and justice, with 169 targets, one of which is to end child marriage by the year 2030 (SDG, 2016). Specifically under SDG5, "Achieve gender equality and empower all girls," Target 5.3 is to "eliminate all harmful practices, such as child, early and forced marriage and female genital mutilations" (SDG, 2016). While complete elimination of the practice within 15 years is a lofty goal, this elimination can have far-reaching consequences for improved health, safety, and well-being for women and girls, as well as families and communities, on a global scale. In this chapter, we outline data on prevalence and contexts of child marriage, its social and health impact, promising solutions to date, and implications for future work in this area.

Prevalence of Girl Child Marriage

Each year, approximately 14 million girls globally are married as minors (<age 18 years), which amounts to 39,000 girl child marriages each day (UNICEF and UNFPA, 2013). Approximately one-third of these child marriages occur with a bride less than 15 years of age (Vogelstein, 2013). While marriage of girls aged 15 years and under has demonstrated rapid declines in the past 20 years, marriage of 16–17-year-olds has not shown the same deceleration, particularly in South Asia and West and Central Africa, where some of the highest prevalence rates of child marriage persist (Raj, McDougal, & Rusch, 2012; UNICEF, 2014). Hence, the rate of decline in child marriages is grossly inadequate. Given the current trajectory of decline, we would still expect to see approximately 60 million adolescent wives in 2030 (UNICEF, 2014), which is a far cry from the aforementioned SDG 5.3 target of complete elimination of child marriages in 2030. Clearly an accelerated effort to impede child marriage is needed, and that acceleration must be targeted to those nations and groups disproportionately affected by the practice.

While child marriage prevalence has been measured in many countries and regions, some maintain markedly higher rates of the practice, as indicated in Fig. 1.1. Survey data that ask adult women to report the age at which they were first married indicate that the highest prevalence rates of child marriage by country are in sub-Saharan Africa, particularly in West and Central Africa, where 42% of 20–24-year-old females were married as minors (UNICEF, 2016). Niger has the highest prevalence of child marriage for women in this age group, with 76% reporting child marriage; closely followed by Central African Republic and Chad, where 68% of 20–24-year-old women were married as minors (UNICEF, 2016). Although child marriage prevalence is higher in many West and Central African nations, prevalence is still very high in South Asia (e.g., 52% and 47% prevalence among women aged 20–24 years in Bangladesh and India, respectively), a region that is also more populous. Consequently, two in five child brides reside in South Asia,

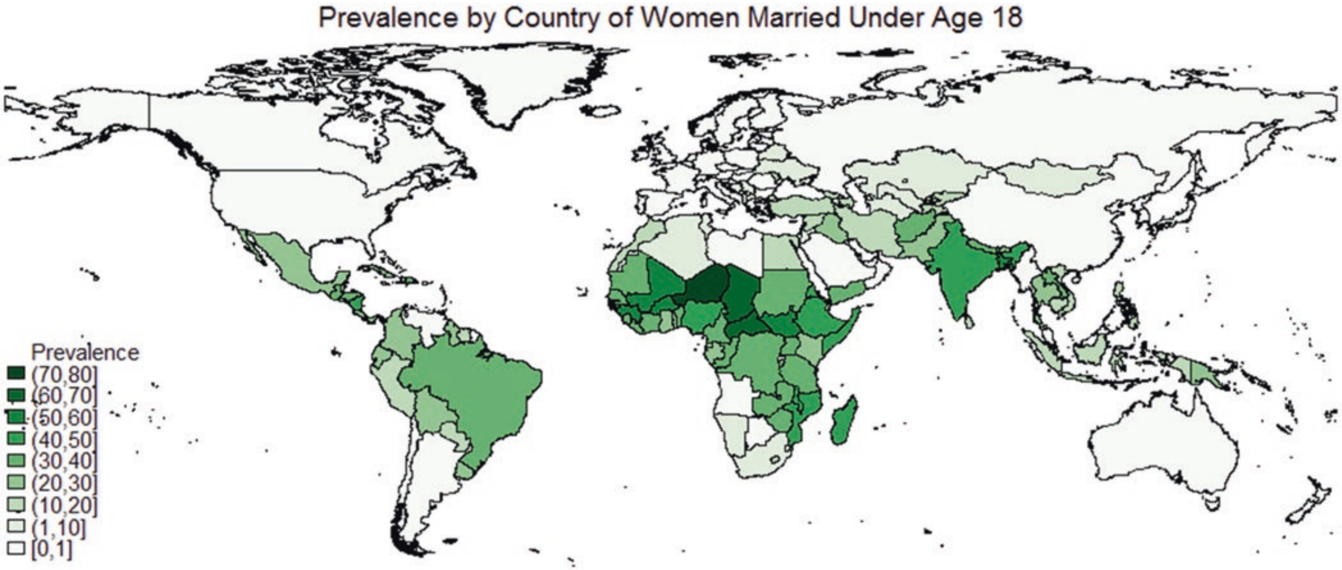

Fig. 1.1 Prevalence of child marriage (<18 years) among women aged 20–24 years by country (most recently available data). *Percentage of women aged 20 to 24 years who were first married or in union before age 18 (UNICEF, June 2016). See more at http://data.unicef.org/child-protection/child-marriage.html#sthash.U5G6H104.dpuf*

and one in three are in India alone (UNICEF, 2014). Child marriage prevalence for young women in Eastern and Southern Africa (36%), Latin America and the Caribbean (23%), and the Middle East and North Africa (18%) is not negligible, indicating the need for a global focus (UNICEF, 2016). Child marriage in North American and Europe has also been investigated with research indicating the harmful physical and mental health effects of the practice (Hotchkiss, Godha, Gage, & Cappa, 2016; McFarlane, Nava, Gilroy, & Maddoux, 2016).

Context of Girl Child Marriage

Across nations, socioeconomic indicators including lesser education, rural residence, and poverty are key factors associated with child marriage, suggesting the importance of development to curb the practice (Raj, 2010; Raj & Boehmer, 2013; UNICEF, 2014). Further reinforcing the roles of social inequities and development in the practice are findings documenting that risk for child marriage is exacerbated in cases of greater or sudden social, economic, or emotional deprivation, such as when there has been loss of a parent, national or regional conflict/insecurity, drought, or other natural disaster (Raj, 2010). However, global analysis also indicates that nations with higher gender inequality, as indicated by factors such as relatively higher male-to-female education ratio imbalance and higher rates of adolescent pregnancy, are more vulnerable to the practice, and in fact, the gender inequality index (GII) is a better predictor of child marriage than the human development index (HDI) is (Raj & Boehmer, 2013). GII is based on indicators of health (maternal mortality ratio and adolescent birth rates), empowerment (ratio of females to males in terms of parliamentary seats and receipt of any secondary education among adults 25 years and older), and economic status (ratio of females to males on labor force participation among those aged 15 years and older). HDI is based on mean years of schooling, expected years of schooling, life expectancy at birth, and gross national income per capita. These findings suggest that treatment and value of girls play a major role in the continuation of the practice of girl child marriage, across national contexts.

Girl child marriage has been identified by the global development sector as a harmful social practice rooted in gender inequities (SDG, 2016). Expectations related to marital age and gender roles and expectations within marriage are often culturally ingrained, and preference for girl child marriage can often stem from cultural norms and expectations for female subservience in marriage and sexual purity at marriage, both of which are believed to be better guaranteed by having a younger wife (Montazeri, Gharacheh, Mohammadi, Alaghband Rad, & Eftekhar Ardabili, 2016; Raj, 2010; Raj, Gomez, & Silverman, 2011). Girls married as minors are more likely to marry male partners ten or more years older than them, and these males are also more likely to have had more education and income generation opportunity, further creating a gender-based imbalance advantaging husbands over wives (Raj, 2010; Raj, Saggurti, Balaiah, & Silverman, 2009).

Marital control and choice in more traditional cultures or aggravated circumstances (e.g., conflict or disaster) often starts with the parents or other elders deciding upon the girl's marriage, and then is transferred to the husband or husband's family, not necessarily engaging the girl in decision making at all (Raj, 2010; Raj et al., 2011). Sometimes girls are sold into marriage (Raj, 2010), and certainly economic factors, such as management of dowry, bride price, or wedding costs, can be reasons parents choose early marriage for a child (Kyari & Ayodel, 2014; Raj, 2010). These reasons can sound mercenary, but parents may feel that they are acting in the best interest of the child. For example, in situations of conflict or highly impoverished circumstances, parents may feel that they are ensuring their child's safety or giving their child better opportunities via an earlier marriage (Kyari & Ayodel, 2014; Raj, 2010). However, not all cases of child marriage are forced; some may even be initiated by youth to parents. There is growing evidence of cultural shifts where girls and boys are playing key or even primary decision-making roles in their own very young marriages, particularly in situations where dating or a pregnancy may have occurred, but as with the elder-led marriages, such unions appear to be exacerbated in more vulnerable contexts or circumstances, such as poverty, deprivation, or conflict (Raj, 2010).

Sadly, the context and circumstances of child marriage are all too often characterized by gender-based violence. Research demonstrates that child brides are more likely to enter marriage from families characterized by family violence, where girls witness their father's abuse of their mother, or experience their own abuse from parents, and simultaneously, they are also more likely to enter into marriages where they become victims of spousal violence, both physical and sexual (Clark et al., 2016; Nasrullah, Zakar, Zakar, Abbas, & Safdar, 2015; Raj, 2010; Raj, Gomez, & Silverman, 2008; Raj, Saggurti, Lawrence, Balaiah, & Silverman, 2010).

Conflict and violence from outside the family are also more common among girls facing child and forced marriages. At the time of writing this chapter, the civil war in Syria has resulted in 4.5 million refugees fleeing the country, and for those with families, many cite fear of rape and forced marriages by rebel forces as key reasons for leaving (Rodgers, Gritten, Offer, & Asare, 2016; Spencer, 2015). Forced marriage of young girls is being used as a tactic of war or rebellion in other contexts, as well, including in Northern Nigeria (Sieff, 2016). Yet, as noted above, conflict, displacement, and resultant poverty can also result in early marriage, in the hope that it will provide protection and safety, along with economic security for the girl (Bartels & Hamill, 2014; Garba, 2015; Sieff, 2016; Spencer, 2015). Recent indications of an increase in child marriage in Jordan have been attributed to the Syrian refugee crisis (Spencer, 2015), and similar increases attributable to conflict and refugee crises have also been observed in Lebanon, Iraq, Egypt, Turkey, and Nigeria (Garba, 2015; Save-the-Children, 2014). Parents and girls look to marriage as a means of protection from rape from rebels and soldiers or in refugee camps only to place the girls at increased risk for rape in marriage (Clark et al., 2016; Nasrullah et al., 2015; Raj, 2010; Raj et al., 2008; Raj et al., 2011; Raj, Saggurti, Lawrence, et al., 2010). Growing concerns are also erupting that Syrian girls are being sold into marriage or are unknowingly becoming married to traffickers (Bartels & Hamill, 2014), and these findings parallel those seen in South Asia and Mexico documenting use of child marriage as a means of facilitating sex trafficking (Falb et al., 2011; Gupta, Raj, Decker, Reed, & Silverman, 2009; Silverman et al., 2015). Overall, these findings demonstrate that diverse forms of gender-based violence against women intersect child marriage, likely due to shared root causes.

The Social Impact of Girl Child Marriage

The contexts in which child marriage is more likely to occur, including lesser education for women, rural poverty, and acceptability or preponderance of gender-based violence against women, as described above, maintain child brides' vulnerability post-marriage. Recourse to leave the marriage, or even to remain but protect themselves from the violence or control they may face from spouses or in-laws, can be limited (Clark et al., 2016; Raj, 2010; Raj et al., 2011). Once married, girls' opportunities for mobility, both social and physical, can be limited, impeding their development and autonomy. Loss of opportunity to complete their education post-marriage is a particularly well-documented concern, due to an increase in household expectations as well as stigmatization of continued education post-marriage in some cultural contexts (Delprato, Akyeampong, Sabates, & Hernandez-Fernandez, 2015; Kyari & Ayodele, 2014). A recent analysis of child marriage and girl education data from 36 countries in sub-Saharan Africa and South West Asia reveals child marriage as a significant predictor of school dropout for both regions; it also demonstrates that for every year of delay in marriage, there is a .5-year increase in education of girls in sub-Saharan Africa and a .3-year increase in education among girls in South West Asia (Delprato et al., 2015). Cessation of education for married girls not only reduces their development and their social support networks with peers, but it also reduces their access to important sexual and reproductive health education programs and hinders their opportunity and expectations for workforce participation and economic empowerment (Islam, Haque, & Hossain, 2016; Kyari & Ayodele, 2014).

Ultimately, women and girls' lesser education, lack of economic empowerment, and social isolation can drive poverty at community and household levels (Doepke & Tertilt, 2011; Duflo, 2012; Idris, 2015; Kabeer, 2015; Kabeer & Natali, 2013). Women's economic empowerment, through their income generation and their decision-making control over household finances, has been shown to lower household poverty and improve child health, as women are more likely than men to allocate income toward household (e.g., food), education, and child health expenditures (Doepke & Tertilt, 2011; Duflo, 2012; Idris, 2015; Kabeer, 2015; Kabeer & Natali, 2013). Cross-national studies from diverse cultural groups document that when women are educated, are employed, own property, and have control of cash or credit, household investments in family welfare broadly improve (Hanmer & Klugman, 2016; Kabeer, 2015). Some have suggested that women's greater focus on reinvesting in families and communities, relative to men's, can accelerate development and poverty alleviation, if more financial resources are placed into the hands of women (Idris, 2015; Kabeer, 2015). Such indications suggest that child marriage, and its related impediments to girls' education and ultimately women's economic empowerment, may be a key force in impeding development and maintaining poverty at household to population levels, potentially perpetuating not only a cycle of poverty but also the retention of child marriage as a traditional harmful practice. Consideration of how best to engage women with a history of child marriage in economic empowerment programs is required. A review of rigorous evaluation of interventions focused on economic empowerment demonstrates that capital alone cannot create change; skills and support are needed, and young women can only benefit from economic empowerment programs if social restrictions are lessened (Buvinić & Furst-Nichols, 2016).

Negative Health Effects of Girl Child Marriage

Much of the research on the health impact of child marriage relates to the reproductive and maternal health consequences of adolescent motherhood. The vast majority (95%) of the world's births to adolescents occur in low- and middle-income countries; this amounts to more than 20,000 births a day to girls under the age of 18 years (UNFPA, 2013). Ninety percent of these births occur in the context of marriage or union (UNFPA, 2013). Adolescent pregnancy is a leading cause of mortality for adolescent girls, and more than 70,000 girls die each year due to causes related to pregnancy and childbirth (UNFPA, 2013). Maternal mortality risk is particularly high for girls experiencing pregnancy or childbirth at very young ages, and more than a quarter of births to minor-aged girls occur prior to age 15 years (UNFPA, 2013). Obstetric fistula is also more likely among these very young mothers (Melah et al., 2007). Adolescent mothers are also at increased risk for other maternal health complications. A multi-country study of 29 African, Latin American, Asian, and Middle Eastern nations found that mothers aged 10–19 years, relative to those aged 20–24 years, were more likely to experience eclampsia, puerperal endometritis, and systemic infections (Ganchimeg et al., 2014). While these issues could be avoided by greater contraceptive use among young wives, such use is even less likely among those who marry young. Women who marry as minors are more likely than those marrying at majority age to report nonuse of contraceptives, a high unmet need for contraception, and low reproductive control, due to lesser mobility, lesser access to reproductive health knowledge and services, and lesser contraceptive decision-making control (Clark et al., 2016; Godha, Hotchkiss, & Gage, 2013; Nasrullah, Muazzam, Bhutta, & Raj, 2014; Raj, 2010; Raj et al., 2009).

A child born to an adolescent mother is also at a greater risk of morbidity and mortality. A study undertaken in 55 low- and middle-income countries utilizing 118 Demographic and Health Surveys conducted between 1990 and 2008 found that first-born children of adolescent mothers are at highest risk for infant mortality and poor health outcomes (Finlay, Ozaltin, & Canning, 2011). Low birth weight, preterm delivery, and neonatal morbidities, more likely for children born to adolescent mothers, compromise infant survival (Ganchimeg et al., 2014). While poor neonatal health outcomes are likely in part due to inadequate maternal development for a fetus to flourish within these younger mothers, their increased risk for lower health care utilization, including antenatal care and use of a skilled birth attendant, also likely compromises neonatal health and survival (Godha, Gage, Hotchkiss, & Cappa, 2016; Nasrullah, Zakar, & Kramer, 2013). Low birth spacing, which again is more likely among adolescents relative to adult mothers (Godha et al., 2013; Raj et al., 2009), also contributes to heightened risk for infant mortality in this population (Raj, McDougal, & Rusch, 2014). In fact, a recent study of demographic data from South Asia revealed that in 2012 alone, 150,000 infant deaths in India were attributable to the combination of adolescent motherhood and low birth spacing (Raj et al., 2014). Longer term health effects on children born to young mothers have also been observed. In India, women who married as minors, relative to those who married at age 18 or older, were more likely to have children affected by malnutrition, even after accounting for maternal social and economic vulnerabilities including maternal education and household poverty (Raj, Saggurti, Winter, et al., 2010). These findings overall reveal intergenerational health effects of girl child marriage on key maternal and child health outcomes.

The effects of child marriage on HIV have been less clear. In a 2004 study from urban Kenya and Zambia, HIV rates were more likely among married relative to unmarried adolescent girls, and child marriage was associated with lower sexual control, including lesser ability to negotiate abstinence and condom use (Clark, 2004). Multi-country research, including data from 29 countries in Africa and Latin America, reinforced current findings by again documenting that, among adolescents, those who were married were more likely to have engaged in unprotected sex and less able to negotiate condom use (Clark, Bruce, & Dude, 2006). However, analysis of data from India did not yield similar findings; age at marriage was not associated with HIV or condom use (Raj, 2010). Lack of findings was in part viewed as an artifact of child marriage being more likely in rural settings, where HIV was more prevalent in urban areas of India (Raj, 2010). Ecological analysis examining associations between rates of child marriage and rates of HIV also did not yield significant findings (Raj & Boehmer, 2013). Geographic region was the primary driver of HIV rates in the ecological analysis. The findings suggest that in the context of a generalized epidemic, girl child marriage and its associations with lesser power in relationships—older male partners and partner violence—can compromise sexual negotiation and thus can increase likelihood of exposure to HIV (Raj, 2010). However, such findings will not hold true if risk of exposure to HIV through unprotected sex in marriage is low.

Some research also exists on the mental health and trauma consequences of child marriage, though there remains inadequate evidence across national settings on the topic. Depression may occur due to early removal from parents or due to isolation not uncommon for child brides; depression and anxiety could also stem from the loss of control many child brides face, particularly from abusive male partners or even in-laws (Nour, 2006, 2009; Raj, 2010). In a study done in Afghanistan, forced and child marriage, along with violence perpetrated by husbands, in-laws, or husband's other wives, was a common precursor to acts of self-immolation (the act of lighting oneself on fire) on the girls' part (Raj et al., 2008). Research from Ethiopia similarly documents that girls married or engaged as minors were more likely to report suicidal ideation and attempts (Gage, 2013). While this quantitative study did not have data to provide insight into the mechanisms of the observed associations, reasons may be similar to that seen from qualitative data from Afghanistan indicating that this association is based on girls taking their own life as they feel they have no other recourse for control in a painful situation (Raj et al., 2011). Research from the United States, a context with very low rates of child marriage, documents associations between child marriage and psychiatric disorders across the life span (Le Strat, Dubertret, & Le Foll, 2011). Inadequate research on this issue across national contexts is in part related to the stigma attached to suicide. More work is needed to consider this topic, including as a long-term health consequence, given that data from the United States indicate risk across the life span.

Strategies to Address Child Marriage: Legal, Prevention Programs, and Post-marriage Interventions

Strategies to address child marriage are predominantly in the forms of laws prohibiting the practice, and programs directed at girls, families, and communities to prevent the practice. Laws guiding minimum age at marriage exist for most nations. A recent analysis of 198 countries and territories found that 96% had such laws, with only six nations lacking a minimum age at marriage standard—Equatorial Guinea, Gambia, Saudi Arabia, Somalia, South Sudan, and Yemen (Sandstrom & Theodorou, 2016). Eighty percent of the nations with a minimum age at marriage law (153 of 192) place this limit at 18 years. However, in almost all of these cases, there are caveats allowing those under age 18 years to wed (Sandstrom & Theodorou, 2016), including conditions of parental consent, Sharia Law, pregnancy, and/or judicial approval (Maswikwa, Richter, Kaufman, & Nandi, 2015; Sandstrom & Theodorou, 2016). Even when laws do exist, they are often not well enforced or are inequitable, with different legal standards for males and females or based on religion, and many believe that in isolation, they are inadequate to ineffectual means for elimination of child marriage (Maswikwa et al., 2015; Raj, 2010; Sandstrom & Theodorou, 2016; Svanemyr & Chandra-Mouli, 2015). A review of the top ten nations with the highest prevalence of marriage does not suggest that laws are a deterrent (see Table 1.1). Research suggests that prosecutions in identified cases are rare, and that in fact many of the most vulnerable girls and families are least aware of the laws (Raj et al., 2011; Svanemyr & Chandra-Mouli, 2015). However, recent research from

Table 1.1 Ten nations with the highest prevalence of child marriage and their legal minimum age at marriage

	Country	Age at marriage ≤15	Age at marriage ≤18	Legal minimum age of marriage (years)
1	Niger	28%	76%	Girls: 15 Boys: No age specified
2	Chad	29%	68%	Girls: 18 Boys: 18
3	Central African Republic	29%	68%	Girls: 18 Boys: 18
4	Mali	15%	55%	Girls: 16 Boys: 18
5	Bangladesh	18%	52%	Girls: 18 Boys: 21
6	South Sudan	9%	52%	Girls: No age specified Boys: No age specified
7	Burkina Faso	10%	52%	Girls: 17 Boys: 20
8	Guinea	21%	52%	Girls: 17 Boys: 21
9	Mozambique	14%	48%	Girls: 18 Boys: 18
10	India	18%	48%	Girls: 18 Boys: 21

Data on prevalence of child marriage by 15 and by 18 were taken from the State of World's Children 2016 (UNICEF, 2016). Data on legal minimum age at marriage by country were taken from the Pew Report on minimum age at marriage (Sandstrom & Theodorou, 2016)

sub-Saharan Africa suggests that laws can be important. This study of 12 countries, 4 of which had a consistent legal minimum age at marriage of 18, revealed that nations with consistent laws have lower rates of child marriage and adolescent pregnancy, relative to nations with no or inconsistent laws on child marriage (Maswikwa et al., 2015). However, as noted in a critique of the paper, these cross-sectional findings cannot be assumed to be causal, and the study does not account for customary or religious laws, or the implementation and enforcement of laws (Svanemyr & Chandra-Mouli, 2015). Nonetheless, establishment of a legal standard for minimum age at marriage is necessary to provide clarity on the social standard, as this standard can spark the necessary community shifts in the practice.

Other efforts to address child marriage largely are in the form of prevention interventions. Reviews on child marriage prevention interventions document a substantial increase in their number over the past 30 years, with only 3 studies of these programs prior to the 1990s, 7 in the 1990s, and an additional 13 by 2011 (Lee-Rife, Malhotra, Warner, & Glinski, 2012). A 2016 review of the literature documents 63 evaluated child marriage prevention interventions, indicating a tripling in number of evaluations of these programs in just the past 5 years (Kalamar, Lee-Rife, & Hindin, 2016). More rigorous evaluations and research across populations demonstrate that the most effective means of preventing child marriage is by incentivizing girls to remain in school (Kalamar et al., 2016). School incentive programs focus on both education and poverty alleviation, key factors related to child marriage, without directly addressing child marriage itself. This approach is scalable, garnering support from local ministries of health and child welfare as well as multilateral organizations like the World Bank, due to narrower scope (Kalamar et al., 2016; Lee-Rife et al., 2012). Incentivized education, through conditional cash transfer (CCTs) and unconditional cash transfers (UCTs), has also been well evaluated, for effects both on enrollment and retention in schools and on delayed marriage (Kalamar et al., 2016; Lee-Rife et al., 2012). The approach is amenable to rigorous cluster (school-level) randomized controlled trials and has largely been led by economists more invested in conducting rigorous designs to evaluate the approach. The literature on CCTs and UCTs is quite robust and demonstrates strong and consistent effects on school enrollment and retention, with strongest effects for CCTs where compliance is monitored and noncompliance is penalized (Baird, Ferreira, Özler, & Woolcock, 2013).

Prior review of child marriage prevention efforts had also shown promise of integrated models of intervention inclusive of sexual and reproductive health (SRH) education, empowerment counseling, and life skill development for girls, typically implemented by nongovernmental organizations (Lee-Rife et al., 2012). However, with expanded and more rigorous evaluation research, a pattern emerged suggesting that integration of child marriage prevention with SRH promotion was not effective, possibly due to diffusion of focus from child marriage prevention (Kalamar et al., 2016). Lesser research has examined incentivized school retention with adolescent SRH programming to determine if that combination may prove more beneficial than programming focused on child marriage prevention messaging and adolescent SRH education concurrently. Such efforts should be considered since focus on child marriage prevention cannot come at the cost of SRH programming for youth. An additional issue for prevention efforts remains the paucity of evidence documenting the utility of engaging the health and education sectors (Kalamar et al., 2016). However, these sectors are actively being engaged to educate and intervene on these issues (Kalamar et al., 2016; Lee-Rife et al., 2012). Research is needed to provide input into interventions that engage teachers and the health sector, as well as for peer-led approaches. The field cannot recommend evidence-based approaches but provide no evidence for health and education sectors to engage in child marriage prevention efforts. Further, notably missing from prevention efforts is engagement with boys and men who may marry girls; potential husbands can be the decision makers for the age of a girl at marriage or the timing of marriage and in many affected contexts may be better able to negotiate these issues than the girls themselves. While certainly a goal should be supporting girls to lead this decision making, engagement of parental decision makers is well recognized as important for child marriage prevention (Kalamar et al., 2016; Lee-Rife et al., 2012; Raj et al., 2011).

Support for girls post-marriage is often discussed in terms of removing girls from their marriages, an approach that can be facilitated by laws against the practice. However, resistance to this option by families, communities, and the girls themselves is not uncommon (Kalamar et al., 2016; Raj, 2010; Raj et al., 2011). More beneficial may be programmatic efforts to support married adolescent girls in their access and utilization of healthcare, including reproductive, maternal, child health, mental health, and HIV-related services, as well as social services that can support married girls' continued education, employment, and safety from violence (Svanemyr, Chandra-Mouli, Raj, Travers, & Sundaram, 2015). Unfortunately, recent analyses of two effective social and health interventions for women suggest diminished effects for women married as minors. A microfinance study documenting reductions in intimate partner violence did not prove to show the same effects for the subsample of women married prior to age 18 years (Falb et al., 2015). Similarly, a public health intervention demonstrating effectiveness in promoting maternal-neonatal continuum of care showed lesser effects for those who married as minors compared to those who married at age ≥18 years (McDougal et al., under review). These findings suggest the need for more tailored programs for those with a history of child marriage.

Conclusions

This chapter documents the ongoing pervasiveness of girl child marriage in many nations across the world, as well as the population-level impact of this health and human rights violation. Girls marrying as minors are more likely to come from socially marginalized and vulnerable circumstances, such as poverty or insecurity, and they are also more likely to face gender inequities, such as lesser education, and gender-based violence prior to entry into marriage. At marriage, they are at increased risk for having a husband who is older and abusive, and are more likely to have restrictions on their mobility and decision-making control, including reproductive decision making. In these contexts, reproductive autonomy is severely compromised, and adolescent motherhood combined with low birth spacing increases child brides' maternal and child health risks. The intergenerational effects of child marriage are not only compromised health and nutrition for her children, but also greater likelihood of a continuing cycle of poverty.

While reductions of child marriage are well documented, these reductions are grossly inadequate to support the health and development goals for the next generation. Laws exist but are too often not enforced. Prevention activities show promise, but are largely limited to incentivizing education enrollment and retention without adequate consideration for the underlying gender inequities that continue to exist for these girls even if their marriage is delayed. Further, even as prevention activities intensify, those already married as minors remain to be left behind, and existing efforts to support women broadly may not be enough to support these more vulnerable women and girls, as indicated by research documenting diminished effects of promising gender-based violence prevention and maternal and child health promotion programs. Political will to address this issue, as indicated by its inclusion as an indicator in the Sustainable Development Goals, is not being sufficiently matched by social and political action, as indicated by ongoing high prevalence of child marriage and inadequate laws or enforcement of laws across many nations. More intensive efforts are needed and these must consider the very gendered nature of this practice (i.e., far greater risk for girls than boys), its link to other gendered risks (e.g., partner violence), and its greater likelihood in nations characterized by greater gender inequities (indicated by Gender Inequality Index scores), as outlined in our above review. Elimination of child marriage can have population-level impact on women and girls' health and well-being, but elimination or even reduction of this practice cannot occur without greater development, support, and value for women and girls globally.

Discussion Questions

1. What do you think is the basis of child marriage being defined as <18 years? What are the benefits and concerns of having a clear marker for age at marriage in international and national laws and policies?
2. What is the relevance of the SDGs and inclusion of child marriage as an SDG indicator for women's health research and practice?
3. Why do the authors describe girl child marriage as a gendered issue and as an issue of gender development?
4. Which stakeholder groups would benefit from reading and learning about this issue and why? Consider policy makers, ministries of health, ministries of women and children's welfare, health providers, health systems, nongovernmental organizations, and others?
5. What are the limitations of the existing evaluated interventions in terms of guiding national program and policy strategies? What would you do to improve the evidence based on child marriage prevention and intervention programs?
6. If programs that indirectly address the child marriage (like CCTs) are effective, but do not address gender inequities, should the approach be prioritized? Why or why not?

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Chapter 2
The Role of Premarital Agency in Delaying Marriage and Reproductive Decision Making in Urban India

Marie A. Brault, Stephen L. Schensul, and Shweta Bankar

Introduction

This chapter focuses on young women's transitions to adulthood, marriage, and reproduction within a globalizing society in a low-income area of 700,000 people in Mumbai, India. Statistics at the national level reinforce the standard image of an India of early marriage, high fertility, low contraceptive use, low education, and widespread poverty. Nearly 50% of women in India, mostly from low-income families, marry below the legal age of 18. National-level data suggests that adolescent marriage is typically followed by early childbearing and limited birth spacing (International Institute for Population Sciences & International, 2007). Although the total fertility rate (TFR) has declined over the past two decades, the decline has been slower than predicted (International Institute for Population Sciences & International, 2007). Reversible contraceptive use remains limited by government programs that almost exclusively emphasize female sterilization (Brault, Schensul, Singh, Verma, & Jadhav, 2015; Connelly, 2009; Matthews, Padmadas, Hutter, McEachran, & Brown, 2009; Murthy, Ramachandar, Pelto, & Vasan, 2002; Srinivasan, 1995). Only 56% of all married women in India use any contraceptive method, and only 10% of women use a reversible method (IIPS NFHS, 2007). For those women who use sterilization, most undergo the operation before the age of 30.

The literature on young women in India frequently focuses on a stereotypical life course trajectory in which gender inequity and lack of agency are the dominant

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narratives. In this portrayal, young women in India experience gender inequity in the form of son preference and a low female-to-male ratio (Patel, 2007; Sen, 2003). The onset of menarche is often a surprise for adolescent girls as there is limited education and information prior to menstruation. The mobility restrictions that follow the onset of menstruation frequently include leaving school at an early age to remain in the home to support the natal family and learn to be a wife (Khanna, Goyal, & Bhawsar, 2005; Nair et al., 2012). Female adolescents must adapt to a family context in which there is high pressure to preserve virginity and the family's *izzat* (honor or reputation), and tension as the family seeks to arrange an appropriate marriage quickly (Bennett, 1983; Dharmalingam, 1994; Garg, Sharma, & Sahay, 2001; Jeffery & Jeffery, 2002; Khanna et al., 2005; Mishra & Mukhopadhyay, 2012). After marriage, many young women describe "first-night" stories of an inexperienced husband demanding sex from a naïve girl (Bloom, Tsui, Plotkin, & Bassett, 2000; Khan, Barge, Sadhwani, & Kale, 2005). The early years of marriage involve adaptation to a low-ranking role in the husband's family, building a relationship with a husband they barely know, dealing with overbearing in-laws, and the pressure to have sons (George, 2002; Kapadia-Kundu, Khale, Upadhaye, & Chavan, 2007).

This stereotypical picture does not account for new opportunities for women in a globalized Indian economy in the realms of education, employment, and societal roles. High levels of inflation and an increasing cost of living in India, combined with national and international support for gender equity and female education, have placed greater emphasis on female literacy allowing women to take advantage of new employment opportunities (Ghosh, 2011; Luke, Munshi, & Rosenzweig, 2004; Nayar, Bhide, Drotner, & Livingstone, 2008). Economic constraints are also associated with changing living arrangements that are driving down fertility rates, as it is no longer feasible or practical to have large families living in the same household in India's increasingly expensive and cramped cities (Gupta, 2005; Niranjan, Nair, & Roy, 2005).

Globalization in India has also been characterized by increased access to technology and media. For young women, expanded access to media provides exposure to a variety of images of "modern" women from both Western and Bollywood films (Ghosh, 2011; V. Mishra, 2011). While Bollywood has long been popular, young women have increasing opportunities to fulfill desires to emulate these images with "skinny jeans" and cosmetics through a growing consumer culture and the spread of shopping malls (Ghosh, 2011; Mankekar, 2004). Young women are increasingly exposed to soap operas, television shows, and media messages that encourage gender equity, reduced family size, and contraceptive use (Brown, 1991; S. Kumar, 2010; Nema & Sharma, 2009). Expanded access to cell phones and Internet also provides adolescent girls with new ways to access information outside parental control (Chakraborty, 2010, 2012).

With an expanded range of options for life choices, young women have new opportunities to make decisions about their lives. An increasing number of relatively economically marginalized young women make decisions regarding their education or employment opportunities and take a more active role in the arrangement of marriage (Fuller & Narasimhan, 2008; Jensen, 2012; Netting, 2010). Once married, many young women have positive sexual experiences, negotiate contraception, and have husbands and in-laws sensitive to their needs (Allendorf, 2013b; Barua, Pande, MacQuarrie, & Walia, 2004; Bojko et al., 2010; Char, Saavala, & Kulmala, 2010).

Although globalization has created a number of new opportunities for young women, the impact of globalization has been unevenly distributed, across both socioeconomic statuses and between urban and rural areas, contributing to variation in marital practices and reproductive health. In light of the rapid social change occurring in India, this chapter employs the life course approach and feminist perspectives to explore variation in young women's agency in their transitions from natal to marital families, and the impact of agency on the timing of marriage and reproductive health.

Feminist anthropological and sociological understandings of agency are central to understanding women not just as passive products of structural and cultural factors, but active participants in practices and decisions that affect their lives (Bourdieu, 1977; Frank, 2006; Ortner, 2001). Agency can be defined as a young woman's ability to make life choices, either through subverting or embracing norms, in a context where independent decision making is not always supported (Abu-Lughod, 1990, 2008; Kabeer, 1999). Understanding variable practices of agency can help in understanding those young women who follow traditional trajectories, as well as young women who do not.

The life course approach provides a framework to explore how precursors such as community and social norms, socialization, education, and familial and peer relationships can shape young adults' trajectories and outcomes (Clausen, 1991; LeVine, 2011; Weisner, 1997; Worthman, 2011). Within life course approaches, adolescence is viewed as a particularly critical stage in which adolescents develop agency and transition from the roles and responsibilities of childhood to those of adulthood (Shanahan, 2000). Of importance for this study, researchers have focused on cultural models of transitions to adulthood, which set culturally constructed paths to become an adult and obtain a "good life." However, researchers also note that periods of social change necessarily alter these cultural models. This study employs a life course perspective by attempting to understand young women's trajectories in the context of power differentials imposed by changing social contexts in which young women differentially gain or lose agency in their transitions from their natal to marital families. In this way, we explore how premarital factors as well as factors external to the marital dyad contribute to reproductive decision making for newly married young women.

Study Area and Methodology

Study Area

The research was conducted in an urban "slum" area in Mumbai, India, of approximately 700,000 people, consisting of Muslims (54%), Hindus (43%), and a small percentage of Buddhists and Christians. The majority of residents of the study area are long-term migrants with a mean time in Mumbai of 15 years (Schensul et al., 2009). Residents from the study area are primarily from Bihar, Uttar Pradesh, rural Maharashtra, Karnataka, and Tamil Nadu. The average household income in the area is 4500 INR per month (approximately $75 USD per month). The study area contains small-scale factories (*zari* industry) that assemble piece goods into garments, bags, shoes, toys, and packaging. There are also scrap, steel polishing, and construction companies. Many men in the study area also work as truck, taxi, or auto-rickshaw (three-wheeled taxi) drivers. Rag-picking, or collecting scraps for resale from the garbage dumping ground, is also a common occupation, particularly for women in the study area.

Healthcare is provided in multiple locations in the study area. Government healthcare is provided through an urban health center (UHC) and three health posts distributed in different parts of the study area. This healthcare is free although there are out-of-pocket costs, such as transportation associated with it. The UHC has a variety of outpatient departments (OPDs) such as general male and female health, pediatric growth and development, antenatal care, immunizations, geriatrics, and sexual health (primarily STI/HIV testing and counseling), as well as a small laboratory and pharmacy. The health posts are satellite clinics that provide immunizations, basic infant and child growth monitoring, Direct Observable Treatment Service (DOTS) for tuberculosis, antimalarial medication, birth control pills and condoms, antenatal vitamins and care for pregnant women, and referrals as needed. Community health volunteers (CHVs) work out of the health posts and make door-to-door rounds to provide education and distribute many of the services available at the health posts.

Nongovernmental organizations (NGOs) also play a role in healthcare in the study area. NGOs provide targeted medical services, similar to the health posts, as well as education on a variety of health problems and reproductive health. NGOs also often refer women and children to more specialized healthcare services.

In terms of the household composition, most households are nuclear (47%), followed by joint households (37.1%), and households consisting of men only (15.8%). In the study area a nuclear household is one which consists of a married couple and their children. A joint family is one which consists of a married couple, their children, and the husband or wife's family members. The average size of a home in the study area is one room, and the average number of people per household is 6.4, although there is evidence to suggest that average family size is decreasing concurrently with a decrease in fertility required by the limitations of space and income (Allendorf, 2013a; Niranjan et al., 2005; Schensul et al., 2009).

The Overall Study

The data presented here come from a larger study examining factors related to sexual and reproductive health outcomes of young women in low-income communities in Mumbai, India. Fieldwork was conducted over the course of 13 months between 2012 and 2015. The study employed a sequential explanatory research design (Creswell, 2013; Ivankova, Creswell, & Stick, 2006). In this design, the first study phase utilized qualitative methods for identification and discovery and to enhance the validity of quantitative instruments. The second, quantitative stage was used to test hypotheses concerning the relationships between key variables of interest.

Sampling

Married women in the age range of 15–25 were selected for both qualitative ($N = 68$) and quantitative ($N = 150$) samples. Separate samples were used for the qualitative and quantitative portions of the study, but the same sampling criteria were used for both phases of the research. A purposeful sampling approach was used. The parameters of the sampling frames for both interviews and the survey were age at marriage (over and under 18, the legal age at marriage) and religion (Hindu and Muslim). Subareas within the two communities were chosen based on relative socioeconomic status (i.e., equal numbers of more impoverished and less stable areas and less impoverished and more stable areas); however the variable of socioeconomic status was not a significant correlate of the variables examined for this chapter. Within subareas, CHVs, NGO workers, and community mobilizers were enlisted to discuss the study on their door-to-door rounds, and to refer interested and eligible participants. Such partnerships with community "gatekeepers" and community-based organizations are a common method of recruitment in low-income settings (Benoit, Jansson, Millar, & Phillips, 2005; Rashid, 2007, 2011). Women who participated in the study would often tell neighbors, female relatives, or friends about the study and refer them to us as well. In this way, samples for both the qualitative and quantitative portions of the study were obtained.

Data Collection

The first stage consisted of qualitative data collection including key informant interviews ($N = 25$) and in-depth interviews with married young women ($N = 68$). Interviews were conducted in Hindi and Marathi with the aid of a research assistant. The second stage consisted of quantitative data collection with a structured survey instrument administered to married young women ($N = 150$).

In this chapter, we focus on relationships between the following variables: premarital agency, age at marriage, marital communication, amount of time between marriage and first pregnancy, and postmarital gender equity norms. *Premarital agency* is a scale measuring a woman's decision-making power in their natal families before marriage. This scale was adapted from a female agency scale developed for married women in the study area (Kostick et al., 2010). Additional items specific to adolescents were added based on the in-depth qualitative interviews collected in the first stage of the research. The scale has 16 items and a Cronbach's alpha of .730. *Marital communication* is a scale developed for married women in the study area (Stephen L Schensul et al., 2009). The marital communication scale consists of 16 items and had a Cronbach's alpha of .805. The scale included items related to ease of marital communication on different topics such as household matters and feelings, and the extent to which the woman's husband helps with different household chores and work (cleaning, cooking, childcare, taking family members to the doctor). *Postmarital agency and gender norms* is a scale measuring a woman's beliefs concerning gender equity and postmarital decision making. Although neither this scale nor the study includes men's perspectives on gender equity, during the original development of the scale, men's opinions were elicited and used to develop specific items (Kostick et al., 2010; Kostick, Schensul, Singh, Pelto, & Saggurti, 2011). The scale combined items previously developed for women in the study area (Kostick et al., 2010; Kostick et al., 2011), and has 38 items and a Cronbach's alpha of .857. The other variables consisted of single questions. The survey was translated into Hindi and Marathi and administered with the aid of a research assistant.

Data Analysis

Interviews were audio recorded, translated, and transcribed in English. Codes and transcribed text were entered into Atlas.tiV6.2, a qualitative data analysis software (Murh, 2004). Codes were developed in this research utilizing a tree diagram method in which factors were embedded in domains, allowing analysis to occur at the domain and the factor level (S. L. Schensul, 1993). The coding scheme was deductively developed based on the domains in the research model and modified by the content of the key informant and in-depth interviews. Coding was conducted in multiple iterations to enable the emergence of novel themes. Text were coded and reviewed for patterns related to consistency, variation, and exemplary cases related to reproductive decision making.

Quantitative data were entered into SPSS 22.0 (SPSS, 2001). Descriptive statistics were obtained for continuous and categorical variables. To develop scales, we conducted factor and reliability analyses. To calculate each scale, means were taken of all items to be included. Cronbach's alpha was calculated to assess the reliability of the scale. Scale variables were all normally distributed, and did not require transformation. For the variables of interest in this study, simple univariate correlations and regressions were conducted.

The parent study from which the data for this chapter is drawn was funded by the National Science Foundation and received IRB approval (protocol H13-138) from the University of Connecticut. Written informed consent was obtained from all participants. For illiterate participants (17% of the sample who attended little or no school), the consent form was read to them and they provided a signature or marking indicating their comprehension and consent to participate.

Results

Demographics of the Sample

Table 2.1 provides key demographic characteristics of the sample and the descriptive statistics for the variables of interest. The average educational attainment is relatively low, with most girls receiving no secondary education, and leaving school early in adolescence. The majority of marriages continue to be arranged, although the number of love marriages has increased in recent years. Over half of the women in the sample lived in extended families with their husband and in-laws, but in keeping with trends towards smaller families in urban settings, many women in the sample lived in nuclear families. In terms of reproductive histories, pregnancy within the first year of marriage is the norm. The average number of pregnancies and living children is lower than national trends, but not all women in the sample had been pregnant or completed their families. The frequency of medically terminated

Table 2.1 Characteristics of the study sample ($N = 150$)

Variable	Frequency
Average age of participant (range)	21.7 (16–25)
Average educational attainment (range)	6.4 years (0–17)
Average premarital agency (range)	1.468 (1.000–1.938)
Average age at marriage (range)	17.85 years old (13–24)
Type of marriage	66% ($N = 99$) arranged 34% ($N = 51$) “love”
Average age at marriage (range)	17.85 years old (12–24)
Family type	53% ($N = 80$) extended 47% ($N = 70$) nuclear
Average marital communication score (range)	1.934 (1.19–2.75)
Average postmarital agency and gender norms (range)	1.428 (1.05–1.89)
Average age at first pregnancy (range)	18.6 years old (14–24)
Average amount of time between marriage and first pregnancy (range)	10.8 months (1–4 years)
Average number of pregnancies (range)	1.83 (0–6)
Average number of living children (range)	1.32 (0–4)
MTPs	13.3% ($N = 20$)
Miscarriages	13.3% ($N = 20$)

Table 2.2 Type of contraceptives used by women at the time of the study ($N = 50$)

Type of contraceptive	Percentage (%)
Sterilization	34
Condoms	26
Copper-T	16
Birth control pills	14
Hormonal contraceptive injections	8
Safe period	2
Total	100

pregnancies (MTPs or abortions) and miscarriages was relatively low among women in the sample. The low frequency of MTPs and miscarriages prevented us from conducting further analyses on the role of MTPs or miscarriages on fertility patterns.

Overall, contraceptive use in the sample was relatively low, with 39% ($N = 59$) of the participants having ever used contraceptives and 33% ($N = 50$) using contraceptives at the time of the study. Details on contraceptive use are provided in Table 2.2. Sterilization was the most prevalent form of contraceptive used, and the average age at sterilization was 21.7 years old. Condoms were commonly used, but other forms of reversible contraceptives were used less often.

Relationships between Premarital Agency and the Timing of Marriage

Qualitative and quantitative analyses revealed relationships between women's experiences in their natal families and the timing of marriage. Premarital agency was significantly associated with age at marriage ($B = 3.177$, $R^2 = .122$, $p < .001$), indicating that as premarital agency increases, so does the age at marriage. Women who married as adolescents tended to have limited opportunities to make decisions for themselves before marriage, leaving decisions related to education, employment, mobility, socialization, and timing of their marriage to their parents or other family members. As one young Muslim woman stated, "In our religion, they don't ask us if we want to get married. My mother and father were talking about my marriage, and so that's how I knew about it."

Women with more agency described how their natal families supported them to make decisions for themselves, particularly with respect to education, employment, and timing of marriage, and many women who delayed their marriage did so to pursue educational or employment opportunities. One young woman typical of this pattern was allowed to delay her marriage to complete her high school education, and was then allowed by her in-laws and husband to pursue a college degree. She explained,

> "In the village, people complain about girls who get educated, and they spread rumors about girls who go to college. I was given a choice of who I married, but most girls don't get that. In this family [indicating husband's family] and my family, the environment is good. They totally supported my studies." (20 year old Hindu woman)

Relationships between Timing of Marriage and Postmarital Factors

Age at marriage is associated with several postmarital factors. Age at marriage is positively and significantly associated with both marital communication ($B = .031$ $R^2 = .031$, $p < .05$) and postmarital gender equity ($B = .164$, $R^2 = .027$, $p > .05$). These positive relationships suggest that the older a woman is when she gets married, the more positive her marital communication is (suggesting more communication with her husband), and the more equitable her postmarital gender norms are.

An unexpected finding was that women who marry earlier delay their first pregnancy for longer periods than women who delay marriage. We found a negative correlation between age at marriage and amount of time between marriage and first pregnancy ($R = -.301$, $p < .001$). This suggests that although women who marry young tend to have limited agency before marriage they may not follow the traditional trajectory of early childbearing and limited reproductive decision making. At the same time, women who marry later tend to have greater natal family agency, but also to have their first pregnancy closer to the time of marriage.

Relationships Between the Timing of Marriage and Reproductive Decision Making

Early Marriage and Support to Delay the First Pregnancy

Several young women stated that they and their husband wanted some time to settle into their marital relationship before having a child. As a result, these couples would use condoms or birth control pills to avoid conceiving soon after marriage. Support from the husband and in-laws is a key factor for married adolescents delaying pregnancy. A number of participants stated that when they got married, their in-laws and husband viewed them as "too small" to take on the roles of a wife, including housework, cooking, and childbearing. These young women appreciated that their in-laws and husband took the responsibility of decision making out of their hands. As one woman stated, "I have my mother-in-law to take decisions, so it's not my headache to make any decisions." Women in this subgroup also had more family support for contraceptive use for spacing pregnancies and maintaining a smaller family size. One young woman stated, "I didn't know anything about contraceptives before marriage. After I delivered my first child, my in-laws told me to take some pills, so there would be space before my next child. They said it wouldn't be good to have the next child so soon."

Due to their age at marriage, young women in this subgroup were not always expected to begin having intercourse with their husband immediately after marriage. These young women were allowed to ease into their new roles and did not have the traumatic forced sex experiences described by many women in their "first-night" stories. Other young women had husbands working outside of Mumbai or India, and did not immediately move in with their husband, instead remaining with their natal families after marriage.

Women also received support from their in-laws and husbands to access contraceptives. Many married adolescents stated that they knew little or nothing about contraceptives before marriage, but learned about them from their in-laws and/or husband. As a result of this support young women felt that they were more likely to use contraceptives to delay their first pregnancy. Many couples made the joint decision to use contraceptives (either birth control pills or condoms) to delay pregnancy until they and their families were more financially stable, reflecting increasing financial pressures in the urban setting. Women, husbands, and in-laws in this subgroup tended to have internalized media and national health campaigns supporting a smaller ideal family size (generally two to three children). They also did not express very strong gender preferences for their children, feeling that they could be happy with daughters or only one son. A sentiment expressed by one woman and shared by many others was, "Nowadays who expects more than two or three children? Because, you have to look after them, you have to educate them, you have to give them everything that they need. Nowadays, it's not possible to look after so many children."

The support women receive from family also makes them less susceptible to community gossip. Women stated that neighborhood speculation about their fertility or contraceptive use was less of a problem because they felt well supported by their husband and in-laws. One woman described feeling stress over neighborhood gossip about her lack of children, but that her husband had told her to disregard their neighbors. Although some women are marrying early, suggesting lack of agency and poor outcomes, the support provided by family enables them to delay pregnancies and access contraceptives.

Early Marriage and Early Childbearing

However, there is a subgroup of women who marry early and begin conceiving early, as evidenced by quantitative data suggesting that married adolescents have more pregnancies than those women who delay marriage (comparison of mean number of pregnancies between early and delayed marriage is significant, $p < .01$). After marriage, women in this subgroup typically receive less support from their husbands and have poorer intra-marital communication. Poor marital communication and support often limits women's ability to communicate with their husbands about family planning or their fertility preferences. For this subset, it is the pronatalist husbands and in-laws who take control of fertility decisions, encouraging the young wife to conceive as soon as possible after marriage. These traditional views and limited agency, compounded by poor communication, contribute to these women having fewer options for delaying pregnancy. One 18-year-old participant stated that she wanted to wait 3 years before conceiving her first child, but her husband did not and she explained, "Whatever my husband says, that is what will happen. No one will listen to me. My husband is the one who will take the decision." Other young women described how their mothers-in-law would ask about their menstrual cycle, and scold them when they had not yet conceived.

For some Muslim couples, religious beliefs played a significant role in the choice to not use contraceptives. Many Muslims in the study area feel that contraceptive use is forbidden in Islam. Several women stated that they and/or their husband refused contraceptive use, because the timing and number of children were "up to God."

Community gossip is also a factor for women who are unable to use contraceptives or delay their first pregnancy. Several women reported that their neighbors would begin judging the young woman and/or her husband if they did not conceive immediately. One woman described feeling frustrated, as she knew little about contraceptives, but was accused by neighbors of "taking something" to prevent pregnancy. As she explained, "He [her husband] was working in Pune, and I am staying here. But, my neighbors and family members were saying all kinds of rubbish things, like I am taking contraceptives, and that's why I am not conceiving a child. So, when my husband came here, I got pregnant."

For the women who preferred to delay conception, an additional challenge is lack of knowledge about contraceptives. When asked if they would like to delay pregnancies, many women stated that they would, but did not know how to other than abstaining from sex. The lack of knowledge or support for contraceptive use leads many women in this subgroup to exceed their ideal family size and have multiple unwanted pregnancies. As a result, the qualitative data suggest that abortions and sterilization were more common among women in this subgroup. A few women had exceeded their ideal family size, and were unable to negotiate condom use with their husbands. The inability to prevent further pregnancies led these young women to seek sterilization or injectable hormonal contraceptives in secret, with the aid of a sympathetic female relative or NGO worker. These long-term contraceptives can be obtained without the knowledge of others, have relatively few side effects, and do not require follow-up visits. Thus, married adolescents who conceive soon after marriage are less likely to use contraceptives to delay or space pregnancies, and may only obtain long-term contraceptives after multiple unwanted pregnancies.

Delayed Marriage and Childbearing Soon After Marriage

For women who married at an older age, marriage often signaled the beginning of their family. As a result, many women did not plan or discuss the timing of the first pregnancy, and left it to chance. These women stated that they were not concerned about the timing of the first pregnancy, which was why they did not actively seek contraceptives to delay their first pregnancy.

Having already dealt with the pressures surrounding delayed marriage, these women saw less need to further confront the issues associated with delaying pregnancy. However, pressure from family and community members also contributed to women in this subgroup conceiving sooner. Some young women who delay marriage marry into families with more traditional beliefs, and women who have already acted outside expected norms may feel additional pressure to conform to the wishes of their husband and in-laws. One participant who wanted to delay her first pregnancy so she could finish her coursework felt pressure from her mother-in-law to become pregnant. As a result, the woman discontinued birth control and attempted to conceive. As these women have already delayed marriage, they often feel that they cannot also delay childbearing.

Some women also deliberately timed their pregnancy to alleviate household tensions. As has been documented elsewhere (Moonzwe Davis et al., 2014), when a woman becomes pregnant her status typically increases. Several young women who moved in with their husband's family outside of Mumbai wanted to have a child soon after marriage, so they would have fewer disagreements with their in-laws. One woman stated that, "… my in-laws only accepted me after I became pregnant … They thought because I am from Mumbai, I am too fashionable, and won't be able to adjust to them." A woman's first pregnancy/birth is also typically a time when she can return to her natal family and be relieved from regular household responsibilities, thus providing further incentive to become pregnant sooner rather than later.

The women in this subgroup had strong family size preferences. They commonly reported that having more than two children was financially impossible and irresponsible, and generally felt that their husband and in-laws were supportive of a small family. Although women who marry later are less likely to delay the first pregnancy or use contraceptives initially, qualitative findings suggest that they are able to make more fully informed decisions about their fertility and contraceptive use, and ultimately have better reproductive outcomes in terms of fewer overall and unplanned pregnancies.

Delayed Marriage and Delayed Childbearing

There are also a small number of women who marry later and also choose to delay their first pregnancy to pursue opportunities for work or school after marriage. Women who marry later have high levels of premarital agency, which persist as they tend to marry into families with equitable gender norms and continue to feel encouraged to make decisions for themselves. As one woman explained, "My husband has no problem at all, my mother-in-law has no problem at all. I am free to take my own decisions … With my husband and my in-laws, I can communicate very freely." The higher levels of agency and support translate into more marital support to use contraceptives, with many husbands leaving the decision to their wives.

The women in this subgroup also have knowledge of contraceptives and desire to use them both to delay first pregnancy and to space pregnancies. As one woman explained:

> "In the beginning, we [participant and husband] decided that we shouldn't have any children for at least 2 to 3 years. Because, if I conceive a child right away, it will be a problem for me to look after myself, my baby, the house, and my studies. So, I didn't want to have a child right away. Then, for 5 or 6 months, I thought about it and I took some pills in the beginning, so I wouldn't conceive a child."

Some young women take advantage of their positive marital relationships and confidence in decision making to obtain contraceptives and delay pregnancy after marriage to continue pursuing their academic or employment goals or to enable themselves time to adjust to marriage. The young women in this subgroup are relatively free of many of the social and familial expectations to prove fertility placed on the young women in other subgroups. These young women have the individual and social resources to firmly maintain their postmarital agency.

Discussion and Conclusions

India is undergoing a period of rapid economic and social change, especially with respect to roles and norms for women. These changes are impacting young women from economically marginal communities as they transition into adulthood. The data presented in this chapter describe the complex trajectories of young women transitioning to marriage and adulthood in low-income communities in Mumbai, India. Young women with the agency and support to make their decisions are increasingly choosing to delay marriage, but many girls continue to marry as adolescents. Women with greater agency who marry later make independent decisions regarding the timing of their first pregnancy and contraceptive use. Women with little premarital agency leave much of their reproductive decision making to their husband and in-laws.

The spectrum of choices made by women and their families argues against the overly simplistic stereotypes in which women with little agency have no voice in their fertility translating into poor outcomes, and women with more agency choose to actively plan their families through immediate contraceptive adoption. Rather, there is a need to explore intragroup variation to fully understand women's experiences and elaborate on their variable practices of agency (Abu-Lughod, 1990, 2008; Kabeer, 1999). The trajectories described here also suggest that characteristics of the marital relationship and reproductive decision making are shaped before marriage and by factors outside the marital dyad, requiring a life course perspective that is attentive to the impacts of social change (Clausen, 1991; Edmeades, Lee-Rife, & Malhotra, 2010; LeVine, 2011; Weisner, 1997).

Women with higher levels of premarital agency often come from families in which female decision making, education, and employment are valued and encouraged. These young women are experiencing the benefits of international and national discourses on the rights of girls and women, which are providing a more supportive social environment for these girls and women to gain and exercise agency. Women with higher levels of agency can delay marriage until they are ready, and tend to marry husbands who have similar gender-equitable norms, as evidenced by their improved marital communication and support. These women draw on their individual and social resources to take advantage of national policies and programs that have promoted female literacy and education, a career orientation, and smaller family norms.

Girls who marry as adolescents have little agency, as their natal families constrain opportunities for independent decision making, leaving reproductive decisions in the hands of husbands and in-laws. However, life after marriage offers a variety of possibilities and adaptations for women entering marriage with little agency. Although these women may have little knowledge or desire to delay their first pregnancy or to have small families, some marry into families in which norms about small family size have been accepted. The acceptance of smaller families is largely an adaptation to rising costs and space limitations associated with life in Mumbai. In this way, low-income adolescents who would stereotypically have less access to contraceptives and less support for smaller families are nonetheless able to delay their first pregnancy by negotiating sex and using contraceptives due to the changing socioeconomic constraints placed on their families and communities.

Concurrently, many adolescents continue to marry into families with patriarchal norms dictating that women prove themselves to be “good” daughters-in-law and wives by producing children soon after marriage. Due to lack of knowledge of contraceptives and lack of support to delay pregnancy, these women become pregnant early in marriage and have higher fertility. These women also represent the uneven nature of globalization’s impacts. Their families neither support pro-gender equality development agendas nor attempt to adapt to the economic realities of “new India” which dictate smaller families. Often families constrain agency and education due to lack of resources. Early marriage is desired as a way to unburden the family of another mouth to feed as well as the stress associated with protecting a woman’s *izzat (honor)*. For these young women with limited agency, international and national human rights policies and programs have not addressed the underlying social and economic inequities perpetuating early marriage and gender inequity (Rashid, 2011).

Although contraceptive use and fertility have often been tied directly to education and economic development, researchers are now arguing for a more nuanced understanding of the factors contributing to fertility decline in India as well as other South Asian countries (Bates, Maselko, & Schuler, 2007; Caldwell, 2000; Chaurasia, 2014; Edmeades et al., 2010; A. Kumar & Mohanty, 2011; Reed et al., 2016). Consistent with previous work, this study documents the uneven impacts of globalization on gender equity and female agency (Arora, 2012; Desai & Andrist, 2010), as well as the marital factors commonly associated with reproductive decision making (Chaurasia, 2014; Edmeades et al., 2010; Khanna, Sudha, & Rajan, 2009; Stephenson & Tsui, 2003). However, by incorporating both qualitative and quantitative data as well as a life course approach, this study provides new insights into how premarital factors are being shaped by social change and impacting the timing of the first pregnancy. Given the dynamic marital and reproductive patterns described here, it will be important for healthcare providers and policy makers to adapt current family planning policies and programs to meet the changing needs and desires of women and their families in India.

Discussion Questions

1. How does this chapter conceptualize female agency? Do you agree or disagree with the authors' understanding of agency? Please explain your answer.
2. Globalization has been conceptualized in many different ways, but is largely seen as a process by which goods, people, and ideas move across national boundaries in a way that is both accelerated and unprecedented. Considering the data presented in this chapter, as well as in other readings, what are the ways in which globalization particularly impacts adolescent girls' socialization and health?
3. This study employs a mixed methods approach by integrating both qualitative and quantitative data. What are the benefits and challenges of this approach to understanding issues related to adolescent sexual and reproductive health?
4. Imagine that you have been asked to design new reproductive health programming for girls and women in urban India. What would your programming consist of? What would be your program goals and policy recommendations?

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Chapter 3
The Case for a Multi-Sectoral Approach to Preventing Child Marriage and Early Childbearing in Sub-Saharan Africa

Eunice Muthengi and Karen Austrian

Background

In many parts of the world, adolescence is considered a period of growth and maturation, and adolescents typically spend most of their time in school or engaged in extracurricular and leisure activities. However, in developing countries, many girls become wives and mothers before reaching the age of maturity, often cutting short their education. Delaying the age of marriage and childbearing can significantly improve the health and well-being of young girls by allowing them to develop socially, emotionally, physically, and mentally before taking on the roles and responsibilities associated with marriage and childbearing (Mathur, Green, & Malhotra, 2006).

According to a 2014 United Nations Children's Fund (UNICEF) report, the highest rates of child marriage are found in South Asia and sub-Saharan Africa. Globally, approximately 29% of women aged 20–49 years were married before the age of 18, compared to 56% of women in South Asia, 46% of women in West and Central Africa, and 38% of women in Eastern and Southern Africa (UNICEF, 2014). Almost all adolescent births in developing countries (90%) occur within marriage (WHO, 2008). This includes pregnancies that occur after marriage, as well as cases where girls get married as a result of their pregnancy. A United Nations Population Fund (UNFPA) review of adolescent pregnancy estimates from Demographic and Health Surveys indicates that 19% of 20- to 24-year-olds in developing countries had given birth by age 18, compared to 28% in West and Central Africa, 25% in Eastern and Southern Africa, and 22% in South Asia. In terms of absolute numbers, sub-Saharan Africa accounted for 28% of the 36.4 million women aged 20–24 who had given birth before the age of 18 (Loaiza & Liang, 2013).

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The timing of marriage and childbearing is a key outcome of interest in the field of adolescent reproductive health in Africa, and it has implications for economic development on a national and regional level. This chapter provides the case for a multi-sectoral approach to preventing child marriage and early childbearing. First we provide a conceptual framework and overview of the evidence on the drivers and consequences of early marriage and childbearing, and then we discuss previous program approaches to address these issues and the need for a multi-sectoral approach. We provide a case study of a program in Kenya, the Adolescent Girls Initiative-Kenya (AGI-K), designed to understand the cost-effectiveness of this type of approach.

Drivers of Early Marriage and Early Childbearing

The sociocultural reasons for early marriage and early childbearing can be summarized using Rindfuss and St. John's (1983) categorization of factors influencing the timing of first birth. These include contextual factors, background factors, early adolescent factors, and simultaneous factors. Some of these factors can influence the timing of childbearing directly, but considering the context in sub-Saharan Africa, most of the drivers are explained in regard to their impact on the timing of marriage, which then often results in early childbearing.

Contextual factors that affect the timing of marriage include demographic factors, labor market or economic systems, gender norms, and other cultural factors. It is no coincidence that early marriage is most common in rural areas of some of the poorest countries in the world. With few job opportunities for educated women, parents are less likely to invest in education of girls and more likely to view marriage as a way to ensure their daughters' financial security. Marriage enables poor families to improve their socioeconomic status and allows wealthy families to maintain their status by forming alliances with other wealthier families and clans (Mathur et al., 2006). In addition, poor families can benefit financially by receiving bride-price payments from the groom's family. Cultural factors also play a role in perpetuating the practice of early marriage. The status of women in some societies is closely tied to the roles of being a wife and a mother (Nour, 2006). Therefore, young girls may be stigmatized if they are not married by late adolescence and they may face pressure from friends and family members to have a child soon after marriage. The timing of childbearing can also be influenced by the social acceptance of modern contraceptive methods as well as adolescent girls' knowledge of and access to family planning. In communities where a high value is placed on women's virginity at marriage, early marriage can be viewed as a way to prevent the shame associated with premarital sex and pregnancy (Dagne, 1994; Mathur et al., 2006; Schuler, Bates, Islam, & Islam, 2006).

Family background factors may place certain girls at greater or less risk of early marriage or early childbearing. Educated parents are more aware of the negative consequences of early marriage and more likely to adopt changing norms favoring the delay of marriage and childbearing (Aryal, 2007; Bates, Maselko, & Schuler, 2007; Choe, Thapa, & Mishra, 2005). Wealthy families may be more likely to invest in the education of their daughters and to delay their age of marriage. On the other hand, poor families may have a greater incentive to marry their eldest daughters in order to reduce the economic burden the daughters place on the family. The effect of the socioeconomic status of the household of origin on early childbearing differs across countries or regions. One study in Bangladesh found that an aggregate measure of household resources and living conditions is not associated with early childbearing (Gupta & Mahy, 2003). However, household wealth and access to electricity are both associated with a decreased probability of early childbearing based on data from 16 countries in sub-Saharan Africa (DeRose & Kravdal, 2007).

Early adolescent factors that might be associated with the timing of first birth include the size of her family of origin, her birth order, and orphan status. Girls from larger families and higher birth orders (more younger siblings) are more likely to marry and their disadvantaged background could reduce the length of time they continue living with their parents after marriage, decreasing their age at first sex and the age at first birth (Choe et al., 2005). Losing a parent to death or divorce at a young age could further reduce the amount of resources available to an adolescent or increase her incentives to marry and consummate the marriage as a way to improve her future economic security (Miller, Benson, & Galbraith, 2001; Moore et al., 1993).

Education is both a cause and a consequence of early marriage and early childbearing. In fact, decisions about the timing of education and marriage are often made simultaneously (Brien & Lillard, 1994). Several studies show that girls are less likely to marry or give birth at an early age if they are enrolled in school and if they have at least a primary school education (Choe et al., 2005; Gupta & Mahy, 2003; Singh, 1998; Singh & Samara, 1996; Yabiku, 2005). School attendance during the period of adolescence can delay the age of marriage and the age of childbearing in several ways. Education can increase a girl's aspirations by broadening her perspective on the world, and presenting her work opportunities and other alternatives (Jejeebhoy, 1995; Yabiku, 2005). Educated girls are more likely to have a say in decisions regarding the timing of their marriage, and they are also more likely to be aware of the costs and consequences associated with early marriage or childbearing (Bates et al., 2007; Mensch, Bruce, & Greene, 1998). In addition, girls with higher levels of education are more likely to have knowledge and access to contraceptives, which can delay their age at first birth (DeRose & Kravdal, 2007).

On the other hand, early marriage or childbearing can limit a girl's educational attainment. For a young girl marriage brings new roles and responsibilities that affect her future expectations and opportunities (Nour, 2006; Singh & Samara, 1996). Marriage and childbearing further reduce the likelihood that an adolescent female will continue her education, even if opportunities are available. According to Eloundou-Enyegue (2004), gender differences in educational attainment in Cameroon are largely attributable to rates of adolescent pregnancy. However, in a study using DHS data from Burkina Faso, Cameroon, Cote d'Ivoire, Guinea, and Togo, Lloyd and Mensch (2008) find that child marriage is a better predictor of school dropout than early childbirth.

Why Delay the Age of Marriage and First Birth?

Consequences of early marriage and childbearing in developing countries include socioeconomic effects, reduction in economic power, and health consequences. These are depicted in a conceptual framework drawn from three theories: the human capital theory (Becker, 1962), the theory of gender stratification (Blumberg, 1988), and the human capabilities approach (Sen, 1999a). The conceptual framework shown in Fig. 3.1 shows the drivers of early marriage and childbearing on the left side and the consequences on the right side.

According to human capital theory, adolescence is a critical period for building human capital, defined as physical and mental abilities that can influence future income and wealth (Sweetland, 1996). These include investment in formal education, on-the-job training, occupation-specific study programs, and health care (Schultz, 1961). Marriage or childbearing during adolescence can limit investment in education due to fewer resources and additional responsibilities that reduce the time and effort girls can dedicate to their schooling.

Few studies have examined the causal effect of marriage timing on education, but there is some evidence that early marriage is associated with reduced educational attainment (Field & Ambrus, 2008). The literature on socioeconomic effects of early childbearing is more extensive, particularly research on premarital teenage pregnancy in developed countries. Adolescent childbearing is associated with reduced earnings, schooling, experience, and job tenure, and differences in human capital investments largely account for difference in earnings, adjusting for measures

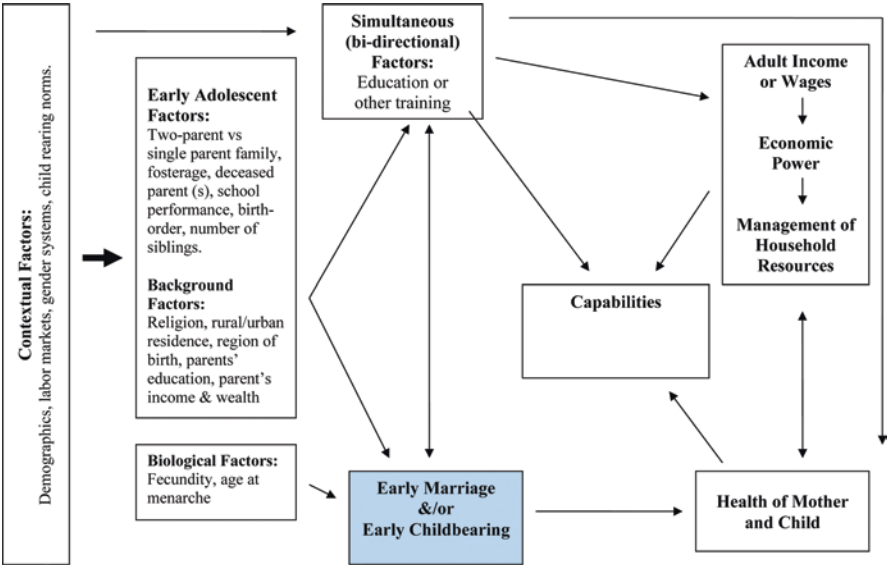

Fig. 3.1 Conceptual framework of determinants and consequences of early marriage and childbearing

of family background and fixed unobserved factors (Blackburn, Bloom, & Neumark, 1993; Klepinger, Lundberg, & Plotnick, 1999). One of the few studies estimating long-term effects of early childbearing on poverty indicators in developing countries was conducted by Buvinic (1998) using longitudinal data from Barbados, Chile, Guatemala, and Mexico. She found that early childbearing is associated with lower earnings and poorer nutritional status among women from poor backgrounds, but not among women from more advantaged backgrounds. Similarly, in a study conducted in the United States, Hotz et al. (2005) find that adverse consequences associated with early childbearing are mostly attributable to socioeconomic circumstances rather than the timing of their first birth, and young mothers are able to overcome many of these shortcomings over time.

The theory of gender stratification describes the impact of early marriage and childbearing on women's autonomy through reduced economic power, defined as women's control (relative to men) over economic resources such as income, property, and other means of production (Blumberg, 1988). Net economic power can indirectly influence women's leverage in household power, increasing their say in decision making regarding fertility, sexuality, economics, domestic issues, and division of household responsibilities. This theory is supported by empirical evidence showing that increases in women's income are associated with increased autonomy and improvements in reproductive health (Amin, Ahmed, Chowdhury, & Ahmed, 1994; Blumberg, 1988, 1991; Schuler & Hashemi, 1994; Schuler, Hashemi, & Riley, 1997). In addition, studies in both developed and developing countries show that women with greater education and income have more power to assert their preferences in favor of their daughters, are more likely to spend their income on food, and are less likely to spend it on alcohol and cigarettes (Hoddinott & Haddad, 1995; Thomas, 1994).

While human capital theory focuses on the utility of abilities and skills for economic production, Amartya Sen proposes a broader framework that describes people's capabilities or the freedom to live the life that they value (Sen, 1999a; Sen, 1999b, 1999c, 2002). This approach emphasizes the importance of examining effects of child marriage and early childbearing on women's agency as well as their health and education.

Health consequences of early marriage include sexually transmitted diseases, cervical cancer, HIV infection, and adolescent pregnancy. Other factors that make them more vulnerable to sexually transmitted diseases include their low autonomy, which decreases their involvement in decisions affecting their sexual and reproductive health, and the fact that they tend to marry older men who have had more sexual partners (Clark, Bruce, & Dude, 2006). Health effects of early childbearing operate through a combination of biological, behavioral, and psychological mechanisms (Fraser, Brockert, & Ward, 1995; Magill & Wilcox, 2007). Marriage increases the period of sexual exposure between puberty and menopause, and in sub-Saharan Africa, married girls tend to have riskier partners than unmarried girls (Clark, 2004; Clark et al., 2006; Gavin et al., 2006; Nour, 2006). Early marriage is also associated with lower use of contraceptives to delay their first pregnancy and greater experience of gender-based violence (Santhya et al., 2010). Adolescent mothers are physiologically unprepared for pregnancy, and they are more likely to have a larger number of children with inadequate birth spacing. As a result, early childbearing increases the risk of anemia, maternal morbidity, maternal mortality, obstetric fistula, preterm birth, low-birth-weight babies, and infant mortality (Letamo & Majelantle, 2001; Magill & Wilcox, 2007; Makinson, 1985).

Previous Programs Designed to Prevent Early Marriage and Early Childbearing

In parts of developing countries where marriage precedes first pregnancy, programmatic focus is on delaying the marital union, which will in turn delay the first pregnancy. There is some evidence from studies in developing countries showing that interventions using multiple strategies can potentially be effective in delaying the age of marriage for adolescent girls (Amin, Ahmed, Saha, Hossain, & Haque, 2016; Amin & Sedgh, 1998; Erulkar & Muthengi, 2007, 2009; International Center for Research on Women (ICRW), 2007; Mathur, Mehta, Malhotra, & Ickovics, 2004). In developed countries and in some settings of developing countries, where pregnancy precedes marriage, the programmatic focus is on delaying the age at first sex and increasing the use of contraceptives for adolescents who are sexually active.

Three main strategies that have been utilized in adolescent pregnancy prevention programs include education, contraceptive services, and community-based life option programs (DiCenso, Guyatt, Willan, & Griffith, 2002; Nitz, 1999). Educational programs provide information on sexuality, reproductive health, decision making, and sexual relationships. Interventions based on family planning clinics and school clinics provide youth with access to contraceptive methods, as well as psychosocial counseling. Community-based programs consist of a range of services for adolescents, parents, and other community members, such as workshops and group activities to improve decision-making skills or to enhance communication between adolescents and adults. Other strategies that have been included in comprehensive pregnancy prevention programs are media campaigns, recreation programs, monetary incentives, mentoring, physical and mental health services, and job clubs.

While many programs have been effective in increasing knowledge or changing sexual behaviors, there is little empirical evidence that they significantly reduce the incidence of teenage pregnancies. DiCenso et al. (2002) conducted a systematic review of randomized controlled trials of teenage-pregnancy prevention programs. They identified 26 programs that fit their criteria, including school-based sex education, multifaceted programs, family planning clinic-based programs, and abstinence programs. Authors found no evidence that these primary prevention strategies are effective in delaying the initiation of sex, or increasing contraceptive use for adolescent males and females. Furthermore, results of the meta-analysis show no reductions in teenage pregnancy. A 2016 Cochrane review on interventions for preventing unintended pregnancy among adolescents examined 53 randomized controlled trials in high-, middle-, and low-income countries (Oringanje et al., 2016). Based on meta-analysis, only interventions including multiple components (i.e., education and contraception promotion) were found to significantly reduce unintended pregnancy.

Multi-sectoral interventions can be defined as those that target change in more than one thematic sector, such as education, health, and economic development. One benefit of using multi-sectoral interventions is the ability to simultaneously address three types of factors that influence health-related behavior: predisposing, reinforcing, and enabling factors (Green, Kreuter, Deeds, Partridge, & Bartlett, 1980). Predisposing factors, including knowledge, values, beliefs, and attitudes, motivate a behavior before it occurs. Enabling factors facilitate the performance of an action and are generally conditions of the adolescent's environment. Reinforcing factors reward the behavior after it occurs and increase the chance that it will continue. Another reason why multidimensional approaches are particularly important when working with adolescent girls in sub-Saharan Africa is the fact that the root causes of the outcomes of interest are often interrelated. These include the multiple background and early adolescent factors described above. When designing multi-sectoral interventions, it is helpful to have a clear theory of change that describes how the different components will address different predisposing, reinforcing, and enabling factors needed to reach the desired outcomes. One example of such a program is the Adolescent Girls Initiative-Kenya.

Case Study: The Adolescent Girls Initiative-Kenya

This chapter uses the *development and design* of one particular study in order to demonstrate the importance of the multi-sectoral approach. The findings from the analysis of survey data will be published in the future. The Adolescent Girls Initiative-Kenya (AGI-K) is a program that is taking a multi-sectoral approach to addressing early marriage and pregnancy. AGI-K includes interventions from four sectors: violence prevention, education, health, and economic strengthening. A randomized controlled trial with a 4-year longitudinal study will be used to test the additional impact and cost-effectiveness of each layered intervention component (Austrian et al., 2016). The four study arms are (1) violence prevention only, (2) violence prevention + education, (3) violence prevention + education + health, and (4) violence prevention + education + health + wealth creation. The first wave of results from AGI-K will be available in early 2018 and will give an indication if the evidence supports the hypotheses on the multi-sectoral pathway to delaying early pregnancy. A follow-up round of data will be collected two years after the intervention that will assess longer term impact and will be available in early 2020.

AGI-K is being implemented in two very different settings. The first is Kibera, a large, urban informal settlement in Kenya's capital Nairobi. Kibera is characterized by crowded living conditions, lack of formal government services, high rates of violence, and political instability. The second site is rural Wajir County in Northeast

Kenya along the border of Somalia. Wajir is almost exclusively made up of a Muslim, Somali Kenyan population; it is very sparsely populated and has a stark lack of physical infrastructure and a limited cash economy. Early pregnancy is a key issue in both settings. According to the 2013–2014 Kenya Demographic and Health Survey (2015), 17.4% of 15–19-year-olds had given birth or were currently pregnant in Wajir, and half of 25–29-year-olds had given birth before or at the age of 19 years. Estimates from the 2012 Nairobi Cross-Sectional Slum Survey (2014) showed that 22% of 15–19-year-olds had given birth in Nairobi urban slums, and 38% of women between the ages of 20 and 24 had given birth before or at the age of 19. However, a key difference between the two sites is that in Wajir, the majority of teenage pregnancy occurs within the context of marriage; in Kibera, most teenage pregnancy occurs outside of marriage. Among women between the ages of 25 and 49 in Wajir, the median age at first marriage (18.1) was lower than the median age at first birth (20.8). On the other hand, in Nairobi slums, among 25–49-year-old women, the median age at marriage was higher (22 years) than the median age at first birth among women aged 25–39 (20 years).

Therefore, in Wajir, delaying marriage is the primary pathway to delaying childbearing, while in the Nairobi slums, it is delaying sexual debut and/or increasing contraceptive use. In both settings, in order to address the wide range of predisposing, reinforcing, and enabling factors that are driving early pregnancy—social and cultural norms that undervalue girls, school dropout, lack of health knowledge, lack of economic independence, and low self-esteem and communication skills—effects from each single-sector intervention are expected to contribute to achieving the overall goal in a particular way (see Fig. 3.2).

The interventions for AGI-K were based on the asset building theory of change that posits that girls need a combination of education, social, health, and economic assets to make a safe, healthy, and productive transition from childhood into young adulthood (Austrian & Ghati, 2010; Bruce & Sebstad, 2004). In addition, community norms regarding girls' values must be strengthened to facilitate the increase in assets for girls and the resulting improvements in medium- and longer term outcomes (see Fig. 3.3). Below is a description of each intervention and the specific causal mechanisms that will be tested in the research study.

Violence Prevention

The violence prevention intervention is a community-level intervention that uses the community dialogues and contracts strategy. The strategy is to engage community members in dialogue to identify problems, develop their own solutions, and gain a sense of ownership in addressing social issues. It is important to involve key stakeholders that are often gatekeepers to girls' well-being. In addition, the definition of violence within the community is not limited to sexual and physical violence, but is a broader conceptualization of violence as the devaluation of girls, including early marriage, lack of education, and female genital mutilation/cutting (FGM/C). Once

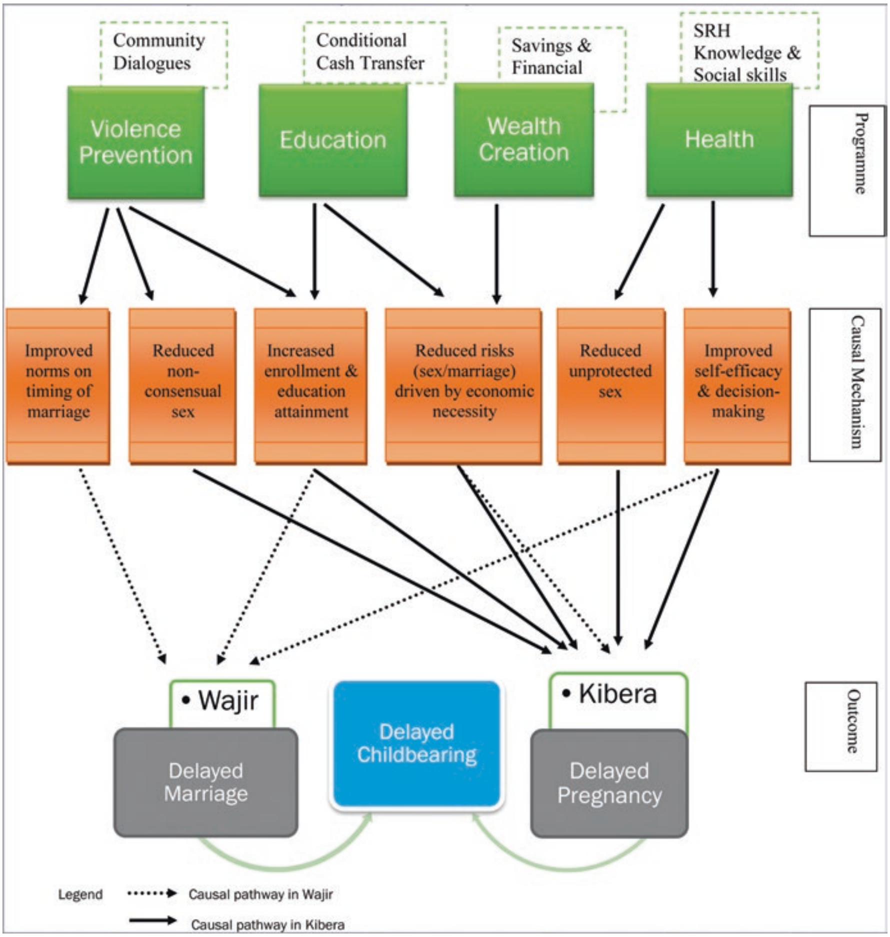

Fig. 3.2 Adolescent Girls Initiative-Kenya (AGI-K) causal mechanisms by which interventions may affect the timing of childbearing

a core committee is established in each village, they are taken through a facilitated process where they learn to identify the key issues in the community that lead to the undervaluing of girls, develop a "contract" of steps to address those issues, and then carry out activities to implement the contract over the course of the intervention period. A small amount of funds is available to implement the contract in each community. The committee is comprised of religious leaders, community leaders, parents, teachers, and young men and women.

The violence prevention intervention is designed to have an immediate effect on the value of girls at the community level. In Wajir, this increased value will be expected to change attitudes, perceptions, and norms on the timing of marriage for girls (i.e., marrying older is better for girls for a range of reasons), and this is expected to delay marriage directly. Delaying marriage is expected to result in a

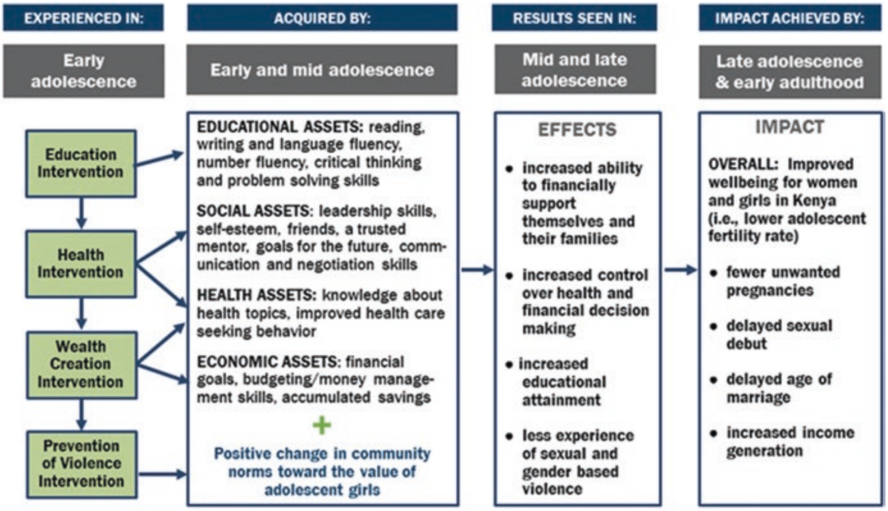

Fig. 3.3 Adolescent Girls Initiative-Kenya (AGI-K) theory of change

delay in childbearing, since in Wajir almost all births occur within marriage. In both Kibera and Wajir, the intervention is also expected to increase the importance that the community places on educating girls at the primary level and beyond, which should lead to an increase in educational attainment, which is also associated with delayed marriage and delayed childbearing. In Kibera, the change in attitudes, perceptions, and norms around sexual violence against girls is expected to lead to a decrease in unintended pregnancies by reducing the incidence of nonconsensual sex.

Education

The education intervention is a conditional cash transfer (CCT) based on confirmed enrollment and attendance over the course of a term. All girls are eligible for the interventions irrespective of baseline schooling status (in or out of school). A girl is eligible for the CCT for the entire 2-year period and receives the payment in any term where she meets the condition. There are four components to the transfer including (1) a payment toward school fees made directly to the school; (2) a cash payment to the head of the household twice per term; (3) a schooling kit containing sanitary towels, underwear, a pen, a notebook, and soap given directly to the girl at the start of the term; and (4) an incentive payment to the school equivalent to US$5 per girl for program management.

The education conditional cash transfer intervention is hypothesized to affect the timing of childbirth through two main mechanisms. The first is through girls staying in school longer (Baird, Chirwa, McIntosh, & Özler, 2010; Diamond, Newby, & Varle, 1999; Lloyd, 2006). As described above, in Kibera increased schooling is expected to directly delay childbearing, while in Wajir it is expected to impact childbearing through a delay in the timing of marriage. The second causal mechanism is through increased household income, which can reduce risks to girls driven by economic necessity (Lloyd & Blanc, 1996). In Wajir, it is anticipated that increased income may lower the economic incentive for parents to marry their daughters, thus delaying the age of marriage. In Kibera, the hypothesis is that access to economic assets will allow girls to have more control over their sexual partnerships, decreasing their likelihood of engaging in transactional sex in which they have less power to negotiate for safer sex (Austrian & Anderson, 2015). Therefore, a reduction in these types of sexual relationships is expected to reduce unwanted pregnancies and delay childbearing.

Health

The health intervention makes use of the safe spaces model (Austrian & Ghati, 2010) in which girls meet in groups once a week over the course of 2 years under the guidance of a female mentor from the community. Groups are segmented by age (11–12 vs. 13–14) in Kibera and by schooling status (in school vs. out of school) in Wajir. The groups will follow a structured curriculum and will allow time for open discussion. The curriculum will include topics on hygiene, nutrition, HIV/AIDS, sexual and reproductive health, communication/negotiation skills, gender norms, sexual and gender-based violence, female genital mutilation/cutting (FGM/C), early marriage, leadership skills, and relationships.

Groups meet in spaces identified in the community as safe and appropriate for girls, which could be community halls, schools, churches, mosques, community leaders' residences, and others. The groups have a twofold purpose: (1) to serve as the platform through which the health and life skills curriculum are delivered and (2) to foster the development of positive peer relationships and self-esteem and provide a place where girls can express themselves and share their problems, experiences, and questions.

The health intervention will increase knowledge of sexual and reproductive health, as well as social support through strengthened peer networks and adult female mentors. This intervention will then work through two key mechanisms to delay childbirth. The first is through improved self-efficacy (Lee-Rife, Malhotra, Warner, & Glinski, 2012; Santhya et al., 2010), which in Wajir girls can draw on to have more say in the timing of their marriage, or to engage community leaders (through the mentor) to intervene in the case of stopping a planned marriage. In Kibera, the improved self-efficacy is expected to lead girls to change their sexual behaviors—either through delaying sex all together or through increased ability to negotiate for contraceptive use during sex (Hendriksen, Pettifor, Lee, Coates, & Rees, 2007; Young, Martin, Young, & Ting, 2001). The second mechanism is through increased SRH knowledge, which will primarily be relevant in the Kibera slum setting due to the frequency of premarital sex and increased access to contraception as compared to Wajir, where a reduction in unprotected sex is expected—either through delaying sex/abstaining or through increased contraceptive use.

Wealth Creation

The wealth creation intervention is composed of savings and financial education, added on to the safe spaces groups. A financial education (FE) curriculum is added to the group sessions for the girls in the wealth creation arm. These sessions help girls develop basic money management skills such as saving, budgeting, and differentiating between needs and wants. In Wajir, girls in the wealth creation arm also receive a home bank (piggy bank) with US$3 in cash deposited inside after completing the first unit of five financial education sessions. The purpose of the cash is to allow girls to immediately put into effect the skills learned through the financial education sessions. The results of two recent literature reviews evaluating financial education suggest that financial education is most effective in achieving sustained behavior change when the lessons learned can be put into practice at the time of the education (Fernandes, Lynch Jr, & Netemeyer, 2014; Miller, Reichelstein, Salas, & Zia, 2014). Therefore, the design includes an immediate opportunity for girls to start acting on their savings goals and budgets. An additional US$3 will be distributed at the start of the second year of the intervention for the same purpose.

In Kibera, girls in the wealth creation arm are aided in opening SMATA accounts with the Kenya Post Office Savings Bank (Postbank). These accounts differ from other "junior accounts" in the market in that they are opened and managed by the girls themselves. Girls need a cosignatory to open the account and make withdrawals. The cosignatory is a trusted adult above the age of 18 and selected by the girl. The program caters for the US$2 minimum operating balance. A US$3 KES deposit is made at account opening and at the start of the second year, following the reasoning explained above.

The wealth creation intervention will help girls to improve their financial literacy and accumulate savings—informal in the case of Wajir and both formal and informal in Kibera slums. This increased financial independence is expected to lead to a reduced risk of transactional sexual relationships for girls in Nairobi, as described in the education section. In Wajir, where approximately two-thirds of girls are expected to marry by the age of 19, financial literacy and access to financial resources are likely to improve girls' role in decision making. Having increased control over health decision making, including use of contraceptives to delay first birth, could potentially result in an additional delay in childbearing.

Conclusion

This chapter describes the multidimensional drivers of early marriage and early childbearing in developing countries, as well as the complex, interrelated consequences for girls' health, education, and economic well-being. Adolescence is a key period for the development of capabilities that enable individuals to reach their full potential to enable them to become productive members of society and achieve their aspirations. Many adolescent girls in sub-Saharan Africa lack opportunities to develop their capabilities, which places them at a disadvantage compared to other adolescents. As described in the 2016 Lancet Commission on adolescent health and well-being, these capabilities can be enhanced by keeping adolescents in school longer, delaying their transition to marriage and childbearing, and reducing their health risks (Patton et al., 2016). The commission calls for investments in strong multi-sectoral, multilevel, and multicomponent interventions and actions to address the inequalities, norms, legal frameworks, and lack of resources that prevent adolescents in developing countries from fully developing their capabilities. In this chapter, the Adolescent Girls Initiative-Kenya is provided as an example of a multidimensional program including interventions across four sectors (violence prevention, education, health, and wealth creation) and across multiple levels (individual, household, and community) to build girls' education and social, health, and economic assets while improving community norms and the value of girls in society. The overall objectives of this program are to delay the age of childbearing by delaying the age of sex in an urban site, and delaying the age of marriage in a rural site. A rigorous evaluation study will test specific mechanisms hypothesized to link each intervention with the timing of marriage and childbearing, and will assess potential differences in the two sites.

Delaying the age of marriage and childbearing is important from a rights perspective, to enable girls to develop socially, emotionally, and physically, as well as to enable them to complete their education before transitioning to adulthood so they can make informed choices about who to marry and when to have children. It is also important from a development perspective to enable girls to have more productive lives and higher earnings in the future, and to increase a country's overall gross domestic product. According to a World Bank study conducted in 2011, if all adolescent girls in Kenya completed secondary school and all adolescent mothers were employed instead of becoming pregnant early, this would lead to an increase of US3.4 billion in Kenya's annual gross income (Chaaban & Cunningham, 2011).

The evidence points toward a multi-sectoral approach to addressing the high prevalence of child marriage and adolescent pregnancy in sub-Saharan Africa and other developing countries. This requires using multiple intervention components to address predisposing, enabling, and reinforcing factors that perpetuate these outcomes, by simultaneously empowering girls through education, social skills, health knowledge, and economic strengthening while addressing community gender norms, attitudes, and practices. The Adolescent Girls Initiative-Kenya will provide evidence related to the efficacy of the multi-sectoral approach, specifically in terms of which intervention components are more effective, which are less effective, and at what cost, in the search for evidence-based programs that help adolescent girls

Discussion Questions

1. What are the main drivers of early marriage and early childbearing in developing countries, and how are they interrelated?
2. How can a combination of theoretical frameworks help us understand the various consequences of early marriage and childbearing?
3. In your view, what are the key arguments made in the case for a multi-sectoral approach?
4. Thinking about the case study provided, describing the Adolescent Girls Initiative-Kenya (AGI-K), how do the proposed mechanisms strengthen the case for a multi-sectoral approach?
5. Which component of the case study intervention do you think will most likely be the key driver in delaying early pregnancy and childbearing in sub-Saharan Africa? Why?

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Chapter 4
Reframing the Way We Think About Teenage Motherhood

Brittany D. Chambers and Jennifer Toller Erausquin

> *"My God, that should be a Cabbage Patch baby in that bassinet." I said, "Can you believe that's yours?" I told her, "You need to stop having sex."*
>
> (Kaplan, 1997, p. 3)

Introduction

Approximately 8% of births in the United States are to teen mothers (Hamilton et al., 2011). The majority (57%) of births are to minorities and teens from disadvantaged communities (CDC, 2014). Teenage pregnancy is associated with many health disparities for both mother and child, in comparison to women who delay pregnancy until adulthood. For example, only 40.6% of teen mothers under age 15 and 57.5% of teen mothers aged 15–19 received adequate prenatal care (Healthy People 2020, 2014). Consequently, infants born to teen mothers accounted for 14.1% preterm births and 9.8% of infants born at low birth weight (March of Dimes, 2014). As infants of teen mothers become children they are faced with more adversities, such as lower scores on tests assessing language and cognitive abilities compared to children born to adult women (Rafferty et al., 2011). Some scholars argue that young age is not the primary driver of these health disparities; rather they are the impacts of stigma (SmithBattle, 2013). Teenage pregnancy and motherhood stigma emerge from the intersection of oppressive identities such as poor or low income and early motherhood (SmithBattle, 2013). Research indicates that teen mothers feel stigmatized by early transition into motherhood, limiting their interactions with medical facilities, schools, and social services.

This chapter uses a contemporary feminist lens to argue for a shift in the current views of teenage motherhood. Contemporary feminism posits that dominant discourses produce generalizations about groups, people, and situations (Baxter, 2008). In the

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context of teenage pregnancy, current views of teen mothers are overwhelmingly negative and stigmatizing: “promiscuous,” “deviant,” and “social pollution” (Kaplan, 1997; Luker, 1996; Rolfe, 2008). Further, teenage pregnancy has been painted as a direct link to a “dependency culture,” crime, and absent fathers (Luker, 1996). The aim of contemporary feminism is to employ a women-centered perspective, evaluating and describing the perspectives of women. This chapter employs a youth- and women-centered perspective to explain the structural barriers and social definitions of teen pregnancy that have contributed to the current views of teen pregnancy and shine light on the positive experiences of teenage mothers who have been overshadowed, further proposing a contemporary feminist lens in public health research and practice.

Background

Trends of Teenage Pregnancy in the United States

There has been a downward trend in teen birth rates in the United States for the past decade (Center for Disease Control and Prevention [CDC], 2014; Focus on the Family, 2010; National Campaign to Prevention Teen and Unplanned Pregnancy, 2013). In 2011, the US teen birth rate was 31.3 per 1000 teen females aged 15–19 years (CDC, 2014). More specifically, teen birth rates declined 11% for teen females 15–17 years old, and 7% for teen females 18–19 years old (CDC, 2014). This represented an 8% decline from the reported rates in 2010 (CDC, 2014). In fact, teen birth rates have also fallen by 52% since 1991 (NCPTP, 2013).

Similarly, there has been a decline in teen birth rates for all race and ethnicity groups excluding Asian/Pacific Islanders aged 18–19 (CDC, 2014). Although there have been declines in teen birth rates, teen pregnancy is still viewed as a social and economic dilemma (CDC, 2014). Minority teens, and youth from socioeconomically disadvantaged communities, have higher birth rates (CDC, 2014). In fact, Latina and black teens are twice as likely to give birth during adolescences compared to white females (NCPTP, 2013), representing 57% of all births to teen mothers in 2012 (CDC, 2014). Additionally, teens residing in southern states are more likely to birth infants during adolescence (CDC, 2014), where Mississippi, New Mexico, Arkansas, Texas, and Oklahoma had teen births of 50 or higher per 1000 teen females 15–19 in 2010 (Ventura, Hamilton, & Mathews, 2013).

The reasons behind the declining teen pregnancy rates in the United States are under debate. In examining the National Survey of Family Growth, Ventura et al. (2013) attribute changes in teen birth rates to changes in pregnancy, abortion, and fetal loss rates among teens aged 11–19 years. However, these authors also note little to no change in birth rates by race and ethnicity, and thus a continued pattern of health disparities by race, in which Latina and black teens remain more likely than their white peers to become teenage mothers. Similarly, NCPTP (2013) attributes declines to an increase in contraception use and delay of sexual initiation, specifically among Latino and black teens. In contrast, Focus on the Family (2010) amends declines in teen birth rates to abstinence-only sex education, using declines in initiation of sexual intercourse among teens in grades 9–12 as evidence to support this claim; however, Boonstra (2008) at the Guttmacher Institute argues that abstinence-only preventions contribute to high teen births in the United States. Scientific research suggests that abstinence-only programs do not contribute to the delay of initiation of sexual intercourse, or number of sexual partners across the life span. In fact, according to the American Academy of Pediatrics, abstinence-only programs are ineffective and can potentially cause harm by presenting inadequate information that can result in teens' inability to use safe sex practices once they initiate sexual intercourse (Boonstra, 2008). At the very least, there is some evidence that teens are delaying sexual intercourse and/or using protective methods to prevent pregnancy (CDC, 2014).

Reproductive Rights of Teenagers

Teenage pregnancy is a complex issue intersecting adolescence and reproduction. Mainstream US society views adolescence as a time for psychological and physical development; because they are going through a period of transition and growth, teens are therefore treated as incapable of making sound reproductive decisions. This view is supported through the consistent struggle for teens' reproductive rights (e.g., contraception, abortion, and prenatal care) across states in the United States (Luker, 1996). As a result, cultural anxiety is produced where parents do not believe that their children are participating in sexual risk behaviors and may actively oppose policies that allow their children to access reproductive health services without parents' consent. For example, the state of Alaska has been battling with parental involvement laws and abortion for over a decade (Center for Reproductive Rights (CRR), 1992–2013). Alaska's parent involvement law states that parental notification of abortion services for teens under the age of 17 is constitutional, mandating that at least one parent is notified of teens' contemplation of abortion, followed by a 48-h delay before the procedure (CRR, 1992–2013). Although under this law teens have the right to obtain a judicial bypass, in December of 2012 a judge clarified that there must be compelling and concrete evidence to receive one (CRR, 1992–2013).

Historical Trends in Attitudes Toward Mothering

Teenage mothers are often excluded from the notion of "motherhood" due to the tradition of teens being marginalized from the discussion of "good mothering" (Alderson; James & Prout), limiting teen mothers' voices and experiences. Dominant modern concepts of American motherhood were formulated in the mid-1960s, through women of the grassroots breastfeeding advocacy group La Leche League sharing their stories of motherhood and breastfeeding (Weiner, 1994). The La Leche

League is an important piece in social history and feminist thought, as it challenged industrial life in the mid-1960s while owning domesticity and biological aspects of womanhood (Weiner, 1994). While the womanhood movement was empowering for particular groups of women, it also created a dichotomy between a "good mother" and "bad mother." The normative concept of motherhood or "good mothers" includes white, married, middle-classed women who breastfeed their children until toddler years (Weiner, 1994). "Bad mothers" included women of color, low-income, working, single mothers, and women who bottle-fed their children (Weiner, 1994). Not until the late twentieth century that researchers began to focus on socially marginalized groups of women such as low-income, divorced, and drug-using women to show how the normative perspective constrains the concept of motherhood, and produces guilt and shame among marginalized groups of women (Garcia, Surrey, & Weingarten, 1998). Teenage motherhood has been viewed as a threat to the nuclear family, due to the belief that teenage pregnancy leads to poverty, single-parent households, and a continuous cycle of "at-risk" youth. As a result, a majority of teen mothers are marginalized in many ways including socially, discursively, and economically (Rolfe, 2008).

Methodology

This chapter studies the problem of the stigma attached to teenage motherhood and the closely related lack of access to essential support services by examining the structural barriers to access, present-day cultural attitudes toward teenage motherhood, and how teenage mothers themselves conceptualize their situation. The phrases "stigma," "teen pregnancy," "teenage pregnancy," "teen moms" "teenage mom," and "motherhood" were used to locate articles, books, and images in Pubmed, GoogleScholar, University of North Carolina at Greensboro library search engine, and Google. All materials were reviewed. Only relevant materials related to teenage pregnancy, stigma, and access to sexual and reproductive services were included.

Structural Barriers to Access to Services and Support for Teenage Mothers

Structural barriers to access sexual and reproductive health services for teen mothers have increased since the 1950s. Structural barriers directly related to decreasing access to sexual and reproductive health services for teen mothers include changes to the US welfare system, implementation of stigmatizing laws targeting teen mothers, and parental involvement in teens accessing sexual and reproductive health services.

In the 1950s, eligibility for the US welfare system, including Aid to Families with Dependent Children, was expanded to include dependent children of single mothers with absent fathers. These children and mothers, some of whom were black families, had previously been ineligible to access cash benefits. This changed the image of the typical welfare recipient from the widowed single mother to the working single mother. Prior to the expansion of the US welfare system in the 1950s, only widowed women were allowed to seek cash aid assistance from the government. With this shift, the image of the working woman changed to the dependent poor black woman (Geronimus, 1997). As a result, the myth that the majority of women on welfare were black who strived to have children for welfare benefits emerged (Kaplan, 1997; Luker, 1996; SmithBattle, 2012). This is exemplified in the Moynihan Report of 1965, which concluded that black poverty is directly linked to the moral structure of the black community, contributing to low marriage rates and high teen birth rates, postulating that welfare only ameliorates the effects without attacking the fundamental problem (Moynihan, 1965). Consequently, the Welfare Reform of 1996, which rebranded cash benefits as Temporary Assistance for Needy Families (TANF), was implemented and placed a five-year limit on benefits.

Teen pregnancy was identified as a national problem in 1965 through the proposed legislation, the National School-Age Mother and Child Health Act. This act argued that "(1) pregnancy among teens is a serious and growing problem; (2) such pregnancies are the leading cause of school dropout, familial disruption and increasing dependency on welfare and other community resources" (Luker, 1996, p. 71). In 1978 the Teen Health, Services, and Pregnancy Prevention Act was passed launching the national teen pregnancy prevention campaign (Luker, 1996), further arguing that teenage motherhood has negative immediate- and long-term impacts on teens' lives. During the late 1990s, teenage pregnancy was characterized as an essential cause for poverty (Kaplan, 1997; Luker, 1996; SmithBattle, 2012).

Teens were more likely to be impacted by the revisions of the Welfare Reform of 1996. One goal of the Welfare Reform of 1996 was to decrease the amount of money the government spends on teen pregnancy in the social welfare sector (Acs & Koball, 2003; Miranne, & Young, 2002). Acs and Koball (2003) found that there was not a substantial change in teen birth rates in the years immediately following implementation of TANF; however, there was a decrease in teens who were welfare recipients (Levin-Epstein & Schwartz, 2005). Before the implementation of TANF, 25% of teen mothers received welfare cash benefits; however, after welfare reform, only 5% of eligible teen mothers received cash benefits (Acs & Koball, 2003). The decline in TANF participation among teen mothers can be due to new restrictions in TANF eligibility such as living "in the home of a parent, adult relative or guardian and must pursue a high school diploma or GED," in order to receive TANF (cash aid, food stamps, and MediCal) (Miranne, & Young, 2002, p. 7). More recently, one study found that participation in the TANF program has been effective in decreasing high school dropout rates among teen mothers (Koball, 2007); however, these findings have not been confirmed by other studies (Hao & Cherlin, 2004).

Although most states in the United States give minors the right to consent to reproductive care (e.g., contraceptives, testing and treatment for sexually transmitted infections and HIV, prenatal care and delivery), parental consent and school enrollment requirements add additional barriers in teens receiving government assistance (Boonstra & Nash, 2000; Miranne & Young, 2002). In examining "socially constructed boundaries" implemented after the Welfare Reform, Miranne and Young (2002) addressed multiple boundaries that teen parents have experienced in society. "Socially constructed boundaries" are defined as constructs that limit a persons' capacity to function freely in the world (Miranne & Young, 2002). Of the many boundaries discussed, "adult-supervised settings" have been a major constraint in teens obtaining governmental assistance. Policies that were put into place through the Welfare Reform mandated that teens "live in the home of a parent, adult relative or guardian and must pursue a high school diploma or GED," in order to receive TANF (cash aid, food stamps, and MediCal (Medicaid in other states)) (Miranne, & Young, 2002, p. 7). This stipulation imposes on teens' confidentiality and can influence their decisions to take care of their reproductive health, especially during pregnancy.

Teen pregnancy has been labeled as a financial hardship on the American economy (Hoffman, 2008). In 2008, taxpayers spent $8.1 billion on teenage pregnancy, averaging $1647 for each child born to a teen mother (National Campaign to Prevention Teen Pregnancy (NCPTP), 2012). The amount spent on teen pregnancy varies by state, ranging from 16 million (North Dakota) to 1.2 billion (Texas) (NCPTP, 2012). The majority of the funds are spent on public sector health care, child welfare, incarceration, and lost revenue paid by children born to teen mothers due to lower taxes as a result of educational attainment and low wages (NCPTP, 2012).

Societal Images of Teenage Pregnancy Through Mass Media

While teen birth rates are declining in the United States, new interest in the topic has emerged in mass media. In fact, mass media has been identified as an effective source to distribute information, particularly with messaging among teens about sexual risk behaviors. NCPTP (2010) conducted a study among 1008 teens aged 12–19 and found that 79% of females and 67% of males expressed that TV shows addressing teen pregnancy made them think about their sexual risk behaviors. Additionally, 76% of teens reported that displaying love, sex, and relationships on TV shows and other mass media outlets is an effective approach in beginning dialogue with adults about these topics (NCPTP, 2010). Government agencies and organizations have used mass media as prevention strategies to reduce teen pregnancy including the TV hit series *16 and Pregnant* and *Teen Mom*, coverage of the teenage celebrity Jamie Lynn Spears' pregnancy at age 16, and New York City's teen pregnancy prevention poster campaign.

The hit TV series *16 and Pregnant* (and its follow-up, *Teen Mom*) was created through a partnership among MTV, Kaiser Foundation, and the National Campaign to Prevent Teen Pregnancy to motivate teenagers to practice abstinence or use birth control through modeling the negative consequences of teenage pregnancy

(Guglielmo, 2013). However, a series of critical review articles about *16 and Pregnant* and *Teen Mom* argue that the reality TV series does indeed reduce teen pregnancy rates while also exploiting teenage motherhood through framing teen pregnancy as an individual choice and policing teen mothers to conform to "normative motherhood" (Guglielmo, 2013). The normative concept of motherhood or "good mothers" includes white, married, middle-class women who breastfeed their children until toddler years (Weiner, 1994). The TV series *16 and Pregnant* and *Teen Mom* document the transition to motherhood as a linear process. Pregnancy among teens is viewed as a decision to become a mother rather than an event that opens up a series of other choices (i.e., abortion, adoption, or motherhood), where teen mothers' decision processes to keep their children are not explicitly disclosed through the media. Rather, teen mothers implicitly provide a rationale for raising their child, portraying a dominant discourse of teen pregnancy, participating in "adult" behaviors that produce "negative consequences." More specifically, the show emphasizes the ideology that teens who feel that they are grown enough to engage in sexual intercourse should be tough enough to handle the consequences, raising a baby. This limits teens' right to choose what they would like to do with their pregnancy and produces the image of a "good mom" vs. a "bad mom." A "good mom" is classified as a teen mother who prioritizes her motherly duties and overcomes the stereotypes of the "typical" (e.g., welfare dependency, high school dropout) teen mother. In contrast, a "bad mom" is characterized as a teen mother who neglects her child to participate in traditional teen behaviors such as parties, makeup, and hanging out with friends. Mass media's portrayal of a teenage motherhood contributes to the dominant perspective of motherhood (i.e., white, middle class, and mothering), othering teen mothers that do not fit into this profile.

The dominant discourse of a "good mother" policing teen mothers' decisions is also evident in some of the media coverage of teenage television actress Jamie Lynn Spears. At perhaps the height of her fame at age 16, the star discovered that she was pregnant. She spent the next 5 years out of the public eye. When she finally broke her silence she told a reporter that she felt overly scrutinized for making irresponsible decisions to engage in sexual intercourse. When the news broke that she was pregnant, parents were outraged, as they viewed Spears as a role model for their children who watched her TV show, *Zoey 101*, on Nickelodeon. Spears discussed how the tabloids made hurtful statements about her decision to enter teenage motherhood, including statements about "glamorizing teen pregnancy," "giving up her baby," "miscarriage," and asserting that "her partner was cheating." Spears argued that she was doing the best that she could for herself, her family, and her fans:

> "Was it hurtful for my parents to read stuff about their daughters? Yes. Obviously seeing [sister Britney Spears' negative tabloid coverage], I knew how far it could go. I've never wanted to be put under that kind of scrutiny. I just wanted to get away from it as much as I could, to just go away and be a mom and figure out what I wanted, and to earn a sense of respect back for myself. Move to a town in the middle of nowhere and just raise my child. All I could be was a good mother. If anybody had anything to say after that, there was nothing I could do" (Shanker, 2012, p. 2)

Societal views of teen pregnancy projected shame and guilt on Spears, causing her to focus on "good mothering." Spears conformed to "normative motherhood," dropping everything and raising her child.

In 2013, the City of New York's Resources Administration released five posters in efforts to prevent teen pregnancy. These posters contribute to the dominant discourse that teen sexual intercourse leads to a dreadful life as a single mother, further gendering teen pregnancy, where only teen mothers are condemned for not thinking of consequences for child scrutinized. Two of the posters were directly related to fatherhood. One poster is of a black toddler; the poster states, "Honestly mom … chances are he won't stay with you. What happens to me? Are you ready to raise a child by yourself? 50% of teen parents don't marry each other" (NYC Human Resources Administration, Department of Social Services, 2014). The second poster is of a white baby, perhaps 1 year old; the poster states, "Dad, you'll be paying to support me for the next 20 years. Think being a teen parent won't cost you? NY state law requires a parent to pay child support until a child is 21" (NYC Human Resources Administration, Department of Social Services, 2014). These posters are on display at subways and bus shelters throughout New York City (NYC Human Resources Administration, Department of Social Services, 2014). These posters stigmatize teen mothers and do not accurately display the social and economic contexts that contribute to teen pregnancy. Like the media coverage of Jamie Lynn Spears' teenage pregnancy and motherhood and the TV shows *16 and Pregnant* and *Teen Mom*, the NYC teen pregnancy prevention campaign makes broad generalizations of teenage motherhood, silencing the diverse experiences of teen mothers.

Destigmatizing Teen Pregnancy: Stories Unheard

> "Women who are living on welfare, divorced, or unmarried, aged under 20, lesbian, drug-users, or who have committed criminal offences are all marginalized in relation to the category of 'good mother'" (Rolfe, 2008, p. 300)

There is a dearth of information documenting experiences of teenage motherhood. Traditionally, teenage motherhood is excluded from the conversation, marginalizing teen mothers as the "wrong mother." However, research shows that teenage motherhood may not always be a "problem" (Geronimus, 1997; Rolfe, 2008; SmithBattle, 2012). Pregnancy during adolescence can have positive impacts on teens' lives. Teens from disadvantaged communities can view teenage pregnancy as satisfying and prideful, further making the delay of pregnancy insignificant (Geronimus, 1997; Rolfe, 2008). Consequently, teen mothers view motherhood as "an opportunity and achievement, as well as a challenge" (Rolfe, 2008, p. 301). The joys of teenage motherhood are often overshadowed by the negative consequences of teen pregnancy; thus, this section aims to destigmatizing teenage motherhood giving meaning to teenage pregnancy. This provides evidence that teenage pregnancy is not necessarily linked to negative consequences for mother and child.

Research shows that negative consequences associated with teen pregnancy are substantially reduced or eliminated when analyses control for background characteristics including educational attainment, welfare dependency, and poverty (SmithBattle, 2012). More specifically, there were minimal differences found in outcomes between teen mothers and their identical twin sisters who delayed pregnancy until adulthood, teen mothers and teens who aborted or miscarried, and teen mothers and their sisters who also delayed pregnancy until adulthood (SmithBattle, 2012). Similarly, in a study among white women followed for 35 years, there were no differences between women who delayed pregnancy after 20 years old and teen mothers in income, psychological health, and satisfaction in marriage, jobs, and social support. Among this population, there were differences found in mental health outcomes; however, differences were associated with childhood adversities linked to social and economic context, representing a common health disparity experienced by low-income women (SmithBattle, 2012). Additionally, younger teen mothers are more likely to have health complications during pregnancy compared to older teen mothers and adult women; however, late entrance into prenatal care partially explains these differences.

Is teen pregnancy really a health problem? According to the NCPTP (2012), 19% of teen pregnancies are unplanned, indicating that the majority of teen mothers are making conscious decisions to enter motherhood. For some teens, motherhood is viewed as a step toward individualism and safety.

Many teens view motherhood as a path to individuality, where for the first time, they are able to do things their way. Furthermore, teenage motherhood allows teen mothers the opportunity to cultivate positive environments and experiences for their children, including preparing for their future. As shown in the Smith et al. (2012) study, a 14-year-old immigrant living in North Carolina, expecting her first child, described her personal goals and expectations for motherhood:

> "I hope like next year she will be getting better, like growing up good. And I hope my score in school will be getting higher. Yeah, I want to be a good mom and a good student … And be successful" (Smith et al., 2012, p. 8)

This teen is expressing the complexity of motherhood, balance among multiple roles. This quote further suggests that teen mothers are not overwhelmed by motherhood; rather they are ready for the challenge.

Teen mothers also mentioned motherhood as a challenging yet pleasurable experience. Teen mothers discussed their transition to motherhood, including financial strains and celebrating their children's milestones. In a study by Rolfe and colleagues (2008), a teen mother from an underserved community in England is quoted sharing about the process of her transition to motherhood:

> "Oh yeah! [laughing] Never having no money that's worst. Never. Can't just go out and treat yourself. You've got to think about what you've got to spend on these first … That's definitely. There's more good than bad-really …. Like when they first say the first word or they first walk, and like, it was Geraldine's birthday the other week, and you're just dead pleased on her birthday, you know. And she's just started talking as well, so, you know like, when you hear that, and like, when the first tooth comes, and daft things like that-you just get giddy" (Rolfe, 2008, p. 304)

Teen mothers acknowledge the struggles of motherhood. However, teen mothers stressed that the good outweighs the bad. Another teen mother shared her rationale for pregnancy during adolescence stating, “effectively, there was nothing to lose and everything to gain” (Rolfe, 2008, p. 304).

Conclusion

Dominant discourses of teen pregnancy include teen mothers will drop out of high school, head single-parent households, seek government assistance, and live in continuous poverty, placing a victim-blame perspective on teen pregnancy. Societal overgeneralizations of teen pregnancy stigmatize teen mothers and create pervasive stereotypes of teenage motherhood.

The stigmatization of teenage motherhood has been perpetuated through laws and processes that have limited teen mothers’ access to sexual and reproductive health services. As seen with welfare reform of 1996, teen mothers who do not live in the home with a parent or guardian are denied supportive services (e.g., cash aid). These stigmatizing laws cause harm to teen mothers and their children. Among the few studies exploring the stigma of teenage pregnancy and motherhood, findings indicate that pregnant and parenting teens experience stigma in multiple sectors in society: school, medical offices and clinics, social services, the media, and negative glares and verbal assault in public (Fulford & Ford-Gilboe, 2004; Higginbottom et al., 2006; Yardley, 2008). As a result, pregnant and parenting teens reported shame and guilt, which oftentimes leads to unhealthy coping strategies such as avoiding interacting in spaces where they felt stigmatized (Fessler, 2008; Fulford & Ford-Gilboe, 2004; Yardley, 2008). Avoiding medical care during pregnancy and the postpartum period can result in complications during pregnancy, as well as adverse birth outcomes for children.

The stigmatization of teenage motherhood forces teen mothers to “live on the margins,” challenging the notion of the “wrong mother.” Many studies have documented that pregnancy during adolescence can serve as a positive and motivational experience for some mothers. Similar to other groups of women, teen mothers describe motherhood as “rarely unproblematic, being characterized by ambivalence and disruption, as well as happiness and fulfilment” (Rolfe, 2008, p. 300). Many teen mothers have expressed motherhood as a chance to make a difference “to do things differently” or to have someone to love.

Studies also have shown that teen pregnancy is a complex phenomenon (SmithBattle, 2012). High rates of teen pregnancy are associated with structural barriers such as childhood poverty, access to quality education, and low wages (SmithBattle, 2012). Although many teen mothers seek government assistance, teen pregnancy is not the cause of poverty for this population. Teen mothers often come from disadvantaged backgrounds prior to pregnancy. Therefore, to better address teen pregnancy while also cultivating teenage motherhood, public health research and practice should consider structural intervention strategies to eliminate social inequities.

Discussion Questions

1. Compare and contrast the three arguments for declines in teen pregnancy rates. Which argument(s) do you agree with? Why?
2. List attributes of "good" and "bad" mothering. Explain how these attributes can contribute to the stigmatization of teenage motherhood.
3. Identify the goals for the Welfare Reform of 1996. How did these goals positively and negatively impact teen mothers' lives?
4. Based on your own experiences and information presented in this chapter, do you feel TV and social media can influence teens' perceptions and behaviors? How can this influence dominant discourse around teenage pregnancy and motherhood?
5. Reflecting on teen mothers' stories, do you feel society's images of teenage motherhood are accurate? Why or why not?

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Part II
Childbearing

Chapter 5
Vaginal Birth After Cesarean Section (VBAC): Informed Choice and a Source of Empowerment Among Black Women in the United States

Kara Fransisco and Morgan Sanchez

> *"Reproductive freedom is a right that belongs to all women; but its denial is felt the hardest by poor and minority women."*
> *Dorothy E. Roberts, 1990*

Introduction

In the last year alone, the United States has seen over three million births (Martin, Hamilton, & Osterman, 2016). While childbirth is not a new phenomenon by any means, the social conditions under which women give birth have continually evolved over time. For centuries pregnancy and childbirth were considered normal elements of life—in the sense that they remained free from diagnostic testing and prescription drugs, and were often conducted in the home. Today, pregnancy (and childbirth in particular) is regularly considered a medical event (Riessman, 1983)—one which is often dominated by medical professionals and interventions such as cesarean delivery.

Because there are a variety of childbirth experiences within the United States, dependent on (among other things) the types of medical interventions performed as well as the type of laboring assistants present, the current state of birthing is complex and arguably complicated. In part, this complexity is due to the medicalization of childbirth and resulting resistance. Indeed, scholars have argued, even well before the dramatic increases in cesarean deliveries, that childbirth was highly medicalized (Davis-Floyd, 1990, 1994; Fox & Worts, 1999; Graham & Oakley, 1981; Katz Rothman, 1982; Oakley, 1980). While this is true for all women, Black women are

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particularly likely to experience a medicalized childbirth, as they have the highest rates of both cesarean and preterm deliveries (Hamilton, Martin, Osterman, Curtin, & Mathews, 2015).

Medicalization

Historically, the definition of medicalization has been loosely constructed within the social sciences (Conrad, 1992). According to Conrad (1992), medicalization is when we adopt medical frameworks and language, or use interventions to treat human conditions. In the specific context of childbirth then, medicalization is the transformation of what once was a natural biological process into a medical process—allowing physicians or medical institutions the power to potentially shape and control these experiences (Conrad & Schneider, 1980; Riessman, 1983). The medicalization of prenatal care and childbirth can take many forms, from intensive surveillance during both pregnancy and labor to the employment of medical interventions during childbirth such as labor induction, epidural administration of pain medications, and placement of urinary catheters.

Within the United States, cesarean deliveries represent one area of increasing medicalization in women's childbirth experiences. Although some cesarean deliveries are performed due to health risks towards the mother or fetus, scholars, medical professionals, and medical organizations, such as the American Congress of Obstetricians and Gynecologists (ACOG), believe that many cesarean deliveries are unnecessary or excessive. Because cesarean deliveries are not without potential risk and/or complications for mothers (i.e., hemorrhaging and increased risk of placental abnormalities during future pregnancies) as well as newborns (i.e., risk of pulmonary disorders), this research is both timely and important (Zelop & Heffner, 2004; Kolas, Saugstad, Daltveit, Nilsen, & Øian, 2006).

In recent decades, cesarean deliveries have seen a rapid rise. In 1996 for example, the percentage of cesarean sections performed was roughly 20.7% and it has risen every year since then—peaking in 2009 at 32.9% (Hamilton et al., 2015). Although the national cesarean delivery rate for all women declined in both 2013 and 2014 (down to 32.7 and 32.2%, respectively), this change amounted to less than a full percentage point. Additionally, Black women have in the past, and continue to have, the highest rate of cesarean deliveries among all racial groups (Hamilton et al., 2015).

The increasing percentage of cesarean deliveries is related to medicalization—potentially as a by-product of medicalization, as a form of medicalization itself, or both. For instance, cesarean deliveries may be the by-product of medicalization if they result from other forms of medical intervention during labor, such as having an induction or receiving an epidural before active labor begins (Heffner, Elkin, & Fretts, 2003; Klein, 2006). Viewed another way, cesarean deliveries can be a direct form of medicalization, such as policies that deny patients who had previous cesarean deliveries the opportunity to attempt a vaginal labor and delivery. While

ACOG supports vaginal births after cesarean sections (VBACs), the organization has specific recommendations and suggested policies for their occurrence. For instance, they argue that a doctor should be onsite to monitor women continuously, and that the birth facility should have equipment readily available in case another cesarean delivery is necessary.

Despite the existence of these restrictive policies, there is a slow change occurring in the obstetrical landscape. Along with feminist health scholars (whose concerns include the medicalization of women's bodies as well as positive experiences and health outcomes for expectant mothers), medical and healthcare service providers are becoming attentive to the once-rising and still very high cesarean rates. Feminist scholars in particular note the harmfulness of medicalizing women's bodies, which is sometimes accompanied by a reduced sense of power, agency, and choice concerning one's birthing experience. Perhaps as a result of this attention, some women are becoming more informed about their choices during pregnancy and childbirth, particularly with respect to VBACs. Decision-making processes, choice, and control are components of reproductive freedom and autonomy, particularly as they relate to pregnancy and childbirth. This choice can extend to women's mode of delivery. We argue that VBACs can provide a sense of empowerment in childbirth among mothers who actively choose it.

However, this choice is often not without certain obstacles. Studies suggest that Black women may have a higher risk for complications during childbirth than other women. Although this may be true, these risks are then compounded by the risk of cesarean deliveries, as cesareans carry higher rates of complications for both mothers and babies. Additionally, Black women not only have the highest rates of cesarean deliveries, but they also have lower rates of VBACs. This in spite of the fact that Black women have significantly lower risks of uterine rupture compared to other racial groups is a major concern among physicians who prefer to avoid VBAC and favor repeat cesarean (Cahill, Stamilio, Odibo, Peipert, Stevens, & Macones, 2008). It is the intention of this work to examine the childbirth experiences of Black women who choose to have a VBAC despite the potential obstacles.

Pregnancy Experiences, VBACs, and Informed Choice

Although some Black women do choose VBACs, little research has considered their experiences of childbirth after cesarean delivery. Equally little research has examined the role of information and prior birthing experience in this important decision-making process. Overall women's experiences with VBACs indicate that they actively seek out birth narratives from other women online, as well as additional information and emotional support from online discussion boards (Konheim-Kalkstein, Whyte, Miron-Shatz, & Stellmack, 2015). Studies have also found that the issue of VBAC can be confusing, as information from healthcare providers may be contradictory and/or unclear (Lundgren, Begley, Gross, & Bondas, 2012). Given the lack of clarity women receive about VBACs from healthcare providers, along with their likelihood to seek out birth narratives and information from other women online, it is prudent that scholars begin to explore the intersection of birth stories and the Internet.

Although previous research has largely focused on the childbirth experiences of White women, several studies exist which exclusively focus on the childbirth experiences of Black women. One study found that Black women who chose home birth did so in order to maintain desired control; they also reported dissatisfaction with medical aspects of intrapartum care (Farrish & Robertson, 2014). The topic of birth preparation, which is especially pertinent for a VBAC, has also focused largely on White women and subsequently ignored Black women (Abbyad & Robertson, 2011; Lu & Halfon, 2003). Abbyad and Robertson found that Black women tend to rely on family and community for birth preparation, though classes were important for a smaller number of women (2011). Another study found that there was a considerable burden of racism that may have been intensified in Black women by the stressors of pregnancy and childbirth (Jackson, Phillips, Hogue, & Curry-Owens, 2001).

Based on Dorothy Roberts' conceptualization of choice, women can only make a true choice when they are uncoerced in their selected decision and have the actual ability to follow through with that decision (1990). In other words, true informed choice in pregnancy and birthing is more than knowledge acquisition, as it involves multiple stages of decision-making and action-taking processes. One study found that while decision-aid booklets might help in improving knowledge about repeat cesarean deliveries and VBACs, there was little evidence that knowledge alone produced informed choice (Shorten, Shorten, Keogh, West, & Morris, 2005). Given the notable confusion that women feel about the VBAC information they receive from their physicians (Lundgren et al., 2012), the reality that women seek out information online from other women about VBACs (Konheim-Kalkstein et al., 2015), and Black women's appreciation for knowledge gained through life experiences and shared via communities (Banks-Wallace, 2000; Abbyad & Robertson, 2011), we believe that informed choice and empowerment may result from spaces where knowledge is shared and when VBACs are ultimately achieved. To this end, we sought to explore the following research questions: (1) What experiences led these Black women to choose a vaginal delivery after a cesarean section? (2) How did these women seek to empower themselves within this childbirth journey? (3) What if any effect did choosing to have a VBAC have on their perceptions of self?

Methods

The goal of our study was to understand Black women's experiences of having vaginal births after previous cesarean deliveries, particularly among women who narrated and shared their birth stories in online communities. The purpose was to hear the stories from an underexplored population in reproductive health research and better understand the role of prior cesarean deliveries in subsequent births. While we proceeded with a broad inductive strategy, we were also guided by research interest in the role of informed choice in birth stories to better understand if and how VBACs differed from cesarean deliveries for women who experienced both. By examining their birth stories, which often included both birthing plans and preparations, as well as the lived experiences of childbirth, we were able to see if and how informed choice allowed for Black women's empowerment during birth.

In an effort to better understand Black women's experiences with VBAC and repeat cesarean deliveries, we collected online birth narratives that were posted by women between 2013 and 2015. We were interested in the meanings women attach to childbirth, specifically VBACs, and their experiences. This qualitative study uses phenomenological methods (Schutz, 1967), and our questions and data analysis focus on the significance of births to the women who shared their stories. As a result, our project and analyses focus on the significance of these births and the meaning it has to women based on their written narratives.

With the advances in both technology and accessibility, Americans are using the Internet more than ever. The Internet serves as an informant for health-related decisions. In particular, women are using the Internet as a source of information during pregnancy (Sayakhot & Carolan-Olah, 2016; Lagan, Sinclair, & Kernohan, 2010; Romano, 2007; Song, Cramer, McRoy, & May, 2013). This online information seeking also extends to VBACs (Konheim-Kalkstein et al., 2015).

We used Google, one of the most used search engines worldwide, to find publicly shared birth stories. Our first focus was to find women who were engaging in VBACs and sharing their narratives online. We found many communities where women from all over the world were sharing their experiences of VBACs. Our search strategy, detailed below, became more refined as we included racial identifiers to read accounts of Black women in the United States who were not only having VBACs but were also sharing their experiences for other women to read and learn from.

We wanted to find birth narratives that other mothers or women interested in becoming pregnant would find if they were to seek this information out themselves. Both researchers agreed upon search terms, including "VBAC" and "vaginal birth after cesarean/C-section," after reviewing and discussing commonly used terminology in gynecology and in popular online birthing communities, such as BabyCenter. Many other results included blogs and smaller forum-based websites. However, we were interested in a specific population, which required refining our search terms to include "Black" and "African-American" coupled with VBAC terms. Because we were interested in studying a community where birth stories were shared publicly with the purpose of others reading the content, we purposively sampled a community with thousands of members that centered on the experiences of women of color. In addition to the website, this community has a social media presence with a regular flow of activity, indicating that it is an active space where women engage with one another about birthing. The majority of the community's participants identified as living in the United States.

This part of our study examined only the birthing stories that were shared publicly on the community's website. While some of these stories are cross-posted in other areas of the larger community, such as social media, we limited our sample to the narratives presented in blog format. This resulted in a final total of 39 birth stories.

Each birth story was read holistically and then coded line by line by each researcher; we coded five birth stories together and the coded all subsequent narratives individually. Having agreed upon coding terms in the original five stories, we used those codes in the later stories we each read. After all the data were coded, we then compared our codes for each story and came to naming consensus upon new codes that arose in later birth stories.

Although this sample is nonrandom, there is diversity among the women. Although a common challenge in online research can be a lack of demographic information available, the blog format allowed for a more holistic view of the women, their backgrounds, and what parts of their identity were most salient to them when reporting about their births. For instance, a majority of the mothers were in their mid-20s to mid-30s, which falls within the typical reproductive age range. While all women self-identified as Black, some women specifically reported having racially diverse families; around 15% of the sample reported having husbands or partners who were Latino or white. The majority of the respondents expressed religiosity or spirituality. One woman reported being Muslim, while the others expressed general Christian viewpoints without mentioning specific denominations of Christianity.

Findings

Although the cesarean section is viewed as a singular medical event occurring at one point in time, our study has indicated that the effects of the cesarean section impact Black women's lives well beyond the event itself. When making the decision to have another child, women were often required to reflect upon their previous birth experiences. Cesarean sections, and the medicalization of childbirth, were often a traumatic event that impacted future family formation decisions. As a result of this trauma, Black women were often committed to the idea of a VBAC and the resulting agency it provided. Gathering knowledge, and asserting their will through informed choices, allowed Black women to reclaim their birth experience and become empowered. VBACs then served multiple purposes, the most important of which was as a healing and transformative process. Through vaginal delivery, the women of this study described regaining a feeling of wholeness and rejecting notions of bodily imperfection.

Experiencing Past as Present

The women selected for this study often described their previous birth experiences as part of their current birth story. As one woman stated, "I suppose the story of a VBAC must begin with the c-section, and since that's probably the most important part of my story, I'll start there." Almost all of these VBAC stories began with extremely detailed accounts of previous pregnancy and cesarean experiences, indicating their long-term importance to women—even after having a successful VBAC.

In many ways these prior pregnancies and deliveries were wrought with pain and psychological trauma. The cesarean section was a perceived separation of the mother-to-be and the labor itself. Almost all of the women in this study described a feeling of disconnectedness not only from their pregnancy and birth experiences but also from their maternal providers. Alexia recalls speaking to her close friend after an appointment:

> "I remember calling a very close friend after the appointment to voice how much I felt like I was part of a "business." I explained how the in and out atmosphere of the obstetric/gynecology clinic was not how I envisioned my first prenatal experience to be. I was almost teary eyed while on the phone thinking about the cervical check I just had, and how uncomfortable it was."

For Alexia, the very personal experience of pregnancy was suddenly transformed into an impersonal production. Her emotional needs, such as comfort, were pushed aside in favor of efficiency. The less time wasted on the patient, the more patients could be seen, and the more money made. This desire for efficiency was sometimes perceived as both the reason behind the cesarean and the resulting separation of mother and child postdelivery.

Jonna had two children who were born through cesareans. As a result of the medications given during her cesarean, Jonna missed the initial bonding period most mothers take with their children after childbirth. She describes the period following the birth:

> "They didn't bring her to me until after she was already bathed, I lost track of time and it felt like forever before I got to hold my daughter; my husband tells me it was at least an hour and a half … It wasn't until a few months after her birth that the way she came into the world bothered me. I felt like I was lied to, that I wasn't given enough options. Sure, I was happy that we had a healthy baby girl but I felt like something was missing…"

In this quote Jonna is describing a sense of disconnectedness after her delivery. In one sense this disconnection is physical—Jonna misses out on the initial physical bonding experience with her daughter—but it is equally emotional. As a result of the cesarean Jonna describes something as "missing"; she describes a lack of agency—in this case a lack of options that didn't include having cesarean. This lack of agency and choice, in addition to the feeling of disconnection, resulted in emotional trauma for Jonna and most of the other mothers. Further, Jonna feels lied to by her medical professional—which could then impact her future birthing plan.

For Zulu, the actions of her OB/GYN during her first childbirth experience were enough to delay the conception of her second child. Because Zulu's first birth involved having a cesarean under false pretenses, faith in the medical profession was shaken; she required time to build up adequate resources to resist medical dominance. Zulu described her first birth, a cesarean, as unlike anything she imagined: "The birth of my first son was anything but a gentle welcome to parenthood. Instead it was the exact opposite it left parts of me traumatized, broken, and incomplete."

This response suggests two points of interest. First, each mother may hold an imagined road map of how the birth experience proceeds. Secondly, when this road map is unnecessarily and coercively deviated from, it results in a prolonged distress that impacts the mother's sense of self. The trauma that occurs from these types of cesareans is both emotional and physical. The women in this study describe feeling as though their bodies are broken or unable to fulfill their biological purpose; this leaves them feeling incomplete or missing something associated with the birth experience. Many of the women in this study, like Zulu, undergo cesareans under false pretenses. In some cases they suffered from a lack of information, or misinterpretation of diagnostic tools, but far too many were the subjects of falsified information. Jonna describes how her physician lied to her to suit her own ends:

> "My husband and I have two children born via c-section. Our eldest daughter was born via c-section because our doctor told us I failed to progress after only 3 hours of being in labor after my water was broken. We were 23 years old, on our own in a city we didn't know, and enrolled in graduate school, and didn't know much about labor and so we trusted her. We found out later that the real reason she pushed for a c-section was because she wanted to go home to her children. She told us this while I was on the operating table."

For Jonna, the lasting effects of her delivery went beyond physical recuperation; it was a betrayal of trust. In this case, the physician took advantage of Jonna's lack of knowledge concerning childbirth, her and her partner's age, and their newness to the area for her own benefit. Instead of being an advocate and assistant in Jonna's birth experience, the physician coerced Jonna into having a medical procedure and only revealed the real reason why when Jonna was in a vulnerable position. The revelation that her physician lied to her in order to speed up the delivery took several months to sink in, but when it did, it left Jonna feeling like something was missing; this ultimately set the stage for her commitment to a VBAC. Other women in our study, such as Lana, experienced similar deceptions. Lana had her first cesarean as a result of an induction gone wrong. As a result, she was consistently pressured by medical professionals to continue having cesareans. Lana describes the experiences leading up to her commitment to a VBAC:

> "I was always told by my doctors that because I had my first c-section that I would have to keep having them, even though my first c-section was the result of an induction gone wrong. There was no medical reason that I couldn't have a vaginal birth, so when I discovered that women were having vaginal births after c-sections I was angry. I felt lied to, and when I found out how much doctors got paid for c-sections versus vaginal births, I felt manipulated."—Lana

Like many women, Lana's commitment to having a VBAC came after she began educating herself on the business of birth. In this case, the elements of deception involved physicians deliberately spreading misinformation—namely that Lana would be unable to have a VBAC. For Lana, this deception was enough to cause feelings of anger and mistrust in the medical profession, but was furthered as she continued educating herself on the price tag associated with different birth experiences. In this study, women's feelings of disconnection from their birth experience, as well as outrage over being misinformed, often led to a firm commitment to have a VBAC, as well as a commitment to self-empowerment through informed choices.

Making the Commitment

For some women, the preliminary decision to refuse another cesarean was not a political statement or one informed by current debates. Initially, it was based on a reflection of the stress associated with their first birth. For Jocelyn, her first commitment was to herself—she did not wish to experience surgery again; however, this decision marked the beginning of a process and not a single choice. Making the commitment often involved a lengthy course of action—it was not enough to say that one wanted to have a VBAC. Expectant mothers then had to search through numerous providers in order to find one who would be equally as willing to commit to their patients' wishes. This was not a simple task for many of the expectant mothers. Jocelyn describes the process of making her commitment:

> "My first commitment was that I did not want surgery again. I had no idea what VBAC was or that it was controversial in the medical field … I started reading about VBACs and alternative birthing locations. That's when I decided that I didn't want to give birth on a hospital bed. I wanted no part of another c-section, drugs or all the stress hospitals bring for me … I was determined to have my water birth now. I researched and researched and had trouble finding a doctor or a hospital that would fit my (growing but few) demands. No one would take me as a VBAC natural birth candidate. That was until I found [my midwife] … She encouraged me and told me I could do it."

Finding allies was often the second step in the commitment process. The women in this study were in search of professionals who they felt could be trusted; this often meant the incorporation of doulas and midwives—people who could and would advocate for them when the expectant mothers were vulnerable in labor. For some of these mothers, finding someone who understood the racial component of the push for cesareans was an important part in building trust. For Zulu, whose decision to conceive a child was delayed as a result of her traumatizing first birth, having a midwife who understood the implications of race on childbirth experiences was particularly important:

> "Prior to conceiving I had found a midwife who supported my plans for HBAC and a doula who was able to relate to the trauma I had experienced and knew the implications and outcomes of how difficult birth is to achieve for women of color. Although my doula did not have experience with homebirth she knew how realistic the outcomes were for women of color and she knew how we were treated in the hospital system because she was a mother and also a woman of color."

Zulu made the commitment to have her next child at home rather than in the hospital. In doing so, she required even greater understanding from her birthing provider—a woman who understood not only what the pressures and risks were as a Black woman to have a cesarean, but also the disparity in hospital treatment experienced by women of color. The commitment to have a VBAC was also couched in future birth decisions. For Jonna, having a vaginal birth after two cesareans was considered the only option if she wanted more children:

> "When we decided to have our third baby we knew we were at a fork in the road. We knew that a VBA2C was our only shot if we wanted to have more children after this third baby …

> But our friends and family just thought we were crazy for driving that far to deliver a baby and unsure about why we would take the risks that come with vaginal births after C-sections. But we were confident in our choice, we knew that it was our destiny."

In this case, Jonna's commitment to having a VBAC began with her future plans for additions to the family unit. Having a VBAC was seen as an act of agency—one that she was willing to go out of her way to assert. Although the mothers rarely faced any resistance on the part of their families, there was definite resistance from the medical community at large. In order to combat this resistance, the expectant mothers in this study often went above and beyond what was expected of other pregnant women, meticulously researching their rights and options, as well as attempting to maintain their health in an effort to make informed choices and combat the medicalization of their experience.

Informed Choice and Empowerment

Previous research strongly suggests that the treatment of pregnancy has shifted from a natural, biological phenomenon to that of a medical condition. The women of this study were sometimes met with suspicion and displeasure for failure to adhere to this patient role. Often, they reported having little agency or choice in their cesarean deliveries. After making the commitment to VBAC, women began asserting their agency in many ways. For instance, some women became agents by educating themselves as much as possible about the choices involved in the birthing experience. Rachel for example spent much of her time studying and gathering information:

> "I began studying and watching videos on VBACs, reproductive system, health and nutrition, process of labor and birth, cesarean operation[s], labor process in hospital, birth centers and home, breastfeeding, differences between midwife and OB/Gyn, labor assistants, differences in nurses, how to take care of your body after birth and infant care, and more. I was ALL in! … I was ready to have another baby … I chose this OB because he had previously worked with my family members and they said he was a good doctor and he assisted in VBACs before … He was African American too and that put me more at ease because previous doctors I was seen by, of other races, were not so courteous to me or [my] body."

For Rachel, empowering herself meant taking a combined approach of choosing the right medical professional and consuming as much childbirth-related media as possible. Rachel's doctor was equally committed to her choice for a VBAC and showed a greater level of respect for her as a person with rights than other doctors. This is something that Rachel attributed in part to her doctor being of a concordant race. Race then plays an important part in these mothers' quest for empowerment—finding someone who understood their experiences in the context of the medical institution was just one way they exercised informed choice. Finding a medical ally of VBACs was important—as Dorothy Roberts argues that true choice is impossible without the ability to follow through with a decision (1990). Learning about VBACs, one's rights, the medical jargon, and outcomes represented the other half of the equation of informed choice. For expectant mothers such as Cora, educating themselves about these interventions allowed them to advocate for themselves even under intimidation. Cora describes how she advocated for herself during her second pregnancy:

> "Unlike with my first pregnancy, I was educated about the different interventions and medications and was able to advocate for myself. I was confident and bold enough to say no when the doctors on call attempted to rush and intimidate me into breaking my water too early. I was bold enough to fire one doctor who was clearly not in support of my VBAC and was cocky and even rude … The nurses were frustrated because … I wouldn't stay in bed and lay on [my] back like a good patient…"

Like many of the other women in this study, Cora refuses to take on the passive role of patient and surrender her agency to the doctor on call during her VBAC. By empowering herself and asserting her agency in the birthing experience, Cora is challenging medical dominance, which results in her mistreatment by her doctor. Multiple women in the study described their commitment to having a VBAC as resulting in mistreatment by medical professionals. Choosing not to comply was seen as much of an informed choice as the gathering of information prior to childbirth. Crystal describes how she exercised her informed choice to have a VBAC and the role her research played in her decision:

> "I learned my lesson, no more just blindly trusting doctors without real research and proof. No more being compliant … I found out just how sad my little state was when it came to birth. Nobody touched them and our c-section rate is 35%. But I still studied, looked for support online and through mutual friends…"

For Crystal, the entire process of the VBAC was a learning experience. She learned the value of seeking out information and standing up for her rights, as well as the value of online communities. The women of our study used a variety of resources to achieve the births of their choice, and the online community played no small part in the search for resources. Using these online networks, the women of our group became acquainted with others' birth stories and ultimately drew upon those experiences in order to prepare themselves, mentally and intellectually, for the choices and challenges awaiting them in the medical setting. The act of committing to a VBAC and making informed choices, as well as asserting their agency in the hospital room, was a transformative process for the majority of women in our study.

Reembodiment

After having relived their past traumas and making the informed choice to have a VBAC, women described their subsequent birthing process as an act of reembodiment. The experience of prior cesareans, in many ways, disconnected the women from their birthing experience. They described these experiences as missing a crucial component that often left them feeling broken and incomplete. The choice to have a VBAC served as a way of reconnecting with the act of giving life. Many felt redeemed and made whole, such as Violet:

> “This experience was more than I could’ve hoped for. I feel so redeemed, so grateful, so ecstatic to have had this birth. It’s still surreal to me … I have this newfound respect for my body and some for myself. [My partner] is now a homebirth advocate, really, he goes around telling women that they should birth at home…”

Often after having a cesarean, the women of this study felt as if their bodies had been incapable of what they perceived as a natural birth experience. As a result of this subsequent birth experience, Violet felt newfound respect for her body—in addition to a newfound confidence in her ability to have subsequent births at home. The VBAC also served as a transformative experience for her partner who became an advocate for birthing. The return to relative normalcy immediately after the birth event also had a healing effect on these new mothers.

For Alexia, the ability to immediately hold her child, as well as consume fluids and bathe, was seen as having a healing effect. Alexia describes the experience immediately after she gives birth to her son:

> “There were tears and smiles and not much talking during this time. My doula whispered in my ear, “you’re not broken, you’re whole”. There were many tears during this time. This entire experience was so much different from my first birth experience. I was awake and immediately held my baby; my husband was able to cut his cord. Once I was upstairs in the bed, I had skin to skin and was able to breastfeed. I immediately drank fluids, I was able to have a few bites of soup, and I took an herbal bath with baby.”

In this quote we again see the experience of VBAC as a transformative event in women’s lives. The doula in this case serves as a physical and vocal reminder that Alexia is a whole person, unbroken by her previous traumatic experience. Similarly her ability to partake in normal activities with her child right away gave her a sense of connectedness with her baby and her role as a mother. Like Violet and Alexia, LaToya also described a change in the way she viewed her own body and its capabilities:

> “… I was in disbelief. My body had done this all on its own, my body wasn’t a failure … I used to cry whenever I talked about the birth of my oldest children. I felt empty and like something was stolen from me. But now I feel like I have healed…”

Despite being armed with the knowledge of VBACs, having a commitment to see it through, and having supportive providers around her, LaToya was still shocked to discover that she was capable of having a VBAC. Her own thoughts about her body—that it was a failure—dissipated upon the birth of her child. While the effects of her previous experience are not forgotten forever, such as the emptiness she recalls feeling, she describes being healed through the power of birth. As we see here, and with all the women in our study, VBACs are not simply a life-giving event but a body-transforming one, both physically and emotionally. The scars from their cesarean deliveries indicate that the wounds have long since healed, but true healing, for many women, comes once they realize that their bodies are physically capable, and not abstractly, of giving birth vaginally.

Conclusion

Black women are engaging in VBACs and sharing their stories with one another online. Their previous pregnancy and birth experiences are often described negatively and have a considerable impact on women. They become a part of their current story, even after a successful VBAC. For many women, these traumatic experiences are their reasons for pursuing VBACs in the first place.

Black women's experiences with VBACs are tied to their original cesarean deliveries, and those births are often described with a lack of agency. The lack of control women described were often experienced in relation to their relationship with their reproductive health care provider, many of whom gave little information or misinformation. Prior experiences with misinformation or a lack of information were reasons that women sought out additional information about birthing on the Internet. In addition to seeking out birthing options, women also reported reading the stories of other women while they were either trying to conceive or already pregnant in an effort to plan their births—to regain a sense of control and agency that they had lost, which included learning about and seeking out supportive providers. Thus, the decision to have a VBAC is not whimsical or undertaken without considerable thought and research. The knowledge Black women accumulate through support networks, including online communities, along with having the access to willing providers, made VBACs possible through informed choice; this was an empowering process for Black women.

Discussion Questions

1. How do past pregnancy and birth experiences influence future plans, from family formation plans to pregnancy and birth plans?
2. What is the role of informed consent, autonomy, and communication during pregnancy, labor, and delivery experiences (past or present)? What "best practices" should be done by maternal care providers?
3. How can maternal care providers navigate the reality that many women, at least in this study, are dealing with birth trauma from prior unwanted cesareans while simultaneously experiencing a mistrust of the medical establishment?
4. The medicalization of childbirth is well documented by sociologists and other disciplines. Is it possible to "de-medicalize" birth? Should we, and if so how can we, work towards this?
5. The Internet has seen rapid growth, and researchers have called for more studies examining its effect and influence on healthcare. What role does the Internet serve for women seeking and sharing pregnancy and birth information, including VBACs?

Understanding that VBACs are more than simply a mode of delivery is important for providers. They are healing and transformative processes for women who have previously had traumatic pregnancy experiences and undesired cesarean deliveries. With willing and cooperative providers, VBACs serve as an opportunity to rebuild trust in medicine among Black women. More research in this area is essential. Future research could explore the prevalence and impact of misinformation on health disparities, especially because most women in this study reported either a lack of information or misinformation from their providers. Further, as online content continually grows, as well as Internet accessibility, more research should be done to understand the role it plays in many reproductive arenas—from preconception planning to birthing. Future researchers should also address the large gap of research with respect to Black women and their experiences with pregnancy and birth.

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Chapter 6
“Sickness of Shame”: Investigating Challenges and Resilience Among Women Living with Obstetric Fistula in Kenya

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Introduction

Obstetric fistula (OF)—a condition which causes a woman to leak urine or feces—can lead to lifelong ostracism, stigma, and shame. Obstetric fistula results from prolonged or obstructed labor, but indirect causes include lack of antenatal care, birth preparedness, and access to emergency obstetric care; early marriage; living in rural areas; and socioeconomic vulnerability (Dolea & Abou Zahr, 2003; Mehta & Bangser, 2006; Zheng & Anderson, 2009). Global estimates suggest that two million fistula cases exist worldwide with 50,000–100,000 new cases occurring each year (Mehta & Bangser, 2006). Studies demonstrate that despite variable complexity in fistula cases (Genadry, Creanga, Roenneburg, & Wheeless, 2007; WHO, 2006), correctly performed repair surgery and rehabilitative services result in improvement in both women’s physical and mental health by promoting self-esteem and social reintegration (Ahmed & Holtz, 2007; Khisa & Nyamongo, 2012; Lewis & De Bernis, 2006). However, access to surgical repair is often limited by prohibitive cost (100–400 USD), unavailability, or health system constraints (UNFPA & EngenderHealth, 2003). Thus, the silent suffering from this maternal morbidity burdens disadvantaged women living in low- and middle-income countries (LMIC) (Bangser 2007; UNFPA & EngenderHealth, 2003).

Women living with OF not only face stigmatizing and isolating circumstances because of the smell they emit, but also describe how the condition affects their relationships, social functioning, and economic productivity (Bangser, 2007; Mselle & Kohi, 2015). Many women face the threat of separation or divorce from their husband—in part due to the fistula itself and in part due to the limited ability of women with unrepaired fistula to bear children. This not only has a negative effect

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on a woman's self-esteem and sense of worth, but has implications for her motivation to access care. For women living with OF, the challenge of meeting a confluence of social, cultural, and economic normative roles highlights the gender power imbalances within many LMIC contexts that affect disparities in women's health and access to repair (Roush, Kurth, Hutchinson, & Van Devanter, 2012).

A systematic review identified 110 peer-reviewed studies with nine broad barrier types that women might experience when accessing care: psychosocial, cultural, awareness, social, financial, transportation, facility shortages, quality of care, and political factors (Bach, Warren, Baker, & Bellows 2017). These barrier factors enhance our understanding of the Three Delays Model which ascribes underutilization of maternity services to (1) the delay in decisions to seek care; (2) the delay in reaching an adequate health facility; and (3) the delay in receiving adequate care once at a facility (Thaddeus & Maine, 1994). Surgical repair, rehabilitative services, improved awareness, and supportive family and community environments may mitigate some of these delays and enable women to access care (Mselle & Kohi, 2015; Wegner, Ruminjo, Sinclair, Pesso, & Mehta, 2007). However we need to better understand the complexity of how sources of resilience fare in particular contexts to better inform policy and programming.

Here we draw upon the notion of resilience broadly defined as a "positive adaption" of those affected by fistula (Herrman et al., 2011): managing, seeking care, and reintegrating into household and community life. This chapter presents a study that explored the experiences of women affected by OF in Kenya to (1) better understand the barriers to and enablers of access to fistula repair and (2) utilize resilience patterns to recommend improvements in fistula policy and programming.

Methodology

Study Setting: Maternal Health and Fistula in Kenya

Maternal health indicators in Kenya at the time of this study (2008) had stagnated for over a decade. The proportion of women delivered by a skilled birth attendant was 44% nationally; in Central, Coastal, and Eastern provinces it was 74%, 46%, and 43%, respectively. Furthermore, 45–52% of women in these provinces did not receive any postnatal care, compared to the national average of 53% (Kenya National Bureau of Statistics (KNBS) & ICF Macro, 2010). Distances between health facilities and clients in Kenya range from <1 km (23%) to >10 km (13%) (Ministry of Health, Government of Kenya, 2014).

In 2003 the United Nations Population Fund (UNFPA) launched the global "Campaign to End Fistula." In Kenya, a UNFPA survey estimated that 300,000 women were living with fistula with approximately 3000 new cases occurring each year (UNFPA and EngenderHealth, 2003; HERA and IRCH, 2010). In 2004, Kenya Ministry of Health (MOH) initiated a multidisciplinary strategy to combat OF with stakeholders including UNFPA, nongovernmental organizations, medical training institutions, professional associations, and civil society (United Nations Population

Fund 2010). The strategy included awareness-raising through mass media and champions; prevention of OF through family planning and monitoring of labor; prevention through repair camps ("Fistula Fortnight") in selected hospitals to reduce the backlog; training of providers; renovation of facilities and supply of equipment and commodities; and social integration programs (Warren & Mwangi, 2008). Fistula camps make use of volunteer surgeons and complement the regular fistula services in private and public facilities (UNFPA, 2013).

Study Design

This mixed methods study draws on structured questions, case studies, and focus group discussions (FGDs) to understand the experience and social environment of women living with OF. Mixing methods during both data collection and analysis enables the quantitative and qualitative arms to inform one another. Triangulating across method and perspective enriches the trustworthiness of the data (Lincoln & Guba, 1985; Creswell, 2007). Concurrent qualitative exploration of quantitative findings allowed for better understanding of individual, family, and community reactions to identification of OF and subsequent care-seeking pathways.

Participant Selection

A total of 82 women who had experienced OF participated in this study (see Table 6.1 for details), including both those who were currently living with fistula and those who had been repaired. Women were identified through facility records and by community midwives working in surrounding communities. Sixteen FGD ($n = 160$) participants included men and women of reproductive age who were willing and able to talk about their perceptions of and support for women affected by OF, as well as their understanding of fistula causes. Female and male FGD participants included those who (or whose partners) experienced prolonged/obstructed labor and key opinion leaders. Community communication channels (religious gatherings, chiefs' barazas or meetings, and government administrators' notices) were used to invite FGD participants.

Data Collection

Data were collected in May 2008 in communities from four districts in Kenya's Central, Eastern, and Coastal provinces. Professional midwives with counseling skills and trained in data collection conducted interviews with women who had experienced OF. The questionnaire was administered in Kiswahili and comprised of both

Table 6.1 Descriptive statistics of women affected by obstetric fistula

Measure	Frequency	%	*N*
Less than 32 years of age	34	42	82
Highest level of school attended			82
Primary	35	43	
Secondary or above	47	57	
Monthly income			37
Less than 2000 ksh	15	41	
2000–5000 ksh	16	43	
More than 5000 ksh	6	16	
Province			82
Central	9	11	
Eastern	26	32	
Coastal	47	57	
Who did you fist tell?			80
Husband	30	38	
Other female/male relative or friend	21	26	
Hospital staff	16	20	
Mother- or father-in-law	7	9	
Community midwife or TBA	6	8	
How did spouse/sexual partner react?			69
He was supportive/understanding	37	54	
Became abusive and disrespectful	16	23	
Abandoned/sent me away	16	23	
Married another wife	4	6	
How did your family (mother/father) react?			82
They were supportive/understanding	72	88	
Found out about where I could be helped	16	20	
Deserted me	2	2	
Assisted you most financially			82
Mother or father	40	49	
Husband	37	45	
Sister or brother	18	22	
Other female/male relative or friend	12	15	
Mother- or father-in-law	5	6	
Church/Mosque or FBO/CBO/NGO	8	10	
Hospital staff	3	4	
Assisted you most psycho-socially			82
Mother or father	45	55	
Husband	28	34	
Sister or brother	23	28	
Other female/male relative or friend	19	23	
Hospital staff	17	21	
Mother- or father-in-law	8	10	

(continued)

Table 6.1 (continued)

Measure	Frequency	%	*N*
Church/Mosque, FBO/CBO/NGO, or employer	8	10	
Community midwife or TBA	2	2	
Sought care from a health facility after discovering condition	75	91	82
Received OF repair operation	59	72	82
Successful repair	40	68	59
Reintegrated socially	29	81	36
Resumed sexual activity	21	53	40

quantitative and qualitative items to elicit information about the participants including demographics, maternal health history, and fistula experience as well as more nuanced explanations of women's own experience trying to access fistula repair. These nuanced explanations were open ended and are referred to as "case studies" throughout this chapter. Using a semistructured discussion guide, four social scientists facilitated the FGDs in Kiswahili with equal numbers of men and women in each district (two male and two female groups per district) to elicit normative perspectives on OF awareness, care access, and sociocultural dimensions through a community lens. FGDs lasted for 45–60 min and were audio-recorded, transcribed, and translated into English. Ethical approval was obtained from Population Council's and the Kenya Medical Research Institute's institutional review boards.

Data Analysis

Quantitative questionnaires were analyzed using STATA and exploratory techniques. Key dichotomous outcomes described include whether a woman (1) sought care at a health facility after realizing her condition, (2) received a fistula repair operation, (3) felt socially reintegrated upon successful operation, and (4) resumed sexual activity. Primary independent variables of interest included who a woman first told about her problem, spousal reaction, family reaction, and sources of financial and psychosocial support. Spousal reaction was classified and dichotomized as "supportive/understanding," "abusive and disrespectful," "abandoned," and "married another wife." Family reactions were similarly classified as "supportive/understanding," "found out where to get help," and "deserted me." Sources of social support were captured by "who assisted you most financially/psychosocially." Secondary independent variables explored include age (dichotomized below and above mean of 32 years), education level (dichotomized as primary compared to secondary or higher), individual monthly income (<Ksh.2000, Ksh.2000–5000, and >Ksh.5000), and province (Central, Eastern, and Coastal). Descriptive frequencies were assessed for all measures and bivariate cross-tabulations of outcomes with independent variables. Bivariate analyses utilized a chi-square test to assess statistical significance of associations with fistula outcomes.

Qualitative data (case studies and FGDs) were analyzed using thematic analysis (Creswell, 2007). All transcripts were coded using a mixed (inductive and deductive) coding approach. Deductive codes were based on themes identified from a literature review (Bellows et al., 2015) while inductive coding themes emerged from reading the individual and group transcripts. Emergent themes derived from open-ended questions on barriers to and enablers of access were compared across perspective and method to get a fuller picture and generate a list of thematic areas through an iterative process. Consideration of these thematic areas was used to map the complex pathway to accessing fistula repair.

Results

Descriptive and Bivariate Analysis

The majority of women affected by fistula were secondary school educated (57%) with monthly incomes lower than Ksh. 5000 (~50 USD) (84%) (Table 6.1). On recognition of fistula symptoms, most women told their spouse, a relative, friend—or if identified after hospital delivery, a member of staff. Reactions of spouse and family members ranged from support to abandonment. Ninety-one percent sought care from a health facility, though only 72% received an operation, 68% of which were successful. Twenty-nine of the 40 repaired women felt socially reintegrated, while 21 reported having resumed sexual activity. Bivariate associations (Table 6.2) suggest that seeking fistula repair is positively associated with higher income (not statistically significant), informing spouse about fistula, spousal reaction, and financial and psychosocial assistance of a spouse or sibling. Receipt of a fistula repair may be associated by a spouse or family member reaction and support. The support of a sister appears particularly important for all outcomes, particularly reintegration into social life.

Qualitative Results

Barriers to and enablers of access to fistula repair capture acceptability, accessibility, affordability, and availability factors, and fall into broad themes: psychosocial, cultural, awareness, social, financial, transportation, facility shortages, and QoC (Table 6.3). Emergent themes were relatively consistent across sites, between case studies and FGDs, and by gender. Direct quotes are presented to illustrate the themes. Notable differences lay in women having slightly elevated health literacy around OF compared to men, facilities in Eastern and Coastal provinces maintaining stronger "husband-accompaniment" policies that restricted access to repair, and some single/separated women facing distinctly patterned barriers to and enablers of access compared to married women. Though it takes between a few weeks and years to access successful fistula treatment, most participants delayed their initial facility visit by more than a month after the fistula developed.

Table 6.2 Bivariate associations of independent variables with OF outcomes (chi-squared value)

Measure	Sought care at a health facility (*N* = 82)	Received OF repair operation (*N* = 82)	Reintegrated socially (*N* = 36)	Resumed sexual activity (*N* = 40)
Less than 32 years of age	0.52	0.53	0.34	0
Highest level of school: primary (ref: secondary/higher)	0.62	0.16	2.21	6.81**
Monthly income	4.1	5.03	1.63	2.92
Province	1.07	1.47	2.34	0.93
First told husband about condition	4.4*	0.52	0.34	0
Spouse or sexual partner's reaction				
He was very supportive/ understanding	7.6*	3†	0	0.39
Became abusive and disrespectful	7.0**	5.27*	0	0.23
Abandoned (deserted me or sent me away)	0.38	0.07	0.02	1.0
Married another wife	9.1**	4.8*	0.24	1.16
Family's (mother/father's) reaction				
They were very supportive/ understanding	1.92	2.72†	0.4	0.48
They found out where to get help	1.86	0.09	0.04	0.02
Deserted me	0.19	0.49	n/a	n/a
Assisted you most financially				
Husband	6.29*	2.78†	0.39	2.63
Mother	0.01	0	0.17	0.19
Sister	6.80*	6.04*	0.4	0.48
Father	0.08	0.02	0.89	0.03
Brother	3.08†	0.39	1.09	4.02*
Assisted you most psycho-socially				
Husband	3.97*	2.18	0.34	1.52
Mother	0.85	0.09	1.6	0
Sister	3.09†	3.15†	7.88**	4.97*
Father	0.83	1.06	0.09	0.57
Brother	3.08†	0.39	0.09	0.9

**p*-value < 0.05, ***p*-value < 0.01, †*p*-value < 0.1

Acceptability Factors

Psychosocial

Psychosocial barriers—including loss of dignity, depression, anxiety, rejection, and distrusting certain facilities—pose significant barriers to women suffering from fistula. Once women realize that they have a problem and process the stress related to the condition, they may choose to silently suffer or not, based on the types of

Table 6.3 Barriers to and enablers of access OF care (after discovery of leakage)

Themes	Barriers	Enablers
Psycho-social	– Loss of dignity and self-worth – Depression – Social anxiety – Fear of/ability to be sexually active – Feeling rejected – Distrust of particular facilities	– Feeling loved – Has psycho-social support (especially female and husband)
Cultural	– Societal male dominance: necessary male support and permission – Other gender/power imbalance – Blaming woman – Restrictions on female mobility – Domestic responsibility – Belief in church and prayer, not medical services – "Inappropriate" to ask/talk about fistula	– Care for them because "it's not their choice"
Social	– Isolation – Incur social stigma – Widowed/separated/single – Loss or lack of social support – "Do not want to be intrusive" – Husband's reaction: harsh, disrespectful, abandonment, married another wife – Too embarrassed to go to hospital or ask for help because of own smell/shame	– Has social support – Encouraged to resume social activities in community – Has male support – Husband or family to accompany to hospital for repair – Community-facility liaison: "lady," community midwife, organization – Increase community awareness of how to help: financial, "should be taken to hospital"
Awareness	– Unaware that fistula is treatable/where to go for treatment – Lack of information about fistula (particularly men) – Belief that fistula is result of witchcraft or god's punishment – Learn to leave with it/does not disclose – Hope it heals itself	– Aware of where to go for treatment – Community-facility liaison: "lady," community midwife, organization – Increase community awareness of problem, how to treat, how to help
Financial	– Cost of procedure is unaffordable – Poverty and cannot afford care – Lost job	– Has financial support – Got/maintained a job – free operations
Transportation	– Cost of transport is high – Pain and discomfort	– Found transportation
Facility shortages	– Lack specialized surgeons – Surgeons too busy	
Quality of care	– Past unsuccessful repairs – Fistula patients require longer hospitalizations – Fistula patients seen as low priority – Referrals – Inadequacy of follow-up care	– Referrals – Adequacy of follow-up care

support they have in their homes and communities. Women's social anxiety to interact with people given their embarrassment of leaking urine exemplifies the psychosocial barrier to access care. As one women stated, "I had to cope with the discomfort of having rags in between thighs to trap urine. Worse off was the bad smell I emitted all the time. I isolated myself from others and felt dirty all the time" (Case study, Eastern).

As women lived with OF and faced financial or cultural barriers to access repair, the levels of psychological distress increased. A woman related the experience of a friend with OF: "Though her husband and family gave her moral support they couldn't afford to take her to hospital due to financial strains … she suffered isolation since she could not socialize. She was so depressed that at times she could plan to throw herself down a well" (Case study, Eastern).

The notion of "unless they are loved, they will feel rejected" highlighted the importance of loving, understanding, and caring by husbands and families to ensure that women do not feel rejected. Moreover, participants described the critical role family members played in empathetically motivating women to access care. As one male from the Coast said, "People need to be sensitized about this problem and to know where they can go for treatment, then it will not be kept a secret and no shame will be associated with it."

The perception that the condition is "not their choice" appeared in some groups while others suggested that women continue to suffer from blame and the resulting shame.

Cultural

Cultural factors—particularly those around traditional beliefs, conversational taboos, and gender roles—reveal barriers to access, while the altruistic sentiment of "caring" for those who are ill presents an enabling opportunity. Women and men from the Coast described beliefs that place God/faith over medical service, a preference for herbal medicine, and that OF is "a result of witchcraft." These beliefs further silenced and curtailed women's ability to access care; revealed a lack of knowledge; and caused isolation because of the stigmatized condition, and community norm-dictated secrecy. Communities shared the sentiment that one should not intrude or intimate other family's issues. Due to the cultural inappropriateness of discussing OF publically, those suffering from fistula continue suffering in silence. As one male FGD participant explained,

> "The women are afraid of telling when they get it; they are scared of going to hospital, women just hide … People feel shy telling doctors so they go to herbalists who give them herbs to boil and drink. They [men] do not tell friends your wife has urine problem- many believe the disease is incurable. If you go to hospital, it's private and tell the doctor to keep it a secret." (Male FGD, Coast)

In many cases, women isolated themselves, which contributed to years of delayed repair care-seeking. Gender dynamics within households—including a woman's relationship with her husband, mother- or brother-in-law, co-wives, and children—underlie the environment in which she made care-seeking decisions. These dynamics positively or negatively affected OF management. One female participant explained, "It [fistula] is usually a secret that the woman keeps to herself and informs the husband only. But people are different because there are those who will help and others will isolate her. Some in-laws will try to break up her marriage" (Female FGD, Coast).

Women's dependence upon men and their lesser power within the household often limited their access to repair care given its prohibitive costs. An extreme case of a 73-year-old woman was described by her daughter-in-law:

> "Mother in-law said it was taking time and money to repair her. The husband married another two wives and she could not cope. She came back to her marital home later when her firstborn daughter was big who now takes care of her … She has suffered isolation, stigmatization, shame and given up hope of repair. She says her husband has to consent, as she is his property if anything is to be done." (Case study, Eastern)

The notion that women belonged to their spouses led to a complex set of cultural obligations that made it difficult to secure sufficient support to access care. Women's isolation within the home and their domestic responsibilities often prevented fistula repair from being a priority. In contrast, single/separated women experienced a different set of restrictions on their mobility. Irrespective of marital status, having male support (husband, brother, uncle)—particularly financial support and help in securing transport to hospitals for repair care—was critical.

Awareness

Limited awareness of the nature, prevalence, and how to collectively address OF in the community inhibited accessing care. The participants largely agreed that increasing information on where to go for treatment and available support mechanisms would improve access for two main reasons. First, awareness relates closely to the silence around OF; for example, though a woman realizes that she has a problem, she often maintains hope that it will heal on its own, learns to live with it, and as much as possible does not disclose her condition. Second, the embarrassment and shame women felt in going to hospitals for help are exacerbated by social, economic, and cultural reasons that derail their choices to seek care. One woman who had not yet had her fistula repaired discussed this,

> "'I told the TBA but she told me it was normal and healing would take place soon but the urine kept on passing through the wrong way. I tried to consult some members of the community but they told me that the problem couldn't be healed. I told my husband but he became abusive and married a second wife though he comes to see me. I have been isolated for so long from the community members who say I smell. I would have tried to go to the health facility but I'm too poor to meet the hospital bill." (Case study, woman, not yet repaired, Coast)

Many participants described being aware that fistula is treatable, but fewer were aware of the need for follow-up care, how long to wait before engaging in sexual activity, and how to involve communities and intermediary links to facilitate access to care. One woman's comments demonstrated positive behaviors related to awareness of OF treatability, the need for community support, and increased health literacy around post-fistula repair care:

> "The family and community should encourage her, pray with her, bring her firewood and water … They should show her love spending time with her … She should be counseled not to have another child immediately … The woman should go to hospital for treatment so that she can engage well in sexual activity otherwise her husband will become unfaithful." (Female FGD, Eastern)

Social

Social factors are integral to consider as both barriers and enablers. Spouse and family reactions to the condition are important factors in fistula repair care access. Negative reactions by husbands may manifest in degrees of mistreatment. Abandoning wives for co-wives or new brides, and, in some cases, forcing women to have sex before they heal, isolates and disempowers women suffering from OF. One woman recounted her lack of social support:

> "When I told my husband, he started being disrespectful, hurling harsh words at me. Then one day he brought another wife home and sent me back to my maternal home … When I got home and shared with my mother, she didn't say anything. I have not been getting good support from the family so I use the little money I get from doing casual work at someone else's land and sometimes my mother's land to go to the dispensary where they treated me twice for urinary infection without success." (Case study, Central)

Another woman had a similar view: "I have feared to ask money from the community and the mosque because I am embarrassed and I have been told it is a sickness of shame. My husband ran away to stay with his first wife when he learnt that I could not hold urine and told me never to look for him." (Case study, Coast).

Contrastingly, successful repair occurrs when husbands (or other family members) are supportive financially, psychosocially, and instrumentally in helping their wives manage and live with OF and accessing repair care. In situations where women face discrimination, the existence of even one or two solid supporters is critical—spouses, female relatives, and in the case of older women—children. As one man described the case of his wife, "She has lived with the condition for over 20 years and has been discriminated a lot by her community and hence does not relate much with people … But the support from her children has kept her going on" (Male FGD, Coast).

Several participants felt that women ought to be supported by her community in a number of ways to ensure that she gets care and feels socially reintegrated. For example, one male participant said,

"To repair the fistula, money is required so some fundraising should be done to take the victim to hospital … To address the problem further, research should be done so that it is known where others went … She should be integrated into the mainstream society to do some light work so that she is not ostracized."

Another female FGD participant also believed this, saying, "She needs to be counseled. You can tell her that the problem is a result of the delivery complication and then you take her to hospital. You should be supportive so that she doesn't feel abnormal."

Employer support was also viewed as important. Respondents described community-facility liaisons (community midwives, organizations) as potential providers of education around OF awareness, information regarding repair camps, and facilitating transport to care sites for women suffering from OF, and particularly those living in poverty and isolation. Psychosocial, financial, and material support by the husband, families, and communities was believed to be essential—particularly in cases (e.g., Coast) where facilities denied care to women who are unaccompanied by their husband.

Accessibility and Affordability Factors

Financial and transportation barriers to accessing fistula care were discussed across all study participants. High costs often prohibited repair care access; only when free care is offered via a camp or facility, it is realistic that woman receive surgical repair. Unaffordability of care may be due to their own job loss ascribed to OF (e.g., “I left my job -Barmaid- and I had no source of income”), limited family resources to pool funds, overall poverty, and transport expenses. Given that fistula care-seeking decisions are often made in tandem with other household decisions and scarce resources, women often find themselves waiting for long periods (e.g., years) before repair is a viable option. Women described having to sell goats or make compromises to find resources for both transport and repair care. For single, separated, or abandoned women, overcoming financial barriers to access was often dependent on being able to maintain a job (e.g., house help) long enough to save for transport costs. As one woman recounted:

> “By that time, I had no money since 1994. Everybody deserted me so I had no option but to stay indoors at home … In 2006, I saw a lady who was sent to our village to assist women with this problem. She advised me and after that I had to do casual duties in somebody’s shamba [smallholder farm] … That money I used for my bus fare, I was taken to Jamaa Hospital by this lady. I have been operated three times … Now I am very dry.” (Case study, Eastern)

Financial enablers of access—mediated by a community-facility link—include securing a job and free care. Across sites, and particularly in the Coastal province, free care through OF repair camps or certain hospitals was the prevailing method of access to repair care, compared to the few scheduled appointments at hospitals for a fee-for-service.

In addition to cost, the discomfort of traveling for women with OF and their accompanying family members posed a transportation barrier that may further delay access. One woman described the difficulty she faced when traveling to a hospital:

> “As soon as they got off the bus at the bus stop, all the urine that had leaked on polythene papers wrapped on her, let out the urine … It was very embarrassing, and the husband had to look for a place where she could go and change her clothing. 3 weeks after her review, she was admitted for the repair of the fistula. Each time she was ready to go to the theatre, her case was postponed, as there were more urgent cases.” (Case study, Central)

Availability Factors: Facility Shortages and Quality of Care

All participants described facility shortages and low perceived quality of care as a significant barrier to accessing successful OF repairs. Women with positive and negative outcomes of repair operations had often experienced past unsuccessful repairs. While in some cases this may be due to the severity of the fistula or how long a woman has had it, in others, unsuccessful repairs reflected low quality of care. One participant related a narrative of a friend struggling with OF:

> “She informed the hospital and the doctor reviewed her and later an indwelling catheter was inserted of which she was to go home with. She was discharged after seven days then given an appointment for follow-up in the clinic. She was followed up at the hospital for three months then she was booked for surgery to repair the fistula … The first operation was not very successful so after 6 months she had another surgery, which was not very successful as she was still leaking slightly … The third operation was done last year … but she is still leaking urine and has lived with the stress of tying nappies to avoid wetting herself.” (Case study, Coast)

Some women experienced delays and multiple referrals to return to the same or another facility, which were usually linked to a lack of specialized surgeons. When they were available, specialist surgeons were often overwhelmed by caseload and OF patients were made to wait because they had lower priority. As one woman who had not yet been repaired described, “At the hospital, I was examined and each time given another appointment, as the surgeon who was supposed to repair was very busy until I gave up and decided to just learn to live with the problem” (Case study, Central).

In addition to limited human resources, women experience other quality-of-care issues, including misdiagnoses, antibiotic and catheter prescriptions without talk of repair (this may be due to low provider skill, facility resources, or the need to wait for cesarean scars to heal), the need for longer hospitalizations, and the lack of adequate follow-up—a factor that is both linked to supply and demand of fistula repair care. One male participant described his wife’s experience with this:

> “She never healed and on the return visits at the clinic was informed that she would require another repair. She stopped attending clinic since she didn’t have enough money for transport …. Luck fell on her ears last year when she heard from the radio an announcement that there would be a free fistula camp at [X] Hospital. She was repaired and catheter removed on the fourteenth day … Since then she’s been attending review and this month went and was told that she was well healed and that on her consequent delivery would require to be done cesarean section.”

Discussion

The findings suggest variable influences on women’s care-seeking pathways to access care for OF within the range of options available (Fig. 6.1). Each stage of a woman’s repair care-seeking (initial facility visit and referral facilities) is affected by various sets of factors that are often tied to the influence of those around them (spouse, family, community). Psychosocial, awareness, cultural, social, financial,

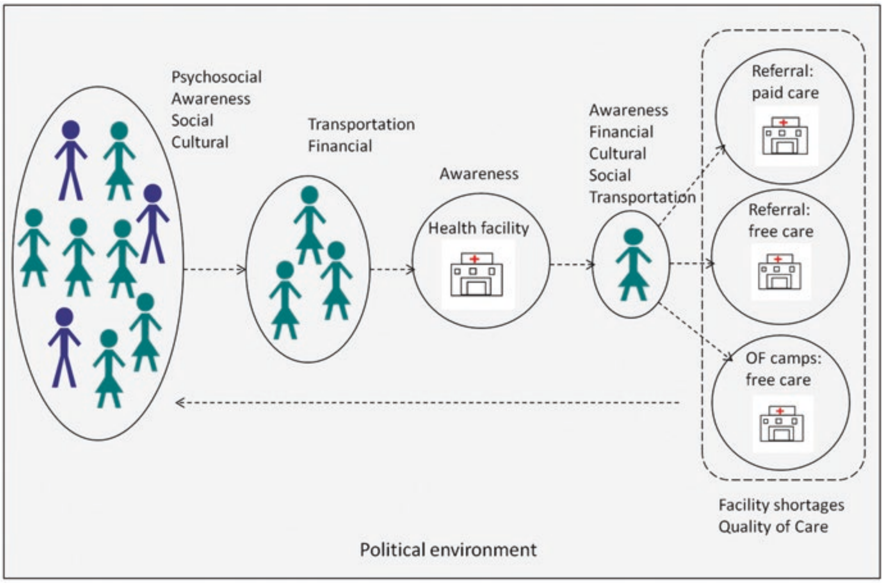

Fig. 6.1 Factors affecting fistula repair access

and transportation factors fall broadly under demand-side barriers and enablers reflective of acceptability, accessibility, and affordability challenges, while availability concerns, such as facility shortages and quality of care, reflect supply-side artifacts. Demand- and supply-side factors are affected by the larger political environment that shapes the coverage, cost, and structure of fistula repair. Attrition at each stage of care-seeking indicates that only a subset of women with OF actually obtains successful repair and reintegration (Pope, Bangser, & Requejo, 2011).

Resilience

Why are some women with fistula more resilient in their repair care-seeking and reintegration? Resilience is a concept used to describe how some individuals fare positively despite living with stigmatizing conditions such as HIV, mental illness, and infertility, and having experienced an abortion or as living part of a sociopolitically disadvantaged group (e.g., refugees, LBGT) (Boardman et al., 2011; Hankivsky et al., 2010; Mutua, Maina, Achia, & Izugbara, 2015; Riessman, 2000). While health-related stigma essentially "socially disqualifies" women living with OF (Weiss, Ramakrishna, & Somma, 2006), resilience reflects those who adapted positively or took steps to managing their condition, sought and received repair care, and were able to return to relative normalcy in their lives. Comparison of women who did and did not obtain successful repair elucidates patterns of resilience against overlapping barriers to access.

Women with higher levels of awareness maintained greater resolve to seek care. This sense of agency almost always intersected with strong social and financial support of close family members that enabled women to take advantage of free care opportunities and return to a “normal” lifestyle. A few women who were disowned by their family found some support through their employers. Overall, women who were successfully repaired demonstrated both coping and empowerment models of resilience (Shih, 2004). In contrast, unrepaired women often lacked sources of social support and agency within their household and communities to mobilize resources for transport and care. Essentially, these “less resilient” women suffered from the psychosocial consequences of OF, the inability to participate in gender normative practices like child-rearing, and a lack of power.

The study also highlighted the importance of loving, understanding, and caring by husbands and families to ensure that women do not feel rejected and the role for family members to prevent women from feeling lonely or worthless. Beyond spousal support that appears to influence care-seeking for OF in particular and reproductive care in general in Kenya, this study showed sisterly support to be critical in motivating women to seek repair care. This concurs with influences of female-female relationships and support for women in Kenya, though the findings may be mixed in terms of whether these ties enable or restrict access as seen from maternity and postabortion literatures (Mutua et al., 2015; Ono, Matsuyama, Karama, & Honda, 2013). Given the stigma experienced by women, sociocultural support appears paramount to overcoming discriminatory adversities faced in daily activities, job environments, social events, and transiting to health facilities. Moreover, post-repair care including spousal patience and restraint from sexual activity until healed was fairly consistent amongst resilient women. Finally, the social normative perception that communities ought to involve women in social spheres both before and after repair promoted a sense of self-worth, which placed women on a resilient trajectory. Findings support the notion that resilience can both emerge from within individuals and develop by building on existing relationships (Boardman et al., 2011).

A Gendered Concern

Beyond resilience, the low priority awarded to fistula repair across households, facilities, and political decision making captures a broader challenge of gender and power relations (Roush et al., 2012). In Kenya, housework, childbearing, and rearing norms fall on women. Those who fail to meet these obligations may be considered a liability and thus cast away—the inability of women with unrepaired fistula to routinely complete tasks, engage in sexual activity, and bear children renders them devalued in their own homes. This reduced status de-prioritizes women’s needs and delays care-seeking decisions (Yeakey, Chipeta, Taulo, & Tsui, 2009). Similarly, OF patients incur low priority at facilities that provide routine repair care. Necessary follow-up care is even less likely, given time and transport challenges of those accompanying women to care and facility human resource constraints. Finally, policies around the need to have an accompanying male family member present in order to receive fistula repair structurally discriminate against and limit women's ability to seek her own care. In cases where facilities deny care to women who are unaccompanied by their husbands, widows and abandoned women therefore comprise a particularly vulnerable subgroup. Recognizing the challenges surrounding the intersectionality of gender, poverty, and health systems manifested in the experiences of women suffering from fistula compels the need for further research and action to promote equitable care options (Hankivsky et al., 2010).

Study Implications

This study illustrates the complexities associated with women's access to fistula repair across the care-seeking continuum and presents notions of resilience in the Kenyan context. Resilience can be enhanced by educating communities about OF, working to destigmatize the condition, and prioritizing repair to household heads and service providers. Building on the altruistic spirit of "it's not their choice" is pivotal to increasing awareness on how communities can identify, support, and facilitate access to care. Future research should explore the effectiveness of community-facility linkages in locating and transporting abandoned women to care, observing quality of care of fistula repair, and further deconstructing operational aspects of resilience. Beyond the challenge of transport, the necessity for repeated trips to facilities for one reason or another related to facility capacity and the lower priority of fistula care increases the imperative to address financial and transport barriers to access. In conclusion, despite the range of barriers that prevent fistula repair, patterns of resilience suggest the need to emphasize women's awareness and empowerment, strengthen linkages to quality surgical care and follow-up, and reinforce social and financial support.

Discussion Questions

1. How does the way we understand factors that influence access to fistula care in low-income countries affect the way in which we address them?
2. Are there methodological approaches that are inherently better for researching key vulnerable populations? How do we apply them in a real-world setting?
3. What are the implications of social and political complexities in promoting access to fistula care for men? For women?
4. Based on this reading and your own experience, what builds resilience amongst stigmatized populations particularly around their capacity to access care and socially reintegrate? In the case of OF? In other stigmatized conditions?
5. What insight does women's resilience on the one hand and lack of power on the other contribute to discourses of culture, structure, and gender-based violence against women and girls?

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Chapter 7
Empowering Women in India to Influence Maternal Healthcare Quality Through Mobile Phones and Crowdsourcing

Aparajita Gogoi, Manju Katoch, and Priya Agrawal

Introduction

The survival and well-being of mothers are not only important in their own right but are also central to solving broader socioeconomic and developmental challenges of any country. In 1990, the global maternal mortality ratio (MMR) was 400 women dying during child birth per hundred thousand live births, which translated into about 540,000 maternal deaths every year. The MMR in India was over 500, which meant approximately 150,000 women dying every year. India at that time contributed 27% of the global maternal deaths. Millennium Development Goal (MDG) 5 aimed to reduce maternal mortality ratio (MMR) by three-quarters between 1990 and 2015. The MDG target for MMR in India was estimated to be 140 maternal deaths per 100,000 live births by the year 2015.

India has made remarkable progress in reducing maternal deaths in the last two decades. Based on the UN Inter–Agency Expert Group's MMR estimates in the publication "Trends in Maternal Mortality: 1990 to 2015," the MMR in India has declined from 556 per hundred thousand live births in 1990 to 174 in 2015. India is now contributing only 15% of the global maternal deaths. However, an estimated 45,000 Indian mothers continue to die every year (Table 7.1).

Severe bleeding (mostly bleeding after childbirth), infections (usually after childbirth), high blood pressure during pregnancy (preeclampsia and eclampsia), complications from delivery, and unsafe abortion account for nearly 75% of all maternal deaths (Say et al., 2014). In addition, a host of socio-economic-cultural determinants like illiteracy, low socioeconomic status, early age of marriage, low women's empowerment,

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Table 7.1 India's maternal mortality ratio, 1990–2015 (source: WHO, 2015)

Year	MMR
1990	556
1995	471
2000	374
2005	280
2010	215
2015	174

traditional preference for home deliveries, and other factors contribute to the delays leading to these deaths (MoHFW, 2014). Most maternal deaths can be prevented if births are attended by skilled health personnel—doctors, nurses, or midwives—who are regularly supervised, have the proper equipment and supplies, and can refer women in a timely manner to emergency obstetric care when complications are diagnosed (Khan, Wojdyla, Say, Gülmezoglu, & Van Look, 2006).

India has tried to address these factors through a host of interventions aimed at improving access to quality and affordable health services as well as address the socio-economic-cultural determinants. Reproductive and Child Health (RCH) program, launched in 1997, was a comprehensive sector-wide flagship program, under the umbrella of the Government of India's (GoI) National Health Mission (NHM) launched in 2005, to reduce maternal and infant mortality and total fertility rates. RCH program also aimed to reduce social and geographical disparities in access to and utilization of quality reproductive, maternal, newborn, child, and adolescent health services. Centrally sponsored government welfare schemes/programs like *Janani Suraksha Yojana* (JSY) offering cash assistance, and *Janani Shishu Suraksha Karyakram* (JSSK), providing service guarantee in the form of entitlements to pregnant women, sick newborns, and infants for free delivery including cesarean section and free treatment in public health institutions, are being implemented to promote institutional delivery among women below the poverty line. The two schemes have been instrumental in encouraging women to deliver in health facilities, resulting in a significant increase in institution deliveries from 53% in 2005 to 73% in 2009–2010 (UNICEF, 2005; 2009) and 85% in 2014 (MoHFW, 2015). The progress, however, has been inequitable and inconsistent (Sanneving, Trygg, Saxena, Mavalankar, & Thomsen, 2013).

Both *actual* and *perceived* quality of care affect whether a woman will choose to deliver in a facility in the first place; if she has a positive experience, she will tell her friends and family about it; if she has a negative one, she may simply stay home to give birth the next time, and warn others to stay away as well (Nair & Panda, 2011). In addition, lack of confidence in the care provided by the facility nearest to the woman often results in bypassing of the lower level facility and overcrowding at higher level health facilities, posing a challenge for provision of quality of care (Salaza, Vora, & Costa, 2016). Therefore, perception of quality can affect each of the three points at which delays can occur in the management of obstetric complications: the decision to seek care, identifying and reaching a facility, and receipt of adequate and appropriate treatment (Thaddeus & Maine, 1994). Addressing the issue of quality of maternal health services at all levels can therefore instill confidence in the health system amongst end users and also help in reducing overcrowding on higher level health facilities.

Given that a woman's perception of the quality of care she receives during labor and delivery is likely to influence her decision whether to seek facility-based health care in the future, it is important to look at what quality of care means from the woman's perspective. The primary role of any quality system is to provide effective means to assuring that the customer (patient) requirements are met fully. Some of the key elements/components of quality that accomplish the patient requirements are patient's safety, staff behavior toward the patients, correct and timely treatment, compliance to treatment protocols, seeking patient feedback and adequate response to it, complete record keeping, acceptable quality care at affordable prices, clear communication to the patients with respect to the services, best practices for fixing appointment and service delivery, reliable diagnostic and laboratory support, reliable support services like canteen, ambulance, and pharmacy, safe and pleasant environment, technical competence, courtesy, and attitude of staff (Sharma, 2012).

Accreditation agencies like the National Accreditation Board for Hospitals & Healthcare Providers (NABH), a constituent of Joint Commission International (JCI), is the highest benchmark standard for hospital quality in India. The voluntary accreditation does involve assessment of patient requirement but tends to focus more on measuring facility infrastructure, clinical practices and procedures, human resources, and safety measures. The public health facilities on the other hand are governed by the Indian Public Health Standards (IPHS) guidelines for community health centers revised in 2012 and issued by Directorate General of Health Services, Ministry of Health and Family Welfare, Government of India.

Studies have shown that health care utilization is sensitive to user perceptions of quality (Acharya & Cleland, 2000; Ager & Pepper, 2005; Akin & Hutchinson, 1999; Alden, Hoa, & Bhawuk, 2004; Choi, Cho, Lee, Lee, & Kim, 2004; Haddad, Fournier, Machouf, & Yatara, 1998; WHO, 2000). Given the subjectivity of client's perspective in assessing quality of care, and the fact that the provider's assessment of what happened may very well differ—little to no effort has been directed toward gaining an understanding of women's perception of quality of care, and to collect and share their perceptions. Given their impact on critical health-seeking behavior, women's feelings and perceptions can provide useful input to a provider who is interested in improving care holistically, and retaining or expanding their clients (Thaddeus & Maine, 1994).

With these considerations in mind, The White Ribbon Alliance for Safe Motherhood,[1] India (WRAI), led by its secretariat organization, Centre for Catalyzing Change[2] (formerly CEDPA India), joined forces with *Merck for Mothers*, a 10-year,

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[1] The White Ribbon Alliance for Safe Motherhood was launched in 1999 as an informal coalition of NGOs, donors, and their global partners, with a view to generate worldwide attention and make safe motherhood a priority for all.

[2] The Centre for Catalyzing Change is a nongovernment organization registered under the Societies

$500 million global health initiative of the global pharmaceutical company Merck, and the mobile technology firm *Gram Vaani* (meaning “voice of the village”). This collaboration aimed to develop a Mobile Monitor for Quality of Maternal Care (MoM-QC). This system would not only *collect data* from a group (crowdsourcing), but also *disseminate data* reported by women receiving maternal health care, creating a powerful feedback loop that turns both women and providers into active contributors toward change. Specifically the MoM-QC would (1) educate women on the maternal care they should expect and demand and the entitlements they are eligible for, (2) allow them to report on their experiences based on recognized evidence-based standards, (3) share this data with communities to help them seek high-quality providers, and (4) share actionable data with providers in a way that would help drive quality improvements.[3]

Defining Quality of Care

To get this project off the ground, the project team needed a better understanding of what “quality” meant from community, health system, and health provider perspectives. WRAI began by conducting a landscape analysis which included a review of available research and resources on the topic, as well as interviews with 22 women (IDIs were conducted with 11 women in their last trimester of pregnancy and 11 women with children up to 6 months of age), their families (FGDs were conducted with five men (husbands), and 6 mothers-in-law across four villages and 15 health providers in 2 public and 2 private health facilities which included respective facility in-charges, medical officers, ANMs, and ASHAs. In addition, director of a leading private health facility; representative of Federation of Obstetric & Gynecological Society, Ranchi, Jharkhand; and Director Quality Assurance Cell, Department of Health, Government of Jharkhand, were also interviewed**.**

The findings revealed that women were generally unaware of what constituted quality care, and that facility administrators were also unaware of the extent to which perceived quality of care influenced a patient’s decision to deliver in a facility. These findings suggested that awareness building around the concept of quality of health care was needed among both providers and the women, followed by advocacy to create and enforce mechanisms that involve facility administrators and public officials in continuous quality assurance and quality improvement mechanisms.

Registration Act, 1860. Its mission is to empower women in all sectors of development. At the core of its work and approach is a belief that achieving gender equality is essential for development, democracy, and global progress.

[3] The authors would like to thank Sanjay Paul, Deepa Jha, and Mohammad Ahsan from Centre for Catalyzing Change, and Aaditeshwar Seth from *Gram Vaani* and M4ID for their contributions to this work. Gratitude is also due toward the team of *Nav Bharat Jagriti Kendra*, the women from the community, and the Government of Jharkhand.

WRAI had developed a checklist to measure quality of care, culled from global and national guidelines and protocols, technical standards, etc. that were being used in other WRAI's initiatives in states like Gujarat, Odisha, Haryana, West Bengal, and Rajasthan. WRAI further refined the checklist through three 1-day workshops held in Jharkhand as well as at the national level during which a working group of 65 local government officials, private providers, health personnel, and women discussed which quality indicators should be included. The working group initially agreed on nine indicators for quality of maternal health care: (1) facility accessibility; (2) cleanliness and hygiene; (3) human resources—the availability of staff; (4) medicines, supplies, and equipment; (5) interpersonal behavior; (6) privacy and confidentiality; (7) emotional support; (8) financial costs of care; and (9) perception of a better pregnancy outcome. A series of message development workshops were held, including one with officers from the government department of health, wherein the list was further narrowed down to four major areas: *timeliness* (waiting time before receiving services); *service* (adequate availability of staff, medicines, supplies, equipment, especially for complication and pain management); *respect* (maintaining comfort, privacy, and confidentiality; absence of abuse); and *cleanliness* (toilets, hygiene, housekeeping services, and sanitation).

Developing MoM-QC

A key goal for this project was to transform the mobile phone—a device conventionally used to make and receive calls—into a powerful tool for two-way communication—that is, to both "push" and "pull" data. Women in rural Jharkhand, where the pilot for the new platform was conducted, have relatively low literacy rates (ASER, 2014);[4] thus to ensure ease of use, and enable more women to participate, developers opted to incorporate interactive voice response (IVR) technology rather than SMS/text messaging. Through a simple automated navigation system, users could learn more about quality maternal health care services vis-à-vis timeliness, service, respect, and cleanliness, and, in addition, financial support they were entitled to. Once armed with this new knowledge, the users could provide their own feedback on the services they received. The IVR prototype was linked to *Gram Vaani*'s *Jharkhand Mobile Vaani,* a popular free call-in radio service available to all users in the state. Connecting the platform to this service allowed the service to reach a ready-made audience of users; *Jharkhand Mobile*

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[4] Although the average basic literacy in the state is 65% (as compared to the national average of 74%), the Annual Status of Education Report for Jharkhand (ASER, 2014) reveals that literacy and numeracy level achieved is much lower than the desired level at respective grades. For example, among children in the eighth grade, 1% cannot read/recognize letters, 3.6% can read letters but not more, 8.4% can read words but not first-grade-level text or higher, 16.7% can read first-grade-level text but not second-grade-level text, and only 70.4% of children in the eighth grade can read second-grade-level text.

Vaani receives an average of 3000–5000 calls a day from users seeking information on topics ranging from agriculture to government entitlements.

To field test the prototype, WRAI worked with a local NGO to make the service available to 494 pregnant women and lactating mothers across 20 villages in Jharkhand (referred to as cohort) on a trial basis. WRA India collaborated with the local government including Village Health Nutrition Sanitation Committee Members and health workers (Accredited Social Health Activists, Auxiliary Nurse Midwives) to promote the toll-free number. The toll-free number was also advertised over the *Jharkhand Mobile Vaani* to capture responses from the free call-in radio service (referred to as non-cohort).

The objective of this first pilot—officially launched in November 2013 with the support of government officials, including the Jharkland Minister for Health and community health workers—was to establish whether rural women could effectively use a mobile IVR platform to provide feedback on the quality of care they received at facilities, and to assess whether IVR could effectively help raise rural women's knowledge and awareness of care.

During the five-month pilot, the service reached far beyond the initial target audience. 10,505 unique listeners dialed into the service through 36,672 calls, primarily to listen to the information provided on maternal health, quality care, and available services.

While private and public telecom operators in the country have specific call charges for their subscribers for outbound calls, incoming calls within the country have been free in India since 2003. To ensure that participants did not have to bear the cost while they engaged with the platform, the system was set up for immediate call backs (a woman would initiate the call to the dedicated number but immediately disconnect; the system would call back, and engagement continued from there). The automated system would guide the user through a menu of options; she could choose to receive information on a variety of topics, listen to any number of dramas (audio clips of stories playing out specific care scenarios), or input her feedback on her own maternity care experience. A caller who chose the feedback channel could respond to questions by selecting a number on the phone dial pad.

The platform's simple, low-tech functionality leveraged the ease of cell phone use while giving each caller the power to "give voice" and rate the services they received. The callers were also given an option to record a message. At any time, callers had the choice to skip and navigate from one channel to the other, or listen to all the channels. The user could end the call anytime during navigation (Fig. 7.1).

Data Validation

During the pilot study, in order to verify that callers understood the questions being asked during the feedback process, out of 451 total callers in first 3 months 75 cohort and 75 non-cohort users (total 30%) were randomly selected for follow-up with a live operator. A high proportion of responses (87%, $n = 65$) among cohort as well as

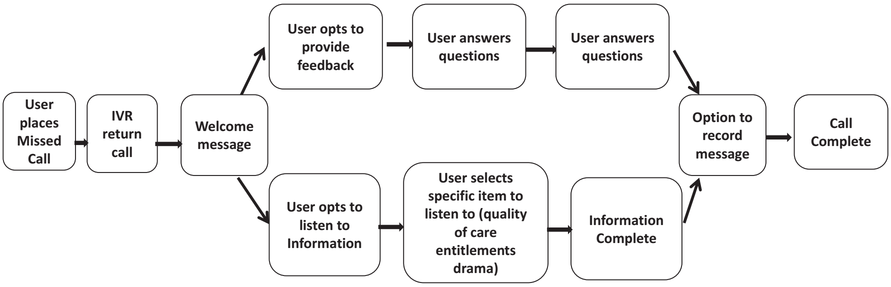

Fig. 7.1 MoM-QC flowchart

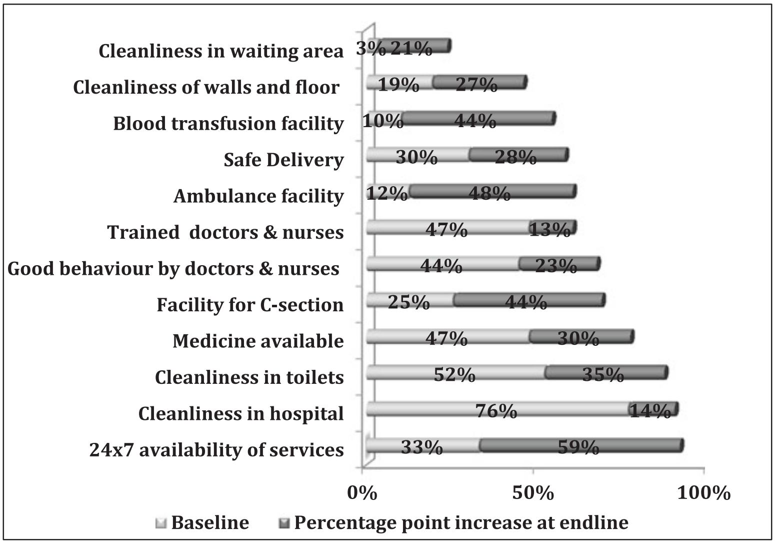

Fig. 7.2 Awareness of quality-of-care indicators

non-cohort sample did in fact match those that had been keyed into the automated system. It was also discovered through these follow-up interviews that a large proportion of the polled cohort users (80%, $n = 60$) had received assistance from community health workers or family members to complete the survey, whereas only 26% ($n = 20$) of the polled non-cohort users had required/received assistance to do so (Fig. 7.2).

Findings

The pilot was initiated for a duration of 5 months out of which the MoM-QC was active for a period of 130 days. The information channels were very popular, as was the dramatized content. During the period, the system received nearly 4100 calls; by the end of the pilot, knowledge of what constitutes quality care (timeliness, service, respect, and cleanliness) and awareness of entitlements under various government schemes/programs on maternal health had increased (Figs. 7.3 and 7.4). To evaluate the project, 130 cohort members were interviewed during the baseline as well as the endline. The most significant gain was in awareness of specific quality of care indicators. At baseline, women were aware of 4 out of 12 indicators, on average; after engaging with the platform, the average number jumped to eight. Prior to the launch of the project, 76% (*n* = 99) of women had said that they were aware of only 1.5 out of 4

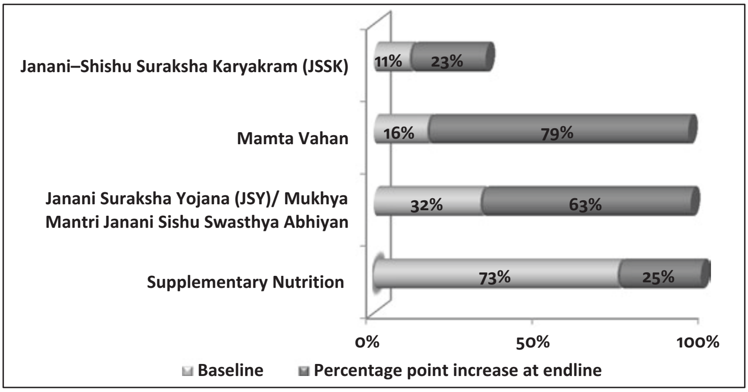

Fig. 7.3 Awareness of government schemes/programs for pregnant and lactating women

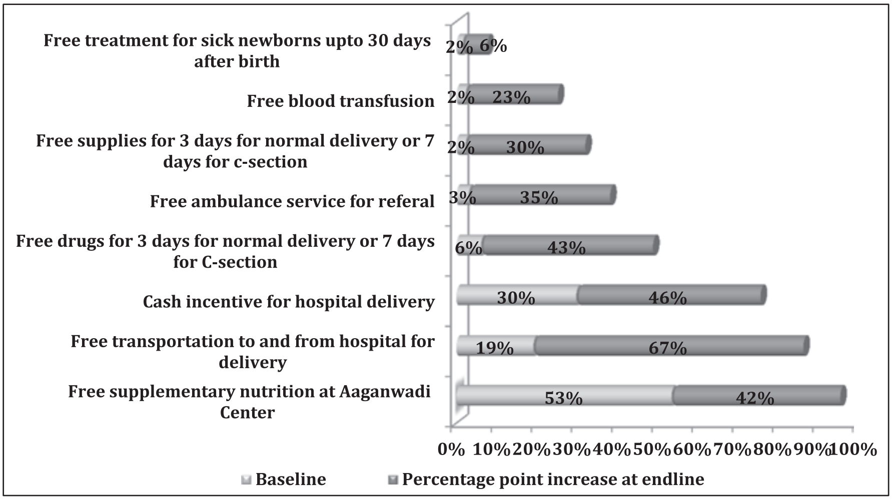

Fig. 7.4 Awareness of entitlements under government schemes/programs for pregnant and lactating women

Box 7.1: How Did MoM-QC Help Women?

Sunita Devi is 22 years old, and was married just before her 18th birthday. Her first child died in 2012 due to complications. She was part of WRAI's baseline study and says that she enjoyed being part of the MoM-QC project, because she learned a lot about quality of care. "I learned to look for clean sheets and food for me," she noted, adding that she also learned about how to be looked after properly by staff. Sunita says that she used the family's mobile phone to call in and listen to messages. Asked about the most valuable thing she learned during the project, Sunita says, "I learnt a lot about my rights. When my first child died, I didn't even ask the doctor why it happened. Now I would ask more questions."

Sita Devi enjoyed being part of the MoM-QC project, listening to the information and feeding back about services twice. "It was easy to use," she said. Sita learned about what services should have been at the hospital during the delivery of her son, Bikky. Many were not, so she gave feedback on lack of quality of care. A few months later, she took her sister-in-law to the local hospital for the delivery. When they arrived, no one was there to attend to them. Another woman in pain was not being looked after. Seeing these Sita, who now knew what the quality of care meant, decided to leave this facility and go to a private facility, where they were satisfied with the service. Sita noted, "We know that it is expensive but life is important and quality is important."

government schemes/programs for pregnant and lactating women, on average; by the end of the project, 98% (*n* = 127) of women had an average awareness of 3.4 out of 4 schemes. Awareness of maternal health entitlements under government schemes/programs also increased, from an average of 1.3 out of 8 entitlements to 4.1 (see Box 7.1).

Influencing Decisions on Where to Seek Care with Facility Ratings

Fifty-one women who had participated in the MoM-QC pilot were later interviewed to understand the influence of the feedback on their decision on seeking care at health facilities. At least 68% (*n* = 35) of women shared that the information provided through the IVR platform had empowered them to make better decisions regarding their own and their family's health, and to demand quality care (see Box 7.2).

The feedback from women was used to develop ratings for the facilities. In the pilot, it was found that the quality-of-care feedback was generally well received by these facility representatives; all expressed a keen interest to use the feedback to improve and/or upgrade their facilities and services. Many further noted that the model could be useful for monitoring progress in facilities, both public and private.

Box 7.2: Women's Responses to Facility Ratings

- 83% (*n* = 41) said that the health care ratings would influence their choice when recommending a facility.
- 77% (*n* = 42) said that feedback on quality of care available in a facility would influence their future choice of going to the facility for their next delivery.
- 87% (*n* = 44) said that the information they received had empowered them to make better decision for themselves and their family members.
- 68% (*n* = 35) felt that they were able to better access current health services after being informed of their entitlements via MoM-QC.

The feedback loop through IVR proved to be successful. Post the pilot, the team explored best ways to share the scores and ratings with the service providers and decision makers through an online dashboard which can signal where facilities scored well, with actionable steps, and for women, an interactive mobile website with graphics and voice recordings to inform women what kind of care to expect, and allow them to rate the care they received.

Lessons Learned

The MoM-QC pilot project and related efforts to use the digital platform to activate the feedback loop demonstrated the following:

1. Women want information on maternal health and quality of care, and want to share their feedback and experience.
2. Interactive voice response is a suitable platform to reach rural, illiterate, and semiliterate women, educate them on quality of care and maternal health entitlements, collect their opinions on quality of care, and develop a community quality of care rating for health facilities.
3. **S**ocioeconomic constraints limit women from having access to a mobile phone with enough minimum balance on their prepaid card to call at their own costs. Despite this and related barriers to reliable mobile phone access, women found a way to participate in a system that values their input, borrowing phones from community health workers, neighbors, and friends in order to make the missed call and receive call back from the IVRS to give their feedback. Their adaptability and willingness to participate despite access difficulties show enormous potential for a sustainable, large-scale effort.
4. Health care providers and therefore the facilities (both public and private) are interested in receiving women's quality ratings. Generating and providing real-time data will require additional backend technology refinements, but would allow for continuous quality improvement for providers, and more informed decision making for women. Future testing is needed to determine the most

efficient and effective means to encourage providers and health officials to improve care through providing a continuous feedback loop.

Further refining of the indicators, based on field testing with women and providers, was done in partnership with M4ID, a design firm, to ensure (1) that women could easily understand and answer the questions, and (2) that facilities could act on the answers provided. Refinements aimed to help with accurate and reliable reporting, including using fact-based indicators (e.g., “Were you slapped?”) vs. subjective indicators (e.g., “Were you treated well?”); using quality standards that are globally recognized or evidence based (and less likely to be challenged or dismissed by providers); and, most importantly, including indicators which are actionable and realistic in the context. Sixteen indicators emerged to be very important, around time taken to received care, behavior of the health provider, use of gloves during each examination, cleanliness, birth companion, privacy, pain management, counseling on danger signs and family planning, breastfeeding, cost of care, availability of medicines and supplies, and if the facility would be recommended to friends and family.

Conclusion

This initiative is premised on the understanding that service quality needs to move beyond technical quality to incorporate perspectives of service seekers and to empower women so as to raise the demand for high-quality health services. Providers have shown great interest in the MoM-QC model and understand its potential to improve quality services through a feedback/rating system.

The feasibility test demonstrated that MoM-QC improved users’ knowledge of maternal health quality and entitlements. The majority of women in the feasibility study were both able and willing to rate quality of care, and health providers and government officials were receptive to receiving women’s feedback to take follow-up action as needed.

Perceived quality of care and patient satisfaction are important factors in improving care-seeking behavior. The user-centered design can be refined, the quality scorecard can be tweaked, and a new channel can be designed to access such service via an interactive mobile website to reach even more users. Future development and testing are needed to optimize the quality scorecard, refine the quality rating system for application in larger geographies, determine the most effective feedback loop to influence decision makers, and measure the impact on service utilization, quality of care, and health outcomes.

The insights gained through the feasibility test show the potential benefit of this model in raising community awareness of what quality of care means, and what government entitlement programs are available to women. What is particularly exciting is that this platform not only dispenses information, but also engages women in two-way communication—creating an interactive push-pull model. Using crowdsourcing, MoM-QC asks women for feedback on the quality of care they received, pools that information, and makes the overall ratings available to community as well as health service providers.

This model has the capacity to build a rich database of community-generated information while empowering women to have a say about the services provided. Taken to scale, crowdsourced ratings of facilities on their quality of care could have the ability to shift care seeking in favor of higher quality facilities. The patient perspective can be used for triangulation and/or verification of clinical and safety measures, such as the availability of drugs, supplies, or a birth companion, and whether the woman received counseling on postpartum family planning before she was discharged. The triangulated data can be used to hold all providers more accountable to offering quality care. With the simple and already common tool of a mobile phone, this could become a grassroots movement.

Discussion Questions

1. Is the initiative described in the chapter (which uses women's voices to monitor, demand, and drive change for improvement of quality of services) likely to be effective in holding health systems accountable for the care they provide? Why or why not?
2. How might researchers and practitioners use different data for different purposes? Compare citizen-generated data with traditional census and household surveys, which are important sources of population-level health and social data. What might user-generated data add?
3. What are some of the challenges in using technology to generate data as described in this chapter?
4. What steps might be necessary to ensure that the data generated is used to promote positive change?

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Part III
Reproductive Control

Chapter 8
The Role of Balinese Culture in Explaining Inconsistencies Between Fertility Intentions and Reproductive Outcomes

Mellissa Withers, Carole Browner, and I. Nengah Ardika Adinata

Introduction

The promotion of women's reproductive rights worldwide includes ensuring the ability to achieve their reproductive goals, including the timing and number of their children. In Indonesia, about 7% of the estimated 4.7 million annual births are unintended and another 12% are mistimed (Hull & Mosley, 2009; UNICEF, 2012). A substantial proportion of married women of reproductive age who do not want any more children are not using contraception in developing countries like Indonesia; therefore addressing barriers to contraceptive use could be an important strategy for reducing the unmet need for family planning. A more thorough understanding of why women are not able to meet their desired fertility can offer insight into barriers to contraception and help women to achieve their reproductive goals. In this qualitative study, we explore the factors that influenced reproductive decision making in a sample of Balinese women, over one-half of whom had not met their reproductive goals as reported 4 years earlier.

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Background

The Previous Study

This study explores the findings of an earlier longitudinal survey conducted over approximately 4 years in a community in East Bali, Indonesia. The study's objective was to determine predictors of consistency between women's fertility intentions (how many more children, if any, she was intending to have) and subsequent reproductive outcomes. A total of 1448 married women of reproductive age in all 19 sub-villages participated in this longitudinal study, representing more than 90% of all eligible women in this community. Only about one-half of women reported contraceptive use at baseline. About one-third reported the desire for no more children; 13.5% said that they were unsure, and the remaining one-half said that they wanted at least one more child. Overall, at four-year follow-up, 57% of women who wanted more children had given birth, while 33% of ambivalent women had given birth, and 29% of those who reported at baseline not wanting any more children had had a subsequent child. The results of this study have been presented elsewhere (Withers, Kano, & Pinatih, 2010; Withers et al., 2011; Withers, Tavrow, & Abe, 2012). This qualitative study explores women's stated fertility preferences and intentions through in-depth interviews conducted among 39 women drawn from the women who participated in the longitudinal study, seeking to understand why a high proportion of women did not achieve their expressed fertility intentions.

Literature

The literature provides insight into the complexity of reproductive decision making. Numerous factors have been associated with inconsistencies between women's fertility preferences and subsequent reproductive outcomes, including younger age, rural residence, shorter length of marriage, lack of access to family planning or other program-related reasons, child death, inability to conceive or divorce, and death or migration of husbands (Bankole & Westoff, 1998; Hayford & Agadjanian, 2012; Islam & Bairagi, 2003; Roy, Ram, Saha, & Khan, 2003; Tan & Tey, 1994; Withers & Browner, 2011). Inconsistent fertility outcomes have also been linked in the literature with reported ambivalence, or uncertain fertility intentions (Bankole & Westoff, 1998; Becker & Sutradhar, 2007; Roy et al., 2003; Speizer & Lance, 2015; Tan & Tey, 1994). Finally, recent studies from many Asian countries, including Bangladesh, India, Vietnam, and South Korea, have confirmed that a strong son preference has an impact on family size preferences (Diamond-Smith, Luke, & McGarvey, 2008; Hoa, Börjesson, Nga, Johansson, & Malqvist, 2012; Roy, Sinha, Koenig, Mohanty, & Patel, 2008; Saha & Bairagi, 2007; Thuy Duong, 2015; Vlassoff, 2012; Westley & Choe, 2007; Yoo, Hayford, & Agadjanian, 2017).

Studies from Asia have found that in many cases, a woman's power to control her fertility may also be determined by others, including husbands and mother-in-laws (Bankole & Westoff, 1998; Barden-O'Fallon & Speizer, 2010; Gipson & Hindin, 2008; Hossain, Phillips, & Mozumder, 2006; Withers et al., 2011; Mishra et al., 2014; Upadyay et al., 2014). Women who discuss their fertility desires with their husbands and women whose husbands have positive attitudes regarding contraceptive use have been shown to be less likely to have an unintended pregnancy (Bankole & Singh, 1998; Bankole & Westoff, 1998; Kamran, Arif, & Vassos, 2011; Prata et al., 2017; Tan & Tey, 1994).

The Study Community

Indonesia is the world's fourth most populous country, with an estimated 258 million people (U.S. CIA, 2016). Dramatic changes in fertility rates and contraceptive use have occurred in Indonesia since 1970 when the National Family Planning Program began. The total fertility rate is currently estimated to be 2.6 and modern contraceptive use among married women has reached 58%. The total fertility rate in urban areas is lower than in rural areas (2.4 children and 2.8 children, respectively) (DHS, 2012). Furthermore, in some of the more remote areas of the country, the total fertility rate is much higher.

This study was conducted in a one large community of 19 sub-villages in East Bali. The estimated 13,000 residents all belonged to the lowest Hindu caste of agriculturalists. Due to lack of roads, many villages were accessible only by off-road motorcycles, which few could afford. During the rainy season, access was even more difficult because the dirt paths leading to the sub-villages became muddy and slippery. The sub-villages were categorized into Zones A and B by a local nongovernmental organization who conducted the baseline study, the East Bali Poverty Project (EBPP). This organization, focused on development, had worked in this community for more than seven years. Zone A's 13 sub-villages were at the highest elevations and the most difficult to access. Many of these sub-villages were so dispersed that residents had little contact with neighboring villages. The six larger sub-villages in Zone B were closer to the main road.

Due in large part to its geographical location, the study community was severely economically disadvantaged; government services, including education and health care, were minimal and education rates, especially among women, were very low. In fact, less than one-half of women had any formal education beyond primary school. Residents earned income through farming small plots on the outskirts of their residences. However, the harsh climate and depleted soil allowed few crops to flourish and malnutrition was a serious problem. Most residents relied on scarce rainwater as their primary water source for cooking, bathing, and watering crops and animals.

Methods

Sample Selection

Semi-structured interviews were conducted with a purposive sample of 39 women selected from a sample of married women who had participated in the longitudinal study. Women were stratified according to consistency category (women who met their fertility intentions versus those who didn't). The sample was also stratified according to zone of residence because we believed that there would be important differences in women's fertility preferences and their ability to meet their fertility intentions by location of their sub-village. Geographical isolation, lack of educational opportunities, and dependence on agriculture in the Zone A sub-villages were all expected to contribute to larger family size preferences.

We selected the potential sample of participants by first randomly selecting three sub-villages in Zone A and four villages in Zone B. Because of the difficulty in reaching these sub-villages, it would not have been logistically feasible to visit all 19 sub-villages for this study. Then, we randomly chose women from each selected sub-village from each of the two reproductive outcome categories. Two attempts were made to contact each eligible participant. If a participant was unavailable, the next eligible woman from the same sub-village was approached for participation. We continued interviewing in this manner until the saturation point was reached.

Study Instruments

The interview guide consisted of 30 semi-structured questions translated into the Indonesian and Balinese languages. The questions were pretested for possible translation problems and cultural sensitivity with five participants in one sub-village not included in the final sample. A revised guide was then used for the rest of the interviews but was regularly modified. The interviews were conducted in respondents' homes by a trained Balinese interviewer. The first author was present during 12 of the interviews. Each interview, which took about 1 h, was audio-taped, transcribed, and translated into English. There were no refusals to participate. Informed consent was obtained before the interview. The UCLA IRB approved this study. Pseudonyms are used throughout this chapter.

Data Analysis

Data analysis was conducted using grounded theory framework. Extensive field notes and observations made by the first author informed this study, along with the transcripts. Atlas.ti software was used to organize the data. Data analysis primarily involved a content analysis of words, semantic units, and themes, which were then sorted into coding categories generated throughout the data collection and analysis periods. The initial codes were developed by the authors but were revised after coding the first five transcripts. The codes reflected both the answers to interview questions and broader themes that emerged from the interviews, field notes, and participant observations. Consistency and reliability of interpretations were achieved by having at least two members of the research team review the transcripts and confirm the interpretation and the results.

Results

Demographic Characteristics

Fifteen respondents were from Zone A (the highest sub-villages) and 24 were from Zone B (along the main road). Table 8.1 offers basic demographic and social characteristics of the sample. All were farmers, except for one teacher and three merchants. Most husbands were farmers, but there was also one mechanic, one merchant, one silver worker, one local foundation staff member, a village leader, and a silversmith. More than half had reproductive outcomes inconsistent with their expressed fertility goals.

Themes

Son Preference

Previous research on Balinese culture indicates that every Balinese man or woman is expected to marry and bear children (Covarrubias, 1972; Parker, 2003). Indeed childbearing is so integral to a woman's identity that after her first child's birth, she becomes known as the mother of the name of that child. A childless family is seen as "a disaster," and many Balinese men will not marry a woman until she is pregnant (Suryani, 2004). These same values were prevalent in the study community. Bearing a son legitimized a woman's contribution to her family and guaranteed her position within her family and her community. A Balinese family is considered incomplete without at least one son, and women who bore only daughters are seen as failures in their own eyes and of those around them. Every woman expressed the desire for a son and reported feeling intense social pressure to produce at least one.

The value of sons in Balinese culture was discussed by many participants, who gave numerous reasons for their son preference. For most participants, the importance of sons was rooted in their desire to maintain Balinese cultural practices. Ceremonies are central to Balinese culture and have deep significance for all Balinese, often requiring large investments of time, money, and labor. The Balinese Hindu religion proscribes a set of important family religious rituals that can only be

Table 8.1 Characteristics of the participants (*n* = 39)

Characteristic	Zone A (most remote) (*n* = 14) Percentage or mean and range	Zone B (less remote) (*n* = 25) Percentage or mean and range
Age	33.64 (range 24–40)	31.12 (range 20–42)
Age at marriage	17.86 (range 14–24)	17.56 (range 14–25)
Years of schooling	2.14 (range 0–9)	4.68 (range 0–15)
Income		
< 300,000	64.3% (9)	24.0% (6)
300,000–399,999	21.5% (3)	32.0% (8)
400,000–499,999	7.1% (1)	16.0% (4)
500,000+	7.1% (1)	28.0% (7)
Number of living children	2.79 (range 0–5)	2.12 (range 0–4)
Experienced infant death	21.4% (3)	16% (4)
Baseline desire for more children		
Yes	35.7% (5)	64.0% (16)
No	57.2% (8)	36.0% (9)
Unsure	7.1% (1)	0.0% (0)
Fertility category		
Successfully avoided unwanted birth	38.5% (5)	24.0% (6)
Had unwanted birth	23.0% (3)	12.0% (3)
Matched number of additional children desired	0.0% (0)	32.0% (8)
Had no additional or less additional children than intended[a]	38.5% (5)	32.0% (8)

[a] Unsure case excluded

conducted by sons, the most important of which are cremation ceremonies upon a parent's death. Only sons can conduct daily rituals at the family temple and inherit family land (Jensen & Suryani, 1992). In addition, the Balinese kinship system is patrilocal and patrilineal and upon marriage, and women are expected to live with their husbands' families and contribute their labor to their new household. Girls were valued less because the costs of raising them would not be recuperated upon marriage, since the dowry system does not exist in Bali. The greater contribution that sons could make to households was another important reason for the strong son preference. Several women said that they preferred sons because daughters moved way upon marriage. For example, Sayang, the mother of two boys and one girl, wanted one more child and thought that four children—two boys and two girls—would be ideal: "The girls will get married off and I will lose the girls. But two boys will be enough to help the household and continue the family line."

Women also felt that continuity of their husband's family name and ancestral line was one of the most important reasons to have a son. Sweni, a 27-year-old pregnant woman who had two daughters and no sons also discussed her wish to have a son. Even though at baseline she had borne the two children that she intended to have, she had recently become pregnant again because of the need for a son: "If this child is a boy, I will stop having babies. But if it is a girl, I will try again for a boy. I will keep trying until there is a boy to continue the family line." This perspective was very common.

Bearing a son appeared to give women more freedom to independently make future reproductive decisions. Unlike many other Asian societies, women in this community did not wish to have numerous sons, and higher status or greater prestige did not accrue to those who had multiple sons (Belanger, 2002; Diamond-Smith et al., 2008; Vlassoff, 1990). One 25-year-old pregnant mother with one daughter and no sons explained why she would continue to bear children despite the difficulty in her household finances: "If this baby is another daughter, I know my husband will want more children. He will want more until we have a boy."

Ideal Family Size Preferences

Another theme that emerged was the discrepancies between the ideal number of children that women reported wanting and the number of children that many actually had. The interviews, along with informal conversations and observations, produced valuable insight into such observed discrepancies. Ideal family size preferences had roots in the Balinese religion and cultural traditions.

Established in 1970, the Indonesian National Family Planning Program was very effective in reducing family size norms and the national birth rate (Hull & Mosley, 2009; Parker, 2003). Part of the credit for this transformation was the national "Two is Enough [Children]" propaganda campaign. Women in the study community reported being exposed to this campaign over the years by word of mouth and through local village family planning programs. In fact 14 women reported two as their ideal number of children, and several women specifically referenced the program.

Despite the smaller family size norms promoted by the government, nine women believed that four children were ideal. Most of them cited religious teachings as the main reason. The number four holds special significance in Balinese culture and religion. Most Balinese practice a form of Hinduism that posits four stages of life, and that there are four ways to achieve perfection or unity with God (Covarrubias, 1972; Eiseman, 1989). Their religion similarly teaches that four spiritual forces, the "four siblings" (Kanda Empat), interact to form the personality, and are manifested at birth as blood, amniotic fluid, placenta, and vernix caseosa. These, in turn, are generated from the four basic elements of life: water, fire, air, and earth (Eiseman, 1989). These four "siblings" are very important in protecting a newborn, and ceremonies are performed to honor them at 1, 3, and 6 months of age (Jensen & Suryani, 1992). The number four also figures in the Balinese practice of naming children, who are named according to birth order and caste, regardless of gender. There are four first names, and if there is a fifth child or more, the order usually begins again (middle names are used to distinguish children from the many other family members who share their first name) (Connor, Asch, Asch, & Seaman, 1996; Mabbett, 1985). The cultural significance of the number four may also have influenced women's perceptions about the ideal number of children. Because four names are available to assign to children, women may have understood this to mean that families should have four children. Also, referring to the vital spiritual forces as "siblings" also seems to presuppose that four children are ideal.

While the ideal gender composition of a family often included an equal number of sons and daughters, actual reproductive behavior was principally dependent on the number of sons a woman had, which helped explain the observed inconsistencies between ideal family size preferences and actual completed sizes. For example, Sweti said that she thought two children would have been ideal. When asked why she had five children, she explained, "This is because my children number one through four are all girls. I wanted to have a boy after the first child. But there were all girls until the fifth, when the boy was born." Many other women expressed similar views.

Other Factors: Economic Considerations

The majority of women also mentioned financial instability as a reason for differences between fertility intentions and subsequent outcomes. Women often cited the costs of food and basic living expenses as reasons why they had decided to stop childbearing before reaching their ideal family size. One example was Parwati, a 36-year-old mother of three from one of the most remote villages, who told us about the economic hardships her family endured. At baseline, she reported wanting one more child but had not had another birth during the study period. She explained that she and her husband jointly decided not to have more children, mainly for economic reasons: She said, "No, we can't afford more children. Now it is very expensive. It is difficult to feed your children if you have many." Many women emphasized the importance and costs of education. For example, Monol, another mother of one boy and one girl, explained that she didn't want more children because: "It is too hard to pay for children in these difficult times. I want to be able to pay for the highest possible level of education…. The economy is very difficult right now. One boy and one girl are ideal because this way I can guarantee that they will have a good future."

Perceived Control Over Fertility

In Balinese culture, an individual's ability to influence outcomes, that is, their sense of power, is perceived to be very limited. Most Balinese believe that the Gods or one's ancestors play key roles in their life events and often reference the Gods or one's ancestors to explain unforeseen events. Most Balinese believe in reincarnation and that what happens in one's life is determined by actions that took place in a previous one. Therefore many may see their life circumstances as predestined and may easily accept them with little question. Jensen and Suryani (1992) refer the fatalistic beliefs engrained in Balinese culture as "passive acceptance" and describe it as "a mechanism of adjustment to life situations that one regards are unchangeable or for which there are no perceived adjustments."

This world view might have been expected to have dramatic consequences for reproductive behavior. We hypothesized that a culture of “learned helplessness” might be present in the community, a consequence of generations of devastating deprivation, extreme isolation, and social and economic disadvantage and a belief system based in predestination. We anticipated that this would translate into women’s perceptions of little control over fertility. If this were true, their responses to survey questions about future fertility intentions would likely be arbitrary and meaningless. This may have explained why a relatively high percentage (13%) of women in this community reported being unsure at baseline of their fertility intentions. However, contrary to our expectations, women reported perceiving a high degree of control over their fertility. When asked who had most control over reproductive decisions, all women said that they alone were in control. Not a single woman interviewed mentioned fate, God, husband, or family. Although the majority of women reported that their husbands were involved in fertility decisions, all but one woman said that she had the final word in whether to continue childbearing or not.

Discussion

This study provides valuable insight into the role of culture in fertility decision making of a sample of Balinese women, of which over one-half had failed to meet their fertility intentions. First, the results refute previous studies’ findings that son preference does not exist in Indonesia (MacCauley, Robey, Blanc, & Geller, 1994; Wongboosin & Ruffalo, 1995). In fact, the importance of sons in this community cannot be overemphasized: son preference was the most significant influence on women’s fertility desires, intentions, and completed fertility. The preference for sons in this community was derived from both the cultural significance and practical value of sons. We found that the desire for at least one son took precedence over any perceived potential financial hardships that might be associated with continuing childbearing. Nevertheless, participants generally felt that one son was sufficient. This preference departed from evidence from other Asian cultures where more sons signify more prestige for women.

Our study helped explain the reasons for the discrepancies between reported fertility intentions and subsequent reproductive outcomes and also cast light on why some reported uncertainty with regard to their intended number of additional children. Rather than attributing this to a woman’s passive acceptance of fate or a lack of decision making, we found that the desire for additional children could vary based on women’s careful assessments of the benefits and costs of another child. Fertility decisions were influenced by their current living conditions and imagined future opportunities, as well as a strong son preference. Once they had at least one son, women made very calculated decisions about how many children they could afford, which probably explained, in part, the discrepancies between ideal family size preferences and actual completed family sizes. To generalize beyond our data, this may also be an important reason why some women report uncertain intentions in other demographic surveys.

Our most significant finding is that assessing fertility intentions among women living in communities in which the value of a child is dependent on numerous factors, many of which are beyond a woman's control, may not provide reliable data because fertility decisions are influenced by many competing factors that may be strongly subject to change. Our results support other research which has found that fertility decision making, especially in developing countries, is not based on individual preferences, but is instead dominated by community norms and cultural beliefs, such as sex preferences, and social changes. Our results suggest that although women may report uncertainty about their fertility intentions, it should not be assumed that this stems from a lack of will or the autonomy to make such decisions. Instead, the findings suggest that the demand for children fluctuates according to the factors cited above. It was clear from interviews and observations that the women in this study had carefully considered the benefits and costs of children. Many women who had inconsistent intentions had simply changed their minds about their intentions based on their reassessment of their need or desire for another child within the current contexts of their lives.

This study draws attention to the methodological challenges of measuring fertility preferences and intentions through population-based surveys (Speizer, Calhoun, Hoke, & Sengupta, 2013; Stone & Campbell, 1984; Withers & Browner, 2011; Withers et al., 2011). Survey data may not reflect women's actual fertility preferences or intentions for several reasons. First, some researchers doubt that fertility preferences and intentions can be validly assessed through close-ended survey questions which generally offer dichotomous responses (yes or no) to questions such as "Do you want more children in the next two years" (Stone & Campbell, 1984). We agree, having shown the complexity and variety of potential influences which can occur. In addition, respondents may put insufficient thought into answering questions, especially when asked a question that has a "yes" or "no" answer. Also, it may be unrealistic to expect women, especially in developing-country settings, in which fertility intentions are dependent on multiple factors, to give clear and reliable answers to questions regarding future childbearing plans. Many questions relating to fertility preferences and intentions are hypothetical in nature and respondents, especially those with low literacy, may have difficulty understanding them or answering them in a way that truly reflected the reality of their lives (Roy et al., 2008; Speizer et al., 2013; Stone & Campbell, 1984).

Future demographic surveys should consider new ways to elicit fertility preferences and intentions. For instance, instead of simply asking about family size preferences, questions about gender preferences should be included. Qualitative methods may produce a more accurate understanding of the complex and variable factors that shape women's fertility preferences and intentions. Such methods can offer a more accurate understanding of actual fertility decision making as an evolving, contextually driven process.

It is important to note that this sample included only married women; the views and experiences of unmarried women were not studied. Another limitation is the follow-up time. Although a 4-year follow-up is sufficient to capture many reproductive events, it is not long enough to capture them all. Women are generally fecund for about 30 years, and it can take many years for changes in attitudes, norms, and intentions to establish themselves, even in today's fast-paced world. Finally, the study took place in one community in Bali and the findings may not be generalizable.

Conclusions

Individual fertility preferences, while influential, turned out to be as important as, or even less consequential than, family and community norms in women's fertility decisions in this community. This study has both practical and theoretical implications for fertility research. Understanding why women are not able to meet their desired fertility goals can help illuminate possible barriers to family planning. This study also provided insight into how strongly cultural factors can affect reproductive behavior in Balinese culture. We also found that, contrary to what is generally found in the literature, despite low levels of education and rural residence, women in this community made thoughtful decisions about fertility based on both cultural values and financial considerations. The women in our sample didn't see themselves as passive entities reflecting cultural norms, but rather as having agency in deciding how to weigh individual preferences and community norms in coming to their own decisions. Finally, we highlighted the problems of using population-based surveys to understand complex fertility decisions, which may be constantly evolving in response to broad and variable contextual factors.

Discussion Questions

1. How do you think your own culture affects women's reproductive roles and fertility preferences?
2. Explain why son preference is such an important influence on fertility preferences in many Asian cultures.
3. Some say modernization will reduce son preference, as girls have more access to education and employment opportunities. Yet, this was not observed in this setting. Do you think we will see diminished preference for sons with modernization? Is it possible that modernization will increase son preference in some cultures? If so, why?
4. Son preference is an obstacle to reducing fertility rates. What strategies might be successful in promoting smaller families in cultures where son preference remains high?
5. Discuss the limitations of the way fertility intentions are generally measured. Suggest other strategies that might better capture the complexities of fertility decisions.

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Chapter 9

Knowing Client Rights and Meeting Their Needs: Provider Knowledge and Attitudes Toward Meeting the Reproductive Needs and Rights of People Living with HIV in South Africa

Deborah Mindry, Pranitha Maharaj, Thabo Letsoalo, Chantal Munthree, and Tamaryn Crankshaw

Introduction

Worldwide almost 36.7 million people are living with HIV (PLHIV); 19 million of these people live in eastern and southern Africa (UNAIDS, 2016). South Africa had one of the most rapidly growing HIV epidemics, rising from less than 1% in 1990 to almost 30% in 2011 (National Department of Health, 2012). The country now has the largest population of PLHIV, estimated at 7.03 million people (Statistics South Africa, 2016). Over the past decade, the government has made tremendous progress in increasing the availability of antiretroviral treatment (ART) and now has the largest population of PLHIV on ART. ART has led to an improvement in the life expectancy of PLHIV and a dramatic reduction in mother-to-child transmission (MTCT) of HIV. Increasingly, there has been a greater emphasis on the provision of appropriate reproductive health services for HIV-infected women and men.

Health legislation in South Africa has been characterized by a strong policy commitment to reproductive health, rights, and equity in line with international declarations. As the result of a broadly consultative process, South Africa has formulated a reproductive health policy package that is widely accepted as one of the most

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progressive in the world (Cooper et al., 2004). However studies have shown that this commitment to providing sexual and reproductive health services may be hindered by provider attitudes and lack of skills and resources (Bharat & Mahendra, 2007; Creel, Sass, & Yinger, 2002; Weisberg, Fraser, Carric, & Wilde, 1995; WHO, 2001).

Contraception policy and promotion of safer conception options for HIV-affected couples, in particular, offer a useful platform for a critical analysis of the policy context surrounding reproductive health and HIV/AIDS in South Africa. As one of the government's most recent reproductive health reforms, the revised contraception policy (National Contraception and Fertility Planning and Service Delivery Policy Guidelines, 2012) was designed to take into account the high HIV prevalence in South Africa. The contraception policy has been revised at a significant time both in the development of South Africa's democracy and in the progress of reproductive rights internationally. This policy has also coincided with an increased global understanding of the importance of safer conception options for the reproductive rights and the health of women. According to the South African National Department of Health (NDoH, 2015), fertility planning is an integral part of the national contraception strategy (NDoH, 2012). This is based on the view that, particularly in the context of HIV, fertility planning must be a major component of the approach to counseling women of childbearing age about their reproductive intentions (NDoH, 2012). The inclusion of safer conception services in the Contraception and Fertility Planning policy has not been carried across to provider guidelines or training curricula.

Contraception and fertility planning policy is only one component of the multisectoral approach that is needed to ensure the reproductive needs and rights of men and women living with HIV. There is limited progress in linking HIV and reproductive health services operationally (Cooper et al., 2009; Gruskin, Ferguson, & O'Malley, 2007). Despite political will at the policy level, providers at the front line face many challenges, including the lack of NDoH-approved guidelines for implementing safer conception counseling for people living with HIV, dwindling resources, expansion of clinical responsibilities, and lack of clarity as to how to provide comprehensive reproductive services that include contraception options to prevent pregnancy, abortion services, safer conception counseling, and PMTCT services (Cooper et al., 2009; Harries, Stinson & Orner, 2009; Gruskin et al., 2007; Harrison et al., 2000).

Over the past decade, the South African Government has made tremendous progress in increasing the availability of antiretroviral treatment, including the 2015 rollout of Option B+, an approach designed to prevent mother-to-child transmission and to promote maternal health. With this rollout, South Africa provides ART to all pregnant and breastfeeding women who test positive for HIV, regardless of their CD4 lymphocyte count. Of the approximately 6.8 million people living with HIV/AIDS in South Africa (Statistics South Africa, 2015) about 3.1 million people are on ART (NDoH, 2015). The increasing availability of ART has led to an improvement in the life expectancy of people living with HIV and a dramatic reduction in mother-to-child transmission of HIV from 9.6% in 2008 to 3.5% in 2015 (2.1% among women receiving ART) (Barron, Pillay, Doherty et al., 2013; Dinh et al., 2015; Goga et al., 2015). With these developments in treatment, men and women living with HIV are living longer and healthier lives and many are either having children or expressing the desire to have children (Cooper, Harries, Myer, Orner, & Bracken, 2007; Cooper et al., 2009; Kaida et al., 2011).

Studies conducted in South Africa show that 29–57% of men and women living with HIV have indicated their desire to have children (Cooper et al., 2007; Myer et al., 2010; Schwartz et al., 2011), and 29% of births are to women living with HIV (NDoH, 2012). While some studies indicate that access to ART has resulted in an increase in the number of children born to women living with HIV (Houle, Pantazas, Kabudula, Tollman, & Clark, 2016; Ibisomi, Williams, Collinson, & Tollman, 2014; Myer et al., 2010), other studies indicate that the fertility of HIV-positive women is lower than HIV-uninfected women and that HAART may have an impact on their fertility (Kongnyuy & Wiysonge, 2008; Kushnir & Lewis, 2011; Zaba & Gregson, 1997). Factors such as perceived physical health, community norms, provider attitudes, and social expectations exert a stronger influence on the desire to have (more) children than the knowledge of an HIV diagnosis (Mindry et al., 2015; Myer, Morroni, & Rebe, 2007; Nduna & Farlane, 2009; Orner et al., 2008; Schwartz et al., 2011).

Guidelines issued by the HIV Clinician's Society in South Africa recommend that fertility and childbearing should be part of routine HIV care (Bekker et al., 2011). These authors advocate for providers to support the fertility desires of their clients living with HIV and outline a range of safer conception options available within a resource-constrained setting such as South Africa (Bekker et al., 2011). To date, these guidelines have not been integrated into routine HIV or reproductive health care.

Research has drawn attention to client needs and attitudes toward childbearing as well as their views on safer conception care (Cooper et al., 2009; Finocharrio-Kessler et al., 2014; Kawale et al., 2013; Mindry et al., 2015), but there is limited research on provider perspectives on safer conception care (Crankshaw, Mindry, Munthree, Letsoalo, & Maharaj, 2014; Finocharrio-Kessler et al., 2014; Goggin et al., 2014). In 2011, we conducted a study to explore provider knowledge and attitudes toward safer conception services for men and women living with HIV in KwaZulu-Natal, South Africa. More specifically the research focused on the role of providers in meeting the reproductive needs of women and men accessing ART services. In this chapter we focus on the challenges providers face in trying to balance their professional commitment to the reproductive rights of their clients with the competing claims of personal ethics and social biases, and the extent to which these personal perspectives shaped their attitudes toward supporting their clients' reproductive rights.

Methods

Research Setting

This study examined the perspectives and experiences of health care providers working at two ART clinics in KwaZulu-Natal, South Africa. These sites served one rural community and one urban community in the greater eThekwini municipality, providing access to different levels of services. The rural site was nested in a tuberculosis hospital setting and referred clients to other Department of Health facilities for prevention of mother-to-child transmission (PMTCT) care and to an urban hospital for specialty care such as obstetrical and gynecological services. The urban ART clinic was located at a state-subsidized hospital facility within the city environs which also had a PMTCT clinic, HIV pediatric care, and a male circumcision program on site. Ethics approval for the study was received from the University of California, Los Angeles, the University of KwaZulu-Natal, Durban, and the KwaZulu-Natal Department of Health with approval from the participating hospital sites.

Sampling and Data Collection

Research was conducted between May and October 2011 with 25 health care providers. This included a focus group discussion at each site (seven nurses and six counselors for a combined total of 13 participants), and six in-depth qualitative interviews with health care providers at each site (five doctors, four nurses, and three counselors for a combined total of 12 interviews). Individual interviews were conducted prior to the focus group discussions to ensure that individual providers would not be influenced by having participated in focus groups. We did not include doctors in the focus group discussions so that the hierarchical relationships among providers would not affect the levels of participation of counselors and nurses who most frequently are the health workers serving these clients. Focus group discussions and in-depth interviews were conducted in a private room at each clinic. We examined provider experiences in delivering reproductive services to both men and women with HIV, and their knowledge and views on providing safer conception services to PLHIV. In particular, we asked providers about their knowledge of three methods for safer conception: (1) manual self-insemination (an HIV-positive female has her HIV-negative male partner collect his sperm sample and she self-inseminates at home using a syringe to insert the collected sperm into her vagina), (2) sperm washing (an HIV-positive male with an HIV-negative female partner collects his sperm sample which is then centrifuged in a laboratory and the clean sample is used to inseminate his partner at a clinic site), and (3) timed intercourse (the HIV-positive partner/s are on ART with viral load suppressed, and the couple is counseled to have unprotected sex during the female's ovulation period). At the time of the interviews and of the writing of this chapter, none of these services were available through the NDoH services or were known to be available in the private sector. In 2016 there are two pilot safer conception projects being offered in Johannesburg (Davies, Mullick, & Schwartz, 2016; Schwartz, Yende, Bassett, Sanne, & Van Rie, 2016). At the time of our research the only publically available source of information were the 2011 guidelines for safer conception developed by researchers and clinicians in South Africa (Bekker et al., 2011). The questions were directed at ascertaining provider knowledge of any of these methods as well as their perspectives on acceptability and feasibility, available resources to support safer conception services in the future, and challenges to providing these services including provider training needs.

Providers were recruited by researchers through general invitation at staff meetings at the two clinics. Interviews and focus group discussions were arranged to fit into provider schedules to avoid disruption of clinic services. A male and a female researcher conducted the interviews primarily in English with Zulu language interviews conducted as preferred or needed. Interviews were audio recorded, translated, and transcribed by the interviewers.

Data Analysis

Following transcription, the interviews were coded in Atlas.ti utilizing a grounded theory approach to develop the coding scheme (Bernard & Ryan, 2010; Ryan & Bernard, 2003). An anthropologist with extensive experience in qualitative research and analysis took the lead in coding and analyzing the data. Data were coded based on major themes and subthemes that emerged within the data. This was reviewed and revised by a second qualitative researcher with intimate knowledge of the settings and the health care context in South Arica. Revisions were made based on consensus agreement.

Results

Supporting Client Reproductive Rights

Many health providers were sensitive to the fertility rights of their clients, and believed it their duty to provide the necessary information to keep their clients healthy and meet their fertility desires. Most providers, interviewed in both the rural and urban setting, recognized the right of their clients to receive information that can help them meet their need to give birth to healthy children, free of HIV:

> “I tell them that they have got needs so if a person is 20-something surely they do need to have a child, but I tell them not to hurry, they must check their CD4 count and viral load.” (Focus group discussion, counselor, rural)

A counselor in the urban setting expressed a similar view:

> “I don’t discourage someone like that, but what I do is to just give all the facts about what might happen, but at the same time they need to know that they are people like everyone else, they need to have children, and they need to have families …” (Focus group discussion, counselor, urban)

Recognizing the reproductive rights of clients living with HIV was also supported by clinicians in both settings. When asked what he said to clients inquiring about children, a doctor in the rural setting told us:

> “Well basically, just to say that people have the right to have children and whenever they like. Then obviously I presume they are asking me, because they want to make sure that everything is alright with the baby.” (In-depth interview, doctor, rural)

While another doctor noted that

> “… it’s about letting them know, because I mean everyone has the right to make their own choice, it’s just about making sure that they have all the information available.” (In-depth interview, doctor, rural)

Counselors' and nurses' opinions and attitudes regarding childbearing among clients living with HIV were varied. Many did recognize the desire and rights of their clients to have children and their role in supporting their clients' reproductive desires. In a focus group discussion at the rural site there was a suggestion of having an advocacy program for PLHIV that sensitized them to their rights as well as informed them of safer conception methods available to them:

> "I will suggest patient advocacy for them [PLHIV] because they have rights as well." (Focus group discussion, counselor, rural)

Anxieties Around Meeting Client Reproductive Desires

Although in principle willing to help, some doctors drew attention to social barriers between themselves and their clients in trying to understand why a woman or man living with HIV—often also living in poverty—would desire to have a child. A number of providers expressed concerns that being of a different cultural background than their clients could be a barrier to understanding why their clients desired or needed to have children. A doctor in the rural clinic noted that he struggled to understand the cultural factors shaping his African (or more specifically, Zulu) clients' desires for children:

> "If anyone wants to have children, they can have children. … whereas I don't know the cultural importance of them [African/Zulu clients] having children you know." (In-depth interview, doctor, rural)

In a discussion with counselors and nurses at the urban clinic, participants noted that gender and race can play an important role in their interactions with clients. They noted that male clients were less likely to respect a female provider but more likely to listen to a male provider. Similarly with regard to race, participants noted that African clients were more likely to respect the authority of a White or an Indian provider than an African provider:

> Counselor: And when you are talking to a man, you can tell that some men don't want to listen to a female. If you are female health worker and you are trying to help, he will be just looking at you.
>
> Nurse2: And especially if you are the same race. But if you (gesturing toward white nurse3 and Indian nurse4) would come and talk to them, they would listen to you.
>
> Nurse 3: I haven't had a problem.

Providers expressed similar reservations related to the economic circumstances of most of their clients. A doctor in the rural clinic expressed concerns about poverty and partner pressures on her female clients living with HIV to become pregnant. The doctor emphasized the challenges she faced in the clinical context, needing to set aside her personal views and focus on her professional responsibilities:

> "Well, we would [follow the] regular protocol [for HIV care] but nothing in depth. A lot of the women here already have children and there's a lot of poverty in the area. There's that balance between you know … it's difficult as people can't come to the clinic because they don't have enough money and at the same time because they have a new partner who wants a child, and to counsel being very impartial but at the same time offer health services is difficult." (In-depth interview, doctor, rural)

Many providers expressed concerns about the financial costs in supporting a large family as well as the care required in raising more children. In a focus group discussion among counselors and nurses at the rural clinic, these issues were at the forefront of providers' concerns. The participants in this discussion went back and forth between acknowledging their responsibility to provide clients with information to make informed choices while also expressing personal sentiments that they felt clients were not always acting responsibly:

> Nurse: Well it depends because sometimes it's a first baby, you cannot say don't fall pregnant, and sometimes it's difficult when the woman has had about three children. In that case you were supposed to say, "No you already have these children and why do you want to have more?" But it's up to her to decide really because you cannot decide for anyone. But according to my point of view I cannot have a child whilst I already have two. No matter [that] now there are drugs, but I don't know, it's not nice.
>
> Counselor 2: It comes to the decision of the parent because as counselors we were not taught to decide. What we do is to give facts and we do ask those questions. What is the reason for you to have to have a child and how many children do you have? Why now? Then a client is able to tell you their story but we can't judge and we cannot say you can't but we give options and make sure that the patient is given all the information she needs.
>
> Counselor 3: And we also check their responsibility whether he or she will afford to have a baby.
>
> Counselor 2: But most of them they can't afford [more children] because it's a responsibility and you know you are sick and want another one. It's sad because the last child cannot be healthy and is going to be rejected. She won't even have time for three of them or four of them.

Some providers were also concerned by multiple sexual partnership behavior among their clients. A doctor in the urban clinic expressed her reservations about serving men living with HIV who are having children with multiple partners. She had difficulty understanding the practice among her male clients who have multiple partners and/or wives:

> "But there are then women who are the second wives. I have had some very challenging cases of educated professionals with two families. He had in all about nine children, and he was an educated professional. That was just a very difficult thing for me to understand." (In-depth interview, doctor, urban)

The discussion among these providers emphasized the challenges in trying to balance their personal views with their professional obligations. Providers were genuinely concerned about what they viewed as "irresponsible" client behavior. A nurse in the urban clinic also expressed frustration at clients' seemingly irresponsible behavior regarding contraception and conception:

> "Most women don't want to go on contraception, they use condoms only. Then there are people who come back and say that the condom broke last month, the condom leaked last month. And now they are on nevirapine. People are given the proper information, but they just don't take responsibility." (Focus group discussion, nurse, urban)

A number of providers focused on the marital status of the client. A 59-year-old nurse in the rural clinic displayed censure of women bearing children outside of marriage:

> "Some of them, we catch them when we are doing pregnancy tests, like in urine. When we test their urine we find out that these HIV-positive patients are pregnant. That's when

> we start asking the person if they wanted to be pregnant and whether or not they are married or maybe are they getting ready to be married. Some of them you find they were not ready to have a child. They are not even married … By ready I mean, according to me some women want to get pregnant but are not ready to be pregnant because they are not married, however those who are married are ready to have a baby." (In-depth interview, nurse, rural)

In her view, the right time to have a child is when a woman is married. Similarly a nurse in the urban clinic noted that she was concerned that children may not have proper care due to lack of support from the nuclear family and the security that is usually associated with such a family formation:

> "I think when they come with this problem the other thing I ask them is about their social welfare first. How they are at home. I would say as far as I know that if you want to bring a child you need to have money, you need to have a house, and then you need to have a father for the child and the mother must be there. Two of you must be together to raise the child together and then some will say, "Oh no, I am working and I can afford financially, I have got a house but I am not married but I think I will manage on my own."" (In-depth interview, nurse, urban)

Another nurse in the rural clinic indicated that she advised her clients against pregnancy due to her concerns about a child's future:

> "For me personally the challenges that I face is that I have got this question at the back of my mind. If I help this person to bring a child, what would be the outcome in the future of this offspring especially being born to a mother who is HIV positive and taking ARVs and what abnormalities would be there? In the long run what's the future for them? I worry about that." (Focus group discussion, nurse, rural)

Another view expressed was that clients were irresponsible in that they only presented themselves at the clinic to seek health advice when they were already pregnant and on treatment for HIV. This was expressed both in the rural and urban clinics. It should also be noted that both clinics had information sessions for those enrolling for HIV treatment. During this information session the topic of pregnancy was raised but merely to inform clients about the risk of being pregnant while living with HIV, with no discussion of how clients might safely conceive a child.

Concerns About Clients' Health

Many providers noted that they prioritized maintaining optimal health of their clients and expressed anxiety about adding the complexities of pregnancy to the management of HIV care:

> My one concern is that there is pressure on women to fall pregnant before they are physically ready to do so. I've had some women who are in really difficult situations, got engaged or married and now they have found out that they are HIV positive and the mother-in-law and the family wants them to have a baby. So to try and get them to postpone falling pregnant for as long as possible is difficult …. But once women are healthy and their viral load is suppressed, then by all means. (In-depth interview, doctor, rural)

Given time constraints some providers noted that discussing childbearing intentions with clients was often not possible given the immediate clinical priorities:

> "I will ask if they are planning another child. And if they are then I will edge on to other questions, you know partner status, that kind of thing. It is part of the consult. There are times, if the patient is on TB treatment and it's a complicated story then sometimes there is no time, or it just gets side tracked." (In-depth interview, nurse, urban).

Providers at both sites reflected that their prior training had been to discourage clients from having children. However, the availability of ART and PMTCT had shifted this position to supporting clients to more safe conception:

> "In the past it was always said you shouldn't have a child, before the ARVs came along. Well as the PMTCT was improving, it makes it easier for them, because of the viral load that is suppressed. … But the most important thing I see is that they don't understand that the husbands' viral load also has to be suppressed so that you won't get re-infected." (In-depth interview, nurse, urban)

Provider's Knowledge About Safer Conception Methods

An obstacle to clients' reproductive rights and access to safer conception services was the general lack of provider awareness and knowledge about safer conception options. Most providers had not received any training in safer conception methods for PLHIV. A doctor in the rural clinic noted that although he had received some training, it was not practical, was too expensive for clients, and not accessible in a resource-constrained setting:

> "Usually in this training and workshops they do include reproductive health, but sometimes you do find that they are convoluted. I have been to one where they were talking about sperm washing and that's of no use to us." (In-depth interview, doctor, rural)

Although sperm washing would be difficult to provide in resource-constrained settings, manual self-insemination and timed unprotected intercourse are both affordable options recommended in the published guidelines developed by Bekker et al. (2011) for use in the South African public health system. Most providers simply did not have the knowledge and training regarding these different methods.

Regarding specific safer conception methods, providers noted that they were not always comfortable discussing methods, in part, because they lacked adequate information:

> "[W]ell to be honest, I'm not even comfortable to talk about [using] a syringe [for insemination]. Because it is something I'm really, really not too sure [about]." (Focus group discussion, nurse, urban)

Although some nurses in the urban clinic were aware of safer conception methods, their knowledge was limited and they indicated that clients were referred to private health facilities for safer conception advice about methods such as sperm washing and artificial insemination. They noted that much of what they learned was through experience and interaction with other medical staff over time and they deferred to doctors.

Acceptability of Safer Conception Methods

In a focus group discussion at the rural clinic with counselors and nurses, the discussion related to the social acceptability of sperm washing as a method of safer conception not only revealing providers' lack of knowledge about the method, which they confused with artificial insemination (using donor sperm), but also drawing attention to provider concerns about the potential cultural barriers to the use of assisted fertility services:

> Nurse: I was also thinking it won't be allowed by Zulu men that a wife can have a child from another man's sperm.
>
> Counselor 2: I think Africans in general not Zulus only, Sothos, Xhosas they would not allow it as well. And you how would you feel? (focus group discussion, rural)

Timed intercourse was the most accepted method for safer conception across both study sites. A counselor in the urban clinic viewed this method as being more acceptable because of affordability:

> "There is this thing called artificial insemination and most of our clients cannot afford that, so maybe the most important thing is to make sure that the positive partner is adhering to the treatment so that there will be less chances of transmitting the virus to the negative partner. That is all that is important, the viral load should be undetectable and also being referred to the doctors; the doctors can give them the right time of trying to impregnate the lady or to be sexually active so that they will be able to have a baby." (Focus group discussion, counselor, urban)

Timed unprotected intercourse was also the preferred choice of providers in the rural clinic. A nurse in the rural clinic noted that she had recently advised a client of this method:

> "Actually this week I had a patient who is positive but his partner is negative, and he wanted to know if they could still have children. I just explained to him that his viral load must be low, and his partner must always get checked, whether she is positive or not and they must come to the clinic so that we can discuss." (Focus group discussion, nurse, rural)

Despite their lack of confidence in sperm washing and insemination procedures, nurses in particular believed that a workshop aimed at providing them with the necessary knowledge to share the details of the procedure, and the viability of it, with their clients was important:

> Nurse: I think there could be a little more counseling. We need something that is absolutely geared for it.
>
> Interviewer: To talk about safe conception?
>
> Nurse: Yes, yes. Like a conception clinic where people can come. Although there are people, I mean clinicians invite them, saying, come to us and we will advise you. (Individual interview, nurse, urban)

Overall the evidence from the interviews indicated that for low-resource settings that have an effective and efficient antiretroviral treatment program, timed intercourse was a method providers were most familiar with and likely to use in advising couples seeking to conceive.

Discussion

The study found that, in general, providers were concerned with ensuring and supporting the reproductive rights of their clients living with HIV. This is in line with the strong professional commitment to the rights-based approach which has been instrumental in shaping reproductive legislation and policy in South Africa. However, the data shows that provider interaction with their clients is also shaped by their own personal attitudes and beliefs. Although there was principle consensus among nurses, doctors, and counselors regarding the right of their clients to bear children and lead normal, sexually active lifestyles, the execution of the rights of individuals living with HIV to have children carried reservations. These reservations were based on providers' personal views and experiences, social and cultural differences between the service providers and clients, and provider's knowledge (or lack thereof) of safer conception methods. There was a tendency of providers to focus on maintaining the health status of their clients and to deter clients from conceiving if they believed that it would compromise their health status. Providers focused on maintaining their clients' good health status and were concerned that unprotected intercourse for conception purposes could result in new infections and pregnancy could compromise a woman's immune system. These anxieties could result in conflicts with their client's desire to have children.

Some providers did not understand why clients choose to exercise their right to have children given their HIV status and struggled with their personal and social attitudes to childbearing. They believed that the economic burden of raising many children should be seen as a reason to curtail future childbearing. However, many men and women will continue to desire a large family. Studies show that in rural and patriarchal communities, men tend to want more children than do women; further, the desire to have children has to do with kinship, strengthening relationships with the in-laws, and as a source of economic and lineage security (Caldwell, 1976). Childbearing also demonstrates a rite of passage into womanhood, a status highly prized in African cultural norms (Mindry et al., 2015; Nduna & Farlane, 2009; Preston-Whyte & Zondi, 1989).

Numerous studies suggest that in African societies high emphasis is placed on the bearing of children (Mkhize, 2006; Morrell, 2006; Preston-Whyte & Zondi, 1989). The success of men and women is usually measured in terms of the number of children they bear. Preston-Whyte and Zondi (1989) found that a wife who does not have a child soon after marriage is often subject to questioning and ridicule and sometimes threatened with divorce. However, marriage is not seen as a necessary precondition for childbearing (Preston-Whyte, 1993). Some providers, mainly nurses of an older generation, expressed the view that clients should not have children outside of marriage. However marriage in South Africa is not the norm with only a third of South Africans reporting that they have ever been married in their lifetime (Hosegood, McGrath, & Moultrie, 2009). Furthermore, feminists who have examined the changes and transformations in gender roles and relations over time argue that women have increasingly rejected marriage and have experienced greater acceptance of childbearing outside of marriage (Preston-Whyte, 1993; van der Vliet, 1991). However, these same authors note the pivotal role that Christianity has played in informing the imperative of women to marry and bear children. The moralizing discourses expressed by providers in our study are at odds with the reality that, in the absence of marriage, many couples attempt to cement relationships through children (Jewkes, Vundule, Maforah, & Jordaan, 2001; Mindry et al., 2011). Balancing personal biases remains a challenge to providers who are required to meet the reproductive needs of all women wishing to have children, irrespective of marital status.

We also found that providers predicted negative consequences if patriarchal lineage could not be irrevocably established—a perceived risk posed by incorrect understandings of sperm washing and artificial insemination. Providers noted that should the father of the baby not be known, (there is a cultural belief that the child may have bad luck later in life) given the customary practice of the paternal family needing to perform rituals for the child that would ensure the child's social identity in belonging to his/her father's lineage (Ngobese, 2009). Paternal investments in children are an important consideration in offering reproductive counseling and safer conception services to PLHIV (Mkhize, 2006; Morrell, 2006). Researchers are becoming increasingly aware of the importance of engaging men in reproductive health care and studies have begun to explore the role of men in supporting their pregnant female partner's engagement in PMTCT care (Van den Berg et al., 2015; Villar-Loubet et al., 2013).

Despite the strong commitment to reproductive health rights in the health policy arena, there are a number of challenges in implementing some of the core principles of the policy. Most notable is that the implementation of reproductive health policy is influenced by the capacity of health systems. Capacity (including personnel, facilities, and training) related problems have had a significant impact on the delivery of service. One of the main problems with the implementation of health policy in South Africa has been the design of policy without a consideration of the existing resources to implement specific reforms (Cooper et al., 2009; Edouard & Bernstein, 2015; Gilson et al., 2003; McIntyre & Klugman, 2003). Empirical evidence suggests that many elements of health system restructuring have been hampered by a "lack of capacity to manage human resources" (Stack & Hlela, 2002:6). Many health systems lack human resource capacity and this has led to low morale among health care providers, a lack of infrastructure, and a negative attitude toward clients (Bharat & Mahendra, 2007; Stack & Hlela, 2002). These are all outcomes that will particularly impact on the quality of reproductive health care services.

Numerous studies have shown that the use of contraception is likely to be influenced by the attitudes of providers (Weisberg et al., 1995, Ananhou, 2014). The study results presented in this chapter show that this can be extended to the concept of safer conception services. It is not simply a lack of provider knowledge that contributes toward provider reluctance to recommend safer conception options but also the attitudes of health providers and their reluctance to outline them. A number of studies have noted that the negative attitudes of health care workers are a major deterrent in individuals living with HIV seeking sexual and reproductive health care (Finocchario-Kessler, Dariotis, Sweat, et al., 2010; Goggin et al., 2014; Kawale, Mindry, Phoya, Jensen, & Hoffman, 2015; Schwartz et al., 2011). This demonstrates that progressive legislation, alone, is insufficient to ensure access to safer conception services.

Providers are a key entry point into any public health system to ensure that appropriate quality and comprehensive services are available to clients to realize their reproductive rights. Staff training and education of providers about safer conception options and reproductive rights of men and women are required for safer conception options to be available and accessible and integrated into any public health system (Goggin et al., 2014). Training programs need to be developed that can be adapted to various contexts, and information packets created to increase knowledge about safer conception options. The perception that clients act irresponsibly is not unique to the study findings. Another South African study found that most nurses felt that clients were irresponsible with regard to sexual and reproductive behaviors (Knudsen, 2006). A further study found that very few nurses in KwaZulu-Natal supported abortion upon request; most health workers supported abortion in the case of rape or incest, or if the pregnancy would endanger a woman's health, but few supported it for social or economic reasons (Harries, Stinson, & Orner, 2009; Harrison, Montgomery, Lurie, & Wilkinson, 2000).

In order to promote supportive provider attitudes, value clarification workshops have been initiated in several countries. These workshops are intended to supplement provider training on the technical and clinical skills for delivering safer conception services, by developing skills in client interactions, beginning with examining their own attitudes, values, and beliefs regarding the reproductive choices of clients living with HIV. Providers require training that enables them to distinguish between their own values and the rights of their clients to have children safely. The aim of the workshops that have been initiated in different countries has been to move providers toward greater acceptance, tolerance, and support for sexual and reproductive health rights (Turner, Hyman, & Gabriel, 2008). In addition, these workshops are an attempt to make services available, accessible, and comfortable for both men and women. Adequate training of providers is essential for health facilities to be able to offer comprehensive, integrated services. In-service training and updated training, especially on safer conception options as part of routine HIV care, should therefore be given priority.

Conclusion

The sexual and reproductive health climate in a country such as South Africa that has not only been experiencing an HIV pandemic but also has a significant proportion of people living with HIV on ART has effected change in the overall fertility patterns in the country (Ibisomi et al., 2014). It is critical that the National Department of Health develop policies and guidelines for the implementation of comprehensive reproductive health services for PLHIV that includes fertility planning and safer conception counseling taking into consideration social and cultural concerns shaping reproductive desires and practices.

Value clarification and specific training on safer conception options, relevant to the local context, are required to ensure that the reproductive rights of clients living with HIV are met. Providers have difficulty in balancing their professional and personal beliefs and perceptions, and need to be supported through this process with respect to safer conception services. Value clarification in the context of safer conception is a promising approach to supporting clients and providers alike.

Discussion Questions

1. What are some of the personal and professional challenges that health care providers may face in counseling people living with HIV on safer conception? How might these challenges make it difficult for providers to support HIV-affected couples' reproductive rights?
2. How do social and cultural factors shape the reproductive health priorities and needs of people living with HIV in South Africa? What do you think would be some of the social and cultural factors that PLHIV in your community might face in ensuring their right to have children?
3. How might providers' attitudes affect the reproductive rights of PLHIV and what could be done to address these issues? What could be done within the health care system to address negative attitudes of providers?
4. What needs to be done within the health care system to facilitate the delivery of safer conception counseling and services? How might health care systems address gender disparities in reproductive health care?
5. What can/should be done to ensure that the reproductive rights of PLHIV are being met? Think about this question in terms of policies, health systems, and community engagement.

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Chapter 10

Claiming the Abortion Narrative: A Qualitative Exploration of Mainstream and Social Media Reflections on Abortion

Natalie Whaley and Jenn Brandt

Introduction

Popular culture representations of abortion both reflect and reinforce powerful narratives about reproductive health and womanhood. Critical evaluation of how traditional media—such as film, television, and print—have depicted abortion illustrates the ways in which cultural representation can reinforce negative social myths of abortion. This includes the myth that abortion is rare and dangerous (Sisson & Kimport, 2014), as well as contributes to the overall stigma surrounding abortion (Purcell, Hilton, & McDaid, 2014). Additionally, these traditional forms of media often reinforce hegemonic perspectives, with minimal representations of poor women or women of color who are more likely to experience undesired pregnancy and abortion. Since the introduction of Facebook in 2004, social networking has emerged as an important form of communication and a transformative popular culture medium. The impact of social media on public opinion and framing of pregnancy and abortion is yet to be elucidated. However, given their popularity and participatory nature, social media platforms—like Twitter and Facebook—have been evaluated as tools for public health research (Altshuler, Gerns Storey, & Prager, 2015) and in targeted sexual health education interventions (Veale et al., 2015; Yonker, Zan, Scirica, Jethwani, & Kinane, 2015). By engaging diverse populations and allowing people to share personal experiences, promote news, and exchange opinions, social media has the potential to become a platform for abortion activism (Stevenson, 2014) that can be used to cultivate an empowering, positive abortion counter-narrative.

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This chapter critically evaluates key media representations of abortion in traditional and social media over the past 10 years. From this analysis, a theoretical framework for understanding how social media has transformed cultural representations of abortion to create a counter-narrative to traditional media conceptualizations will be generated. Case studies of how abortion has been considered in social media will be used to provide examples of how social media has been used to normalize abortion, galvanize political action, and increase women's ability to seek safer abortion care. Ultimately we conclude that, through their participatory nature, social media platforms have the potential to challenge traditional media representations of abortion and can serve as empowering platforms for political and feminist pro-choice activism. Combining backgrounds in popular culture and gender studies, public health, and provision of family planning services we aim to consider the unique intersection of media and reproductive health.

Abortion Stigma—The Impact on Public Health

While the medical experience of abortion is defined by safety, the social experience of abortion is defined by silence, shame, and stigma. Abortion stigma is an increasingly used framework for understanding how women experience abortion. With a recognized impact on provision of care, abortion stigma impacts both providers (Harris, Debbink, Martin, & Hassinger, 2011; Joffe, 2014) and patients in significant ways (Harris, 2012; Hessini, 2014). Individual-level abortion stigma is multifaceted, with factors that include fear of social judgment, isolation, and negative social consequences (Cockrill, Upadhyay, Turan, & Greene Foster, 2013; Hanschmidt, Linde, Hilbert, Riedel-Heller, & Kersting, 2016). An important component of abortion stigma relates to the feelings of deviance experienced by women who choose to end a pregnancy vis-à-vis the deeply rooted cultural values and social pressures surrounding motherhood.

Abortion is a common reproductive experience in the United States, with one in three American women undergoing abortion at some point in their lives (Jones & Kavanaugh, 2011). Yet abortion is concealable and, owing to the power of stigma and the resulting silence, abortion is conceptualized as rare or exceptional. Abortion stigma shapes how women experience abortion, and impacts health outcomes after abortion. In particular, abortion stigma contributes to morbidity when women seek abortion outside of traditional medical contexts or delay care for complications.

Worldwide, unsafe abortion accounts for 13% of all maternal deaths with an estimated 47,000 women dying each year (Ahman & Shah, 2011). The primary burden of deaths attributed to unsafe abortion occur in settings where abortion is illegal; therefore, access to legal and safe abortion care is a key component to decreasing abortion-related mortality. Abortion stigma contributes to the public health burden of unsafe abortion. Globally, the impact of abortion stigma on abortion morbidity occurs in settings where abortion is legal and illegal. For example, in Ghana, where abortion is legal but utilization of safe services is limited by cultural acceptability of abortion, dangerous clandestine procedures or self-abortion practices persist (Payne et al., 2013). Meanwhile, in the United States, fear of disclosure of abortion has been connected to complications and failure to seek appropriate care (Harris, 2012).

Given these potentially dangerous outcomes, there is a growing interest in finding ways to counteract the impact of abortion stigma. In the conceptual model of abortion stigma created by Cockrill and Nack, women experience negative personal and social consequences related to abortion including internalized, felt, and enacted stigma. Further, because abortion is a concealable social experience, women employ behavioral strategies to cope with internalized abortion stigma (Cockrill & Nack, 2013). Informed by this conceptual model, Cockrill et al. (2013) developed a valid and reliable scale to measure individual-level abortion stigma with four factors that include worries about judgment, isolation, self-judgment, and social condemnation.

Role of Popular Culture in Reinforcing/Creating Narratives About Women, Women's Bodies, and Sexuality

Although gains have been made in portrayals of women in the media as complex, multifaceted individuals, more often than not, the virgin/whore dichotomy of womanhood is still perpetuated through the mainstream media today. Archetypes of women as innocent, virtuous, and nurturing caregivers are contrasted by their oversexualized, deviant, and/or villainous counterparts. Younger women, in particular, are sexualized through the media, while older women are more often than not seen as matronly, if they are seen at all. With our national consumption of media across platforms at an all-time high, the consequences of these portrayals affect women in a number of ways. A 2015 report by Common Sense Media (2015) finds that Americans aged 13–18 years consume over 9 h of media per day. The effects of the oversexualization of women in the media on young women are well documented, with eating disorders, low self-esteem, and depression the most common mental health problems associated with this phenomenon (Abramson & Valene, 1991; Durkin & Paxton, 2002; Harrison, 2000; Hofschire & Greenberg, 2001; Mills, Polivy, Herman, & Tiggemann, 2002; Stice, Schupak-Neuberg, Shaw, & Stein, 1994; Thomsen, Weber, & Brown, 2002; Ward, 2002). Feminist scholars have argued that the increased sexualization and objectification of women in the media are a backlash against gains in equality such as Title IX and *Roe v. Wade*, and work as a checkmate against women's empowerment in social and professional domains (Douglas, 2010; Faludi, 1991; Wolf, 1991). This impact is especially seen in young women, who are engaging with media more intensely than women of other age groups.

The hypersexualization of women in the media and culture's obsession with women's appearance intensified as other cultural regulatory myths about women's worth—most often associated with their nurturing abilities as wives and mothers—lost traction after the advances of the women's liberation movement and the second wave of feminism. Pregnancy, in particular, has seen a shift in its representation in the media, with the tabloid "bump watches" of today a far cry from when CBS deemed the term "pregnant" taboo when dealing with Lucille Ball's on-screen and real-life pregnancies. The growth in choices today of how and when women become mothers (if they make this choice at all) has led to an increased scrutiny as to the correct path to motherhood. The result is that those "lone, working, teen, mature, lesbian or feminist mothers who do not fit the idealised image of the white, heterosexual, self-sacrificing, middle-class, 'good' mother or perform in line with the ideology of intensive mothering, tend to be judged, ranked and found wanting within and beyond the media environment" (Feasey, 2012, 2).

Social norms and stigma have been found to play significant roles in reproductive health behavior and pregnancy decision making among women. Formative research using focus groups with low-income women in the United States demonstrated that women recognize and identify community expectations of avoiding pregnancy outside of a monogamous relationship. Further, women in this study felt that in the setting of unplanned pregnancy, continuation of the pregnancy is viewed more positively than abortion or adoption (Smith et al., 2016). Women with unplanned pregnancy are stigmatized regardless of their pregnancy decision making, and this pressure may limit women's ability to make the best decisions about a pregnancy. Additionally, the framework of "planning a pregnancy" or pregnancy intention used when discussing public health imperatives to improve obstetric outcomes and decrease abortion does not reflect how women frame pregnancy decision making (Borrero et al., 2015).

Traditional Media Conceptualizations of Abortion: What We Know

Critical evaluation of popular culture portrayals of abortion in movies and television reveals how cultural stories about abortion help create and reinforce social myths and impact public perception about abortion. Unpacking the complicated relationships between popular culture representations and public opinion can enhance our understanding of how abortion is considered, framed, and conceptualized in media texts. A 2014 analysis of abortion-related plots in American film and television from 1916 to 2013 found variations in abortion storylines over time, suggesting an interplay between media representations, cultural attitudes, and abortion policy. Further, this study found a high proportion of plotlines featuring death as the outcome for women considering abortion, reinforcing the social myth that abortion is dangerous and deadly (Sisson & Kimport, 2014).

A similar analysis evaluated portrayals of women who seek abortions on American television from 2005 to 2014. This study found that televised stories of women seeking abortion were more likely to feature white women and less likely to feature women of color, women who are already mothers, and/or poor women (Sisson & Kimport, 2016b). Evaluation of the reasons women chose abortion in these storylines found an overrepresentation of what are perceived as immature or self-focused rationales (i.e., interference with future opportunities) as opposed to other focused rationales (i.e., impact on other children and financial constraints). The inaccuracy of depictions of the demographics of women who seek abortion is problematic because it perpetuates the myth that abortion is a selfish choice as opposed to a carefully considered need. It also perpetuates the myth that motherhood is the ultimate achievement for women, and to make any other choice is a deviance from "natural" womanhood. When popular media includes accurate representations of women's experience with abortion, social myths are challenged, and often these truer representations are marginalized and/or seen as abnormal. For example, despite positive reviews and numerous independent film nominations and awards, the 2014 film *Obvious Child* only earned slightly over $3 million in box office receipts. Writing for *Entertainment Weekly*, Emily Blake speculated that the film's lack of mainstream recognition was due to its label as an "abortion comedy" (Blake, 2015).

In addition to fictionalized depictions of abortion, several documentary films in the last decade have explored abortion. Documentary films often explore controversial issues and can serve as important vehicles for drawing public attention to a particular issue, changing the narrative, or galvanizing political change, such as *Bowling for Columbine,* which explored gun control in 2002, and *An Inconvenient Truth*, which explored climate change in 2006. Abortion-related documentaries in the past decade include *12th And Delaware* (2010), *After Tiller* (2013), *Vessel* (2014), and *Trapped* (2016) among others. Of these, *After Tiller* is the most well known, in part due to its 2015 News and Documentary Emmy award after it aired on PBS. Starting with the assassination of Dr. George Tiller in his church in 2009, the film provides a complex counterpart to the misinformation and myth that surrounds late-abortion care in the United States. Critical evaluation with audiences revealed that this film was somewhat effective in changing beliefs about abortion (Sisson & Kimport, 2016a). The film's focus on the four remaining doctors that openly perform late-term abortions in the United States, however, suggests that narrative depictions of abortion and abortion providers may have more efficacy with respect to social change than narratives that solely focus on women who chose abortion.

Role of Social Media in Garnering Political Support Normalizing the Abortion Experience

A review of mainstream popular culture representations of abortion suggests that these narratives have contributed to the silence and shame surrounding abortion. Abortion has largely been framed as a moral issue, as opposed to a medical, financial, or women's health issue. In this context, the nuances and complexity of abortion for individuals and society at large are overtaken by a binary conceptualization of abortion as right versus wrong, moral versus immoral, and rhetorically signaled by the simplistic and erroneous "pro-life" and "pro-choice" labels. Studies evaluating private discourse about abortion have shown that person-to-person conversations about abortion allow for a more balanced conversation where women can explore their own thoughts about abortion and disclose personal experiences (Herold, Kimport, & Cockrill, 2015). Building off these personal conversations, successful social media campaigns in the past years have capitalized on moments when abortion was in the national media spotlight and sought to galvanize political support to challenge antiabortion legislation, garner support for abortion providers, protect access to care, and create cultural change to destigmatize abortion through the online sharing of abortion narratives. This "hashtag activism" has become an important tool of social media at large, and particularly for the pro-choice movement.

#StandwithPP

In 2015, an antiabortion organization called the Center for Medical Progress (CMP) released deceptively edited, undercover videos alleging abortion providers and Planned Parenthood profit from the sale of donated fetal tissue. These videos received widespread media coverage, leading to state-level and congressional investigations, as well as attempts to cut federal family planning funding for Planned Parenthood. The objectives of CMP to expose illegal activity on the part of Planned Parenthood and abortion providers were not met—in fact, none of these investigations found any wrongdoing on the part of Planned Parenthood. Instead, investigation of the CMP videos ultimately led to criminal indictment and felony charges for some of the CMP members involved in making the videos (Fernandez, 2016).

While this campaign to reveal illegal activity backfired, the objective of vilifying abortion providers and invoking a narrative that connected abortion provision with monetary gain and immoral activity was successful. In the midst of widespread news coverage of this controversy, social media became an important vehicle for the pro-choice movement to create a counter-narrative. Drawing on a powerful social media presence, Planned Parenthood declared September 29th "Pink Out Day" and offered free STI screening at their clinics across the United States. "Pink Out Day" highlighted the fact that the vast majority of reproductive health services provided by Planned Parenthood are not abortion care, and the campaign elicited widespread community support for the agency. Further, the *#StandwithPP* campaign on Facebook and Twitter created a way for people to show support for abortion access and Planned Parenthood. Reflecting on the hashtag *#StandWithWendy* that supported the 11-h filibuster of a restrictive Texas abortion law by Wendy Davis, the *#StandwithPP* drew on this imagery of standing up for abortion access and rights.

The *#StandwithPP* campaign allowed Facebook members to create a filter for their Facebook profile picture that included a pale pink background and text box frame that said *#StandwithPP*. By changing their Facebook or Twitter profile picture, people could show their support for Planned Parenthood. This media campaign drew the support of politicians and celebrities and brought attention to the attempts to restrict government funding for Planned Parenthood.

#ShoutYourAbortion

Other campaigns on social media have focused on affecting cultural change through direct de-stigmatization of the abortion narrative. In September of 2015, the *#ShoutYourAbortion* campaign was launched with the objective of normalizing abortion as a common reproductive experience. With one in three American women having an abortion by the age of 45, this campaign challenged the silence and shame that characterize abortion in popular discourse.

By creating #ShoutYourAbortion, reproductive rights activists Amelia Bonow, Kimberly Morrison, and Lindy West sought to end the silence and shame around abortion by providing spaces for women to share their personal stories of how access to safe and legal abortion has impacted their lives (Lewin, 2015). Ms. Bonow publically shared her own abortion story on social media and created the hashtag *#ShoutYourAbortion*. With *#ShoutYourAbortion*, a novel way of engaging the public in the narrative of abortion was created, allowing real women to share their non-sensationalized stories of abortion. This campaign is noteworthy in that it stands in contrast to much of the prior focus of reproductive rights activists, which tend to center on the legal challenges to abortion (as was the goal of the *#StandwithPP* campaign).

With the *#ShoutYourAbortion* campaign, women began sharing their abortion stories online—reflecting on the situation surrounding the pregnancy, the difficult considerations they weighed in making the decision, and the way that access to abortion has changed the trajectory of their lives. Using this hashtag, women mention their other children, discuss abusive or damaged relationships, and share stores of isolation and loneliness as they relate to the abortion experience. The collection of honest, raw stories from women across the world via *#ShoutYourAbortion* has created a platform for women's voices within the abortion narrative. As stated on the movement's webpage, "The era of compulsory silence is ending. Abortion is normal. Our stories are ours to tell. This is not a debate. *#ShoutYourAbortion*." This media campaign is ongoing with women continuing to share their stories and experiences every day.

#NotoriousRBG

Among the best examples of the ability of social media to galvanize political activism in young people is the rise of Ruth Bader Ginsburg as a feminist cultural icon. Justice Ginsburg was the second woman to be appointed to the Supreme Court and has served as an Associate Justice since 1993. She is viewed as a defender of progressive principles and her dissenting decisions (Toobin, 2013) in cases like *Burwell v. Hobby Lobby* have helped her to be recognized as a liberal voice and advocate for women's rights within the court (Ohlheiser, 2014). Artwork of Justice Ginsburg with a crown and her trademark lace collar over her Supreme Court robe trend on the "Notorious R.B.G" Tumblr which contrasts the 80-year-old lawyer sharply with the rapper her nickname parodies (Totenberg, 2015). Through social media, Justice Ginsburg's decisions on family planning issues in the Supreme Court have disseminated, making her a hero and advocate for the reproductive rights movement.

The regulation of abortion at the state level is an ever-evolving process and many states introduce several reproductive health and abortion laws each year. For instance, in 2011, legislators introduced more than 1100 abortion-related provisions with 135 of these eventually enacted (Guttmacher Institute, 2012). These laws have significant impact on provision of abortion, access to care, and public health.

The passage of an omnibus abortion bill in Texas in 2012 led to closure of over half abortion clinics in the state of Texas, and became a case study of the public health impact of restricting abortion access (Grossman, Baum, et al., 2014; Grossman, White, Hopkins, & Potter, 2014). Challenge of the constitutionality of law occurred, eventually taken to the level of the Supreme Court in the case *Whole Women's Health v. Hellerstedt.* As the Supreme Court considered the first abortion case in years, the extent that states can legislate abortion policy that ultimately restricts access was questioned.

Ultimately, the court overturned HB2, a historical decision that protects access to abortion vis-à-vis state regulation of abortion. In the wake of the decision, *#NotoriousRBG* trended again, including memes of Justice Ginsburg, including quotes from her concurring decision (Krantz, 2016). While Justice Ginsburg did not write the majority decision, in many ways she remained the voice for the reproductive rights movement and was celebrated along with the decision. Among the many examples of how social media has been engaged in the fight to protect reproductive choice, the *#NotoriousRBG* illustrates how these new forms of media can transform advocacy through the creation of cultural icons.

Role of Social Media in Making Abortion Safer: Accessing Medical Abortion Outside of the Traditional Health System

In contexts where abortion is illegal or practical access is constrained, the ability for women to access information and recourses for self-induced medical abortion outside of traditional health systems fits within a harm-reduction model of care (Briozzo et al., 2006; Erdman, 2012; Hyman, Blanchard, Coeytaux, Grossman, & Teixeira, 2013).

For instance, in Latin America where abortion is legally restricted, the use of misoprostol for self-induced abortion is linked with a decrease in maternal mortality related to unsafe abortion (Dzuba, Winikoff, & Pena, 2013). And, as data to support the expansion of women's roles in self-management of many components of medical abortion grows, an understanding of women's preference for independent use of misoprostol for medical abortion is also evolving.

Studies have shown that the media is an important source of information about safe abortion practices, and that quality of information relates to risk for unsafe abortion. An unmatched case-control study in Sri Lanka evaluated the determinants of decision making in the setting of unplanned pregnancy. Comparing controls who were admitted to the hospital for delivery of an unintended pregnancy to cases admitted to the same hospital for complications of unsafe abortion, risk for unsafe abortion was associated with unreliable sources of information and poor knowledge in addition to limited access to affordable abortion care (Arambepola & Rajapaksa, 2014).

When women do not have access to safe abortion, they turn to unsafe abortion practices. Thus, providing accessible, evidence-based information on how to obtain safe medical abortion outside traditional health systems is an important public health imperative. Use of social media to achieve this goal is an evolving way of delivering public health information.

In an effort to improve the quality of available information about medical abortion on the Internet, Ibis Reproductive Health and the Office of Population Research at Princeton University created a multilingual website called www.medicationabortion.com (Foster et al., 2006). A 2014 study of user e-mails submitted to this website confirms that there is significant demand for online informational resources about medical abortion—both in regions where abortion is legal and illegal (Foster, Wynn, & Trussell, 2014).

Women on Web is another nonprofit project that aims to support women in obtaining safe abortion where legal abortion is not accessible. The website provides informational resources, uses an online or telemedicine consultation service with a physician to determine eligibility, and provides mifepristone and misoprostol via mail for use in medical abortion where these services are not available (Gomperts, Jelinska, Davies, Gemzell-Danielsson, & Kleiverda, 2008). When women do not have access to safe abortion services, they undergo unsafe, dangerous procedures with high morbidity and mortality. Providing medical abortion in this way allows safe abortion practices to be possible in settings where legal abortion is not available. Finding ways to support women who seek abortion in regions of the world where these services are not available is an important strategy to decrease mortality related to unsafe abortion.

Conclusion

Scholarship that critically evaluates the content and messaging of popular culture representations of pregnancy, motherhood, and abortion demonstrates the disconnect between popular culture, representation, and reality of experience as it relates to abortion. As traditional media platforms are still primarily male dominated in content and creation, the participatory nature of social media is one avenue transmitting real narratives of abortion. By including the voices and perspectives of women themselves, abortion stigma can decrease. Through their participatory nature, social media platforms have the potential to challenge traditional media representations of abortion and can serve as an empowering platform for political and feminist pro-choice activism.

Discussion Questions

1. What do you think is the cause of abortion stigma? What are the most effective ways for doctors, public health officials, and ordinary citizens to combat this stigma?
2. How do race, class, and age affect representations of abortion in the media?
3. What are the advantages of using social media for activism? What are the disadvantages?
4. In which ways does social media activism correspond to the intersections of feminist theory and praxis?

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Chapter 11
The Criminalization of Women for Abortion in Chile

Michele Eggers

Introduction

Criminal laws penalizing abortion have been gradually gaining international attention as responsible for poor health outcomes for women, often resultant in maternal mortality. Laws criminalizing abortion perpetuate unsafe conditions for women by pushing abortion underground, but do not eliminate abortions (Huff, 2007; Kismodi, Bueno de Mesquita, Ibañez, Khosla, & Sepúlveda, 2012). In fact, the highest rates of abortion in the world are in countries where abortion is illegal (Cheng, 2012; Singh, Wulf, Hussain, Bankole, & Sedgh, 2009). When abortions are pushed underground, it puts women's health at risk and criminalizes women for the act of terminating an unwanted pregnancy (Ely & Dulmus, 2010; Huff, 2007). The United Nations Special Rapporteur on the Right to Health underscores the inherent discriminatory nature of laws that criminalize "access to sexual and reproductive health-care goods, services and information," noting that "women and girls are punished both when they abide by these laws, and are thus subjected to poor physical and mental health outcomes, and when they do not, and thus face incarceration" (UN Human Rights Council, 2011, p. 6).

Much of the discourse surrounding abortion originates from two paradigms, pro-life and pro-choice, neither of which fully addresses the complexity of women's experience with abortion. According to Smith (2005), where the pro-life paradigm advocates for the rights of the fetus without regard to the rights of women, the pro-choice paradigm fails to fully support the rights of women because this position implies that women have equal choice without taking into consideration issues of access and affordability. Smith (2005) argues that it is not in the definition of the

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fetus as a life where the pro-life movement fails, but rather in the conclusion "that because the fetus is a life, abortion should be criminalized" (p. 121).

Both paradigms of pro-life and pro-choice fail to recognize the impact on women who are marginalized in society (Gillman, Neustadt, & Gordon, 2009). Thus, a pro-life/pro-choice paradigm for addressing abortion is limited by individual analysis and subsequent interventions. Broader issues of inequality need to be taken into consideration to understand the context in which women's reproductive lives are embedded. For example, not all women are treated equal under laws and women who are already marginalized in society are the most impacted by restrictive reproductive health policies. Therefore, neither a pro-life nor pro-choice framework invites a critical analysis of "political exclusion, social isolation, and economic marginalization" (Campbell, 2000, p. 8), which is relevant to women's experience of being criminalized for abortion.

A reproductive justice framework links reproductive health and rights with social justice in order to address historic and contemporary processes of reproductive oppression. For example, reproductive justice acknowledges that women marginalized in society constantly negotiate their reproductive health experience within "interlocking forms of oppression," such as "poverty, racism, environmental degradation, sexism … and injustice…" (Silliman, Fried, Ross, & Gutiérrez, 2004, p. 4). Thus, a reproductive justice framework expands the limited discourse of the dichotomous pro-life and pro-choice paradigms and helps to highlight the power that social, economic, and political constructions hold on women's experience with being criminalized for abortion.

The literature on abortion acknowledges that women who are marginalized in societies are most impacted by restrictive abortion policies, but there is a lack of representation of these women's voices in how living in a highly criminalized environment impacts their lives. Using Chile as a case study from research conducted over an 11-month period, in this chapter I will examine how laws criminalizing abortion are socially constructed depending on the political climate and highlight the impact of this on women marginalized by social, economic, and political inequality (Desjarlais, 1997; Willen, 2007). Choosing Chile as a research site had both theoretical and practical applications. Chile is one of the four countries in Latin America with the most restrictive reproductive health policies; there are no legal exceptions to terminate a pregnancy. Further, Michelle Bachelet, currently in her second term as Chile's president, has stated her intention to decriminalize abortion in three circumstances: in cases to save a woman's life, in cases of rape or incest, and in cases of an unviable fetus (Sopcich, 2015).

This study is guided by a reproductive justice framework as part of a larger social justice approach to contextualize abortion within a broader framework. Shifting the focus from the criminal act of terminating a pregnancy to the women who are impacted by policies and laws that construct them as criminals, this chapter underscores women's narratives of how they experience being criminalized for abortion. Failing to place women's lived experience in the center of abortion discourse perpetuates the stigmatization and marginalization of women by disembodying them from the often multiple overlapping systems of inequality that determine their reproductive health experience.

Methodology

In order to understand the impact of criminalizing women for abortion in Chile, an element of my research focused on the nature of social, economic, and political inequalities that exist within the context of restrictive reproductive health policies through semi-structured interviews with various participants in legal, religious, academic, health, and feminist institutions. In addition, ethnographic observation was employed. I attended many meetings, marches, conferences, seminars, legal and health workshops, community and cultural events, and fundraisers. These events focused on some aspect of race, class, and/or gender inequality and intersected with issues of the decriminalization of abortion; women's, indigenous, and immigrant rights; poverty; torture and disappearances; and violence against women. Lastly, I reviewed historical archives and human rights documents in various libraries, as well as print media and documentaries, and obtained three research reports on abortion while in Chile. These three methods—interviews, observation, and review of documentation—aided in providing a contextual analysis of inequities in which women's reproductive lives are embedded.

The heart of the study was based on in-depth interviews with women who have a history of abortion. The women highlighted in this chapter terminated their pregnancies after 17 years of population policy changes during the dictatorship of Augusto Pinochet. These women identified as at least one of the following: immigrant, indigenous, domestic worker, student, a young woman in their mid-teens to mid-twenties when they had their abortion/s, or having limited to no income. This grounded the research in the narratives of women whose perspectives are generally devalued or ignored (Allen, Flaherty, & Ely, 2010; Cleaveland, 2011). Each of the participants was given a pseudonym in order to protect the identity of the participants while providing a more intimate connection with the reader. Direct quotations from the Spanish interviews were translated into English with the aid of a Spanish-speaking consultant.

Participants were recruited through multiple methods: purposive, snowball, and field encounters. The latter helped to connect with others who would not normally have been in my purview. Forty formal semi-structured and in-depth interviews were conducted in total with thirty-six participants. Twenty-five semi-structured interviews were conducted with participants affiliated with religious and academic institutions and legal, public health, economic, feminist, human rights, and community organizations. Eleven in-depth interviews were conducted with women about their abortion experience. Four of the eleven women were invited for second interviews in order to delve deeper into the phenomena being studied. Interviews were digitally audio-recorded and conducted in both English and Spanish, depending on the preference of the participant. In addition to the formal interviews, I engaged in over 60 substantial informal conversations with a diverse group of people and hundreds of meaningful but more limited interactions, which constantly contributed to and guided my research. In this chapter participant voices from both the context and core interviews are included.

Criminalization

Much of the literature on criminalization focuses on the illegal act itself, such as the criminalization of welfare fraud, drugs, prostitution, and illegal immigration to name a few (Finerty, 2012; Gustafson, 2009; Lucas, 1995; Provine & Doty, 2011). A further analysis helps to shed light on how those already marginalized in societies become criminalized along with the illegal act. Criminalization constructs and perpetuates stigma; restricts access to needed resources and services, including state protection from abuse; excludes participation in society; and sustains social and economic marginalization of individuals perpetuated within a permissive environment of discrimination.

Therefore, the literature on criminalization suggests that the cumulative effect of criminalizing women for abortion is twofold. On the one hand is the direct impact of laws that make women criminals for terminating a pregnancy with the potential risk of being arrested, being put on probation, and/or receiving prison time (Androff & Tavassoli, 2012; Belton, Whittaker, Fonseca, Wells-Brown, & Pais, 2009; Htun, 2003; Shepard & Casas Becerra, 2007; UN Human Rights Council, 2011). For example, in the United States, women are currently being prosecuted for terminating a pregnancy (Rowan, 2015). In some cases women are charged with terminating a pregnancy when in fact they had miscarried. Between 2011 and 2014, the United States enacted 287 new laws that limit access to reproductive health, including abortion (Rowan, 2015). According to Rowan (2015), 38 states have the ability to charge a person with homicide for the "unlawful death of a fetus" (p. 71). Some areas of the United States are more impacted than others. In the Rio Grande Valley in Texas there have been massive cuts to low-income clinics impacting mainly Latina women with limited resources. These women have to travel 50 miles to receive reproductive health care, including contraceptives and annual exams that detect cancer (Texas Latinas Rising, 2015). Thus, women in this area who experience unintended pregnancies are put in a situation to induce their own abortions, sometimes by extreme measures.

Currently it is unknown how many women worldwide are imprisoned for abortion, are put on probation, or receive a fine, but the trend to criminalize women for abortion clearly reflects a race and class bias (Comack, 2006; Flavin, 2009; Sudbury, 2005; Upreti, 2005). Consequently these women experience multiple layers of discrimination in addition to not having equal access to the same legal recourse as other women in a higher social economic class. Specific to poor women is their lack of financial means to seek legal support, lack of access to defense counsel, and lack of understanding about their rights, thereby making them vulnerable to undue process and exploitation (Center for Reproductive Law and Policy, 1998; Ramaseshan, 1997).

In addition to the direct impact on women criminalized for abortion, the focus of this chapter is to highlight the indirect impact of restrictive abortion laws on women's lives. This perspective of criminalizing women for abortion encompasses concrete consequences, such as having to negotiate a climate of discrimination embedded in social, economic, and political structures; being invisible and vulnerable to abuse; having no legal recourse; living in fear and isolation without protection from the state; and suffering severe health complications or dying (Androff & Tavassoli, 2012; Comack, 2006; Flavin, 2009; Gustafson, 2009; Kulczycki, 2007; O'Doherty, 2011; Sutton, 2010; Upreti, 2005).

Unsafe abortion is the third leading cause of maternal mortality in the world (Blyth, 2008; Getchen, 2008; Jayasundara, 2011). Nearly 90% of unsafe abortions happen in the global south where there are higher restrictions on abortion. The women most impacted by restrictive abortion policies are the same women who lack access to basic health and reproductive health care, thereby forcing them to terminate unwanted pregnancies in unsafe conditions and illegal circumstances. Because of the clandestine and criminal nature of abortion these women are regularly treated poorly by abortion providers and told not to return if complications arise (Belton et al., 2009; Casas, 2009; Gillman, Neustadt, & Gordon, 2009; Kumar, Hessini, & Mitchell, 2009). Further, due to their low social and economic status, fear of denouncement, and perpetuation of abortion stigma embedded in discourse, policies, institutions, and communities (Kumar et al., 2009), women criminalized for abortion have multiple challenges to overcome.

According to the United Nations Department of Economic and Social Affairs, Population Division (2014), there are seven categories of legal grounds that permit induced abortion: (1) "to save a woman's life"; (2) "to preserve a woman's physical health"; (3) "to preserve a woman's mental health"; (4) "in case of rape or incest"; (5) "because of fetal impairment"; (6) "for economic or social reasons"; and (7) "on request" (p. 6). As of 2014, Chile, Dominican Republic, El Salvador, Malta, and Nicaragua provide no legal exceptions to terminate a pregnancy, not even in the case of rape or incest or when a woman's life is endangered. Four out of five of these countries are in Latin America. Contrary to prohibition, 56 out of 193 member states support terminating a pregnancy on request, mostly from European, North American, and Asian countries, leaving 132 countries with a range of policies impacting women's access to safe and legal abortion (United Nations Department of Economic and Social Affairs, Population Division, 2014).

Within all levels of legal grounds to terminate a pregnancy there is regular discrepancy between law and practice in the context of gender inequality embedded within societies (Caprioli, Hudson, Stearmer, McDermott, Emmett, & Ballif-Spanvill, 2007). Layers of established social norms, such as attitudes, behaviors, and practices of male dominance, manifest as lack of political will at various levels of government, subsequently regulating the social, legal, and economic autonomy of women, which preserves societal harms toward women. For example, women experience stigma attached to pregnancy outside of marriage or from rape. Thus, the protection or lack thereof of women in society is sustained, including related impacts, such as due process of legal rights (Richards & Haglund, 2015). Therefore, laws are not always clear or enforced and are interpreted differently worldwide.

In the United States where supposedly a woman can get an abortion upon request, there is an ongoing trend to implement restrictive reproductive health policies across states. These include forced sonograms, spousal or parental consent or notice, up to 72-h waiting periods, and lack of public funds to support low-income, indigenous, and military women from receiving abortions (Boonstra & Nash, 2014; Grindlay, Yanow, Jelinska, Gomperts, & Grossman, 2011). Alabama has a new abortion law that puts teenagers on trial for wanting to terminate their pregnancy without parent permission and appoints a public defender for the fetus (Culp-Presser, 2014). Further, women are being sent to prison in El Salvador for having miscarried, in Pakistan women are charged with adultery when they report they have been raped (Htun & Weldon, 2010), and in Brazil a woman died from pregnancy complications due to inadequate health care based on discrimination because she was a woman, poor, and of African descent (Kismodi, Bueno de Mesquita, Ibañez, Khosla, & Sepúlveda, 2012). Hence, reproductive health, including abortion, is a race, class, and gender issue manifest through the regulation of women's bodies. These varying experiences of women are generated through gender-related policies that determine women's experience as being repressed, excluded, or criminalized (Sutton, 2010).

Chilean Context

Laws and policies addressing social issues are a social construction, which are either modified or sustained depending on the political climate. Therefore, abortion discourse in Chile has varied depending on the specific local and international political context of the time. In the 1960s and early 1970s, pre-dictatorship period, Chile had one of the most progressive reproductive health programs in the Americas (Moenne, 2005; Shepard & Casas Becerra, 2007; Vargas, 2008). In part, this was prompted by the high rates of maternal mortality from unsafe abortion. Poor women were most impacted by unsafe abortions. Ani, a human rights lawyer, explained, *"Poor women were the ones who had to confront the consequences of unwanted pregnancies. Those were the women who were dying as a result of abortion, those were the women who were hospitalized."* This was due to the lack of resources that poor women had to obtain a safe abortion, and therefore were reliant on more harmful techniques to terminate their pregnancies.

In addition, during this same time period, the United States was providing aid through the Alliance for Progress to decrease poverty and population growth, which were seen as destabilizing forces in Latin America (Morray, 1968). Thus, Chile became one of the first in the region to implement a state-subsidized family planning program (Casas, 2004; Moenne, 2005; Shepard & Casas Becerra, 2007; Vargas, 2008). In the early 1970s under the administration of Salvador Allende, the program expanded to incorporate sexual education (Casas & Ahumada, 2009; Moenne, 2005), increasing public health outreach to 40% of Chile's population, including to women with a history of unsafe abortions (Casas, 2004; Moenne, 2005). Because of these efforts, both abortion and maternal mortality rates significantly declined.

All of this changed when General Augusto Pinochet came into power. After the military coup in 1973, as part of Milton Friedman's and the Chicago Boys' Chile Project[1] to reverse economic nationalism and increase privatization, public spending was cut by 27%. By 1980 such spending was half of what it was under Allende (Klein, 2007; Sepúlveda, 1997). By 1988, 45% of Chileans had fallen below the poverty line and the richest 10% had increased their income by 83% (Klein, 2007, p. 105). Education and health were hit the hardest based on public funding cuts and the privatization of social services, greatly impacting women's health and reproductive health.

During the dictatorship programs and educational resources provided in public health clinics as part of the family planning awareness campaign were removed, as well as the comprehensive sexuality education programs that were developed earlier (Casas & Ahumada, 2009). Isadora, an activist at a nongovernmental organization, recalled,

> *All of the [sex ed] programs that were started with Frei, all of that was taken [during the dictatorship] and they burned all the [sex education] books … everything was burned and disappeared. Then we had 17 years with nothing in the schools … especially for the poor sectors.*

Pilar, who lived in a low-income neighborhood east of Santiago's city center, acknowledged that she was of the generation who did not have access to sexual education in public schools during the dictatorship. The first time she had sex in 1990, she got pregnant. She never had access to any information and expressed feeling very ignorant. In fact, she said that many girls were ignorant at this time, as sex and information about sex inside and outside of the home were very repressed.

Further, under Pinochet's population policy, restrictive population control policies were developed and administered as a measure to protect national security (Casas, 2004; Moenne, 2005; Vargas, 2008). A pro-birth policy was initiated "… linking the development and defense of the nation to the size of the country's population" (Moenne, 2005, p. 156). In the new era under Pinochet's dictatorship, public health practitioners in clinics and hospitals were encouraged to remove family planning services from public view, and remove poor women's intrauterine devices (IUDs) without their consent, and were mandated to report any woman who came in from postabortion complications (Casas, 2004; Moenne, 2005; Rayas, 1998). These public institutions were now under the scrutiny of the state's secret intelligence, which tracked women who had abortions. Women without economic resources had no other option but to depend on public health facilities when faced with complications from terminating a pregnancy and therefore were most at risk of

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[1] The US Government paid full tuition and expenses for select Chilean university students to study economics at the University of Chicago under Milton Friedman, in order to promote a neoliberal economic agenda in Chile. The students who went through the program were known as the Chicago Boys (Klein, 2007).

being arrested and imprisoned for abortion (Casas-Becerra, 1997; CRLP, 1998; Vargas, 2008).

Since 1931, it had been legal in Chile to obtain a therapeutic abortion to save a woman's life, but in the last weeks of Pinochet's dictatorship in 1989, after 17 years of military rule, Pinochet changed this law rendering all abortions illegal (Casas-Becerra, 1997; Htun, 2003; Rayas, 1998; Vargas, 2008). Twenty-seven years after the return to democracy in 1990, abortion laws in Chile remain one of the most restrictive in the world. There are no legal exceptions to terminate a pregnancy (Casas-Bercerra, 1997; Htun, 2003). There are still some cases where women are being reported to the police and the majority of these women are being reported by public hospital emergency wards. *"Because this is the one place where women get identified,"* Ani reflected.

Further, since the return to democracy in 1990, the Catholic Church has been increasingly focused on restricting reproductive health and rights for women (Shepard, 2000), isolating "abortion as an assault on motherhood, sex roles, and the origins of human life" (Htun, 2003, p. 151). Women who deviate from the construct of acceptable gender norms by terminating a pregnancy are criminalized (Moenne, 2005; Sutton, 2010). This is particularly true for poor women, as they have less access to reproductive health and health care in general, and are more dependent on public health services for care. It is in this context that restrictive abortion legislation and its impact on women's lived experience need to be understood, as inherent inequity in social, economic, and political structures (Casas, 2009; Moenne, 2005; Vargas, 2008).

The difficulties for women who are marginalized in Chilean society are the result of everyday violence, such as poverty, racism, sexism, deficiency in education, and lack of access to health and reproductive health services (Nuñez & Torres, 2007). These existing structures of inequality impact women's lives and serve as the context in which reproductive health choices are limited and controlled. Emilia, a social worker in the south of Chile, explained that women who are poor have very little right, in practice, to exercise choice or decision making. *"We don't own our bodies … it is very evident, with respect to your body, that it is owned by the state,"* she explained.

Impact of Criminalization on Women

A woman's agency is drastically reduced when she is compelled to harm herself. The clandestine environment resulting from the illegality of abortion fosters exploitative, violent, and life-threatening conditions for women. Ani pointed out that criminalizing women for abortion provides the opportunity to reinforce Chile's class structure. For example, illegality determines the level of safety of the abortion procedure based on how much someone can pay. Ani said, *"The [abortion] procedure perhaps can be done in a very secure clinic, you know, [with] technology. And if you're going down the scale, you may have very rudimentary procedures, [which* *are more] high risk."* For low-income women, this reality was highlighted in the experiences shared about the process of seeking a clandestine abortion. Limited financial means determined how or whether they could terminate an unwanted pregnancy.

Violence

Participants highlighted that the physical act of terminating a pregnancy felt like violence to their bodies. Paz, who shared her abortion experience, reflected, *"It's weird because when you're pregnant the only way to take out the baby is like in an intervention and always that intervention is violent … so, I was preoccupied about that, about my body."* Paz aborted after 2010 with Misoprostol[2], which, if used correctly, is a safe method of terminating a pregnancy for women; however she still expressed the process as violent:

> *You have to put chemicals inside your body and you have to pay… You have to search, you have to pay, you have to risk. You have to take pills and put pills inside your body and it's not natural. I don't like pills, but it's the only way that you can do it in your own house and know that it's not dangerous. So, I was there with my head, with a lot of questions, and the pain.*

For Paz, her abortion was a bodily experience on multiple levels. She was in a lot of pain and it felt as if someone had their hand in her uterus and was squeezing, twisting, and turning her insides, *"To stop being pregnant, it's intense,"* she said.

The *sonda* is a dangerous technique, whereby a hollow rubber tube is placed in the cervix to allow air to enter the uterus. In the past, the *sonda* was a common method to terminate a pregnancy generally only on women who had no access to other resources (Paxman, Rizo, Brown, & Benson, 1993). For participants who terminated their pregnancies with the *sonda* technique they expressed experiencing a lot of pain in their body, both from the actual technique and, for Anaís, the infection that developed afterward. For Pilar, who was a teenager when she received her abortion, the *sonda* was incredibly painful. She remembers being full of air *"like a balloon"* and screaming because the pain was so strong, *"It was not just my body that was hurting, but also my spirit."* Marcela, who works at an NGO in the south of Chile, remembers a friend who aborted with the *sonda* technique. She expressed this was *"very violent."* Watching how dangerous this was for her friend, how violent and unsafe the process was, and not having any other alternatives, made her feel helpless. She remembered, *"I have no problem with abortion, I believe it's a decision for women to make and if it can be less violent, it's better for the woman."*

The physical act of having an abortion was not easy for the women interviewed in this study. Especially for poor women, being forced into a situation that was high risk to their bodies and lives reflected the unjustness in the law by how women are

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[2] Misoprostol is used to prevent ulcers, but also for labor induction.

impacted differently. Women's experience of bodily harm demonstrated how violence is palpable and concrete, making an abstract concept corporeal.

Fear

Having to negotiate their way around clandestine spaces was a new experience for women. Women shared that they were afraid of the unknown. Paz expressed fear of the clandestine environment and having to navigate an illegal transaction. Paz purchased Misoprostol online:

> *We start to search on the internet and we found pages where people were selling the pills … but I don't like it because it's always impersonal, you have to buy from an unknown person who only wants your money … there is a risk there because you're going to put [these pills] inside your body. So we were really afraid to do it that way, but the other ways were impossible because we didn't have the money or contacts in big clinics.*

Although the clandestine environments where women terminated their pregnancies were distinct from one another, women revealed a similar sentiment that it was the clandestine nature of abortion that produced fear.

Women also expressed concern about how health complications might lead to legal consequences. Participants constantly expressed fear of having to go to a public hospital if something went wrong with their abortion. Women who aborted with the *sonda* technique were especially fearful of complications arising, as it was a dangerous technique that might warrant a hospital visit. The *sonda* was also easier to detect than more contemporary methods, such as misoprostol. Women were afraid that if they went to the public hospital, they were at risk of coming in contact with law enforcement. For example, Macarena recalled,

> *The only thing I remember [is] that if you arrive in the hospital with the consequence of the abortion, the illegal abortion, of course immediately the doctor called the … police, so you are in trouble, in legal trouble.*

Not only were women afraid of the actual abortion experience and how this might impact their health or subsequent criminalization, but they also expressed fear of others finding out that they were pregnant and that they had had an abortion. For example, Paloma had both fear of dying from the abortion and she was afraid to tell her husband that she was pregnant. Because her husband was jealous and very violent, she feared that if she told him about the pregnancy he would accuse her of having an extramarital affair and that she would be beaten**.**

Silence

The emphasis on criminalization created the condition where women did not have a voice or a place in their abortion experience. In sharing their stories, women often relived the silence they embodied as a result of the clandestine nature of illegality. These stories were suppressed sometimes for years. In addition, women's silence included not disclosing their abortions with medical professionals, making it difficult to calculate the rate of abortion and to provide needed services. Alma, a gynecologist in a public health clinic in the north of Chile, said, *"because abortion is criminalized, we have no reference for the reality of abortion … women do not talk about it."* Francisco, a psychologist who also worked in the north of Chile, shared,

> *With abortion … when we know about cases we kind of scandalize a bit, like, "wow, she had an abortion"… and … we don't like that that happened and the women usually run away. They don't appear here anymore because they know that there is a problem for us, too.*

As a psychologist, Francisco focused on *"the emotional reparation … [rather] than the legal repercussion."* But he could not say that his colleagues would respond in the same way, as they do not talk about it because of the clandestine nature of abortion. Francisco said that abortion is *"so secret"* that often when medical professionals first become aware that a woman had an abortion, it is in the emergency room dealing with complications. Thus, the invisible becomes visible when the body endures health or legal consequences. When an aspect of abortion does become visible, it is in a negative light.

Discourse

Several women described the impact of mainstream discourses surrounding their pregnancies and abortions. With abortion, women are not only going against the law, but also against culture and constructed social norms. For example, Tamara, who works for a religious nonprofit organization, discussed her struggle with coming to terms with the discrepancy between her Catholic upbringing and her path toward advocating for reproductive rights. She was raised to regard contraceptives as *"little versions"* of abortion. She struggled with the concept of abortion, because the messages she received espoused women who had abortions as, *"bad, a criminal, a murderer, a sinner."*

Anaís mentioned aspects of a societal context, which constructs the internalization of blame for women and for her specifically, feeling solely responsible for getting pregnant. For Paz, she felt bad purchasing misoprostol in the black market. She felt like a criminal, buying and dealing illegal drugs. She explained,

> *It's weird because there are pills … in a Ziploc bag, it's like you're feeling like you're doing something bad … always in your head the thing you are doing is not only emotional, but also a legal thing, you know, you are lying to the government. So that feels weird because you feel bad.*

Macarena stated that,

> *The most terrible idea of abortion is the idea that you are killing someone, a person who kills, murders. The word kill carries a lot of weight … I never killed anyone, I killed one ant, you know? The idea of killing somebody, it's like, I don't want to kill anybody, you know? But the idea that society says, "you are killing a baby", it's like, what? What are you saying? I'm not killing a baby. I don't want to kill anybody.*

Francisco describes abortion as invisible in society; people know it is there, but they do not want to look at it. In part, he says, because it is hard to imagine a woman resisting the cultural mores of being a mother,

> *It's hard for us, I think, [to] create an image of a woman deciding the opposite, you know, "I don't want a kid, I don't want to get pregnant, I have a lot of plans in my life"… you just don't think a woman is capable of [abortion].*

Criminalizing women for abortion is the result of the maternal body being morally regulated by the church and state policies, resulting in discriminatory societal attitudes toward women who have had abortions. Paz said, *"Right now we are separated by a system that puts us in one place or another. Are you a good woman or a bad woman? But always… they don't want [us] to find each other."* Thus, when abortion is criminalized it not only reinforces inequalities, but also keeps abortion clandestine in both the physical environment and the internal environment within a woman (Sutton, 2010).

Conclusion

This chapter revealed women's embodied experience with abortion within the context of illegality and clandestine spaces. Many of the same issues exist for women within a legal or an illegal framework of abortion, such as having to negotiate family expectations, relationships, and economic circumstances. However, the backing of legality makes a big difference for women, because it denotes having rights, versus having no rights. Not having any rights creates a highly vulnerable situation and experience for women. Women's experiences of vulnerability in a society that does not give them a space to have a voice demonstrated both the symbolic and concrete positioning of these women in society.

The situation of illegality produces a clandestine environment, which creates and sustains a black market economy around abortion. This constructs further exploitation of women without protection from the state. Specific to poor women, the black market economy gives them very little agency because they cannot afford to buy choice. Thus, poor women are relegated to putting their bodies in harms way, as there is no state regulation or protection of women in the black market. It is in this context that women do not exist and violence, fear, silence, and isolation are interwoven and inscribed on women's bodies.

Lastly, the narrow lens of criminalization results in unnecessary harm by placing the onus of responsibility on individuals, subsequently fostering a permissive discriminatory environment. One of the problems with linking abortion to a criminal act is that it "decontextualizes women from the social and political parameters of their lives" (Pollack, 2000, p. 79). This approach situates the underlying cause of criminality as individual responsibility rather than the construction of laws and policies that do not take into account the conditions of oppression as a contributing factor to terminating a pregnancy. Pollack (2000) states that this is problematic because, “Individualizing social issues can result in blaming individuals for problems that arise from being oppressed in various ways and may be further disempowering to them” (p. 77). Contrary to a criminalization model, a reproductive social justice approach would be inclusive of addressing the broader issues of inequality, such as race, class, and gender as situated within social, economic, and political processes and practices (Mazza, 2011; Silliman, 2002).

Discussion Questions

1. How does using a reproductive justice framework help in understanding how women are directly and indirectly criminalized for abortion?
2. What is the relationship between race, class, and gender inequality and how women are criminalized for abortion?
3. How would instilling an anti-criminalization discourse in the pro-life discourse aid in creating a social justice approach to addressing abortion?
4. What alternative approaches would you use in lieu of a criminal model in addressing abortion?

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Part IV
Violence

Chapter 12
From Violence to Sex Work: Agency, Escaping Violence, and HIV Risk Among Establishment-Based Female Sex Workers in Tijuana, Mexico

Shonali M. Choudhury, Debbie Anglade, and Kyuwon Park

There is a growing literature on the negative impact of gender-based violence on the capacity of sex workers to take measures to protect themselves from sexually transmitted infection (STIs), particularly HIV. Most studies have focused on street workers rather than establishment-based sex workers and/or have focused on violence in the work environment (Katsulis, Lopez, Durfee, & Robillard, 2010; Ulibarri et al., 2010; Wahab, 2005). Moreover, previous studies have concentrated on violence perpetrated after entrance into sex work, the only exception being research on violence in the parental home (i.e., child abuse; Ulibarri et al., 2010). In the present study, we explored establishment-based sex workers who themselves defined the types of violence that had impacted their lives. Because the women gave primary emphasis to the theme of escaping violence inflicted by intimate partners before their entrance into sex work, our study pioneers an examination of the implications of this type of violence and of decisions to leave a violent relationship to preserve their health and quality of life. Drawing on 20 interviews with women who had experienced working in the establishment-based sex industry in Tijuana, we present new insights into how establishment-based sex workers conceptualize violence, self-preservation, and health.

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Background

At the interpersonal level, gender-based violence is strongly linked to the male-female hierarchy and men's needs to reassert a dominant status (González-Guarda, Peragallo, Urrutia, Vasquez, & Mitrani, 2008). Gender norms that support male aggression and female passivity make it difficult for gender-based violence to be validated as a real problem that women face on a regular basis. Reports from human rights organizations such as Amnesty International (2008a, 2008b) have indicated that women in Mexico suffer disproportionately from violence.

Gender and Poverty

According to the Central Intelligence Agency (2012), the per capita gross domestic product (GDP) of Mexico, adjusted for purchasing power parity, was US$15,100. The per capita GDP in Baja California, the Mexican state that houses Tijuana, is 1.03 times that of the country as a whole but 2.32 times the per capita GDP in Chiapas, the southernmost state of Mexico bordering Guatemala (Instituto Nacional de Estadística y Geografía, 2010). Mexico is a country of great income disparity. Per capita GDP in the urban and northern areas, as well as the Federal District (i.e., Mexico City), tends to be higher than in the southern and more rural parts of Mexico. Women in Mexico typically earn less than 50% of what men earn for equal work (GINI index = 51.7 and gender inequality index = 0.448; United Nations Development Programme, 2005, 2012). The Mexican social norm is to consider men as the primary income earners, and women are expected to care for the home and family. Women's work outside of the household tends to be considered as being secondary. The subordinate position of women often makes them economically dependent on a male partner; however, female-headed households are becoming more prevalent and many women are the primary earners. A large percentage of these women earn very low wages (United Nations Development Programme, 2005, 2012).

Tijuana's migrant Mexican population comes primarily from poorer districts in the country to work in the two major economic activities of manufacturing and tourism. Tijuana, however, has experienced high levels of violent crime related to gang violence, the Mexican drug war, and human trafficking, and the surge in violence has reduced the city's attraction for tourists (Vercammen & Rowlands, 2010).

Gender-Based Violence and Power Disparities

The findings from the 2006 National Survey on Family Relations in Mexico indicated that 67% of women have experienced some form of violence, including 47% of women who experienced interpersonal violence with a romantic partner

(Amnesty International, 2008a). Research has shown that the percentage of women who experience some form of violence has been increasing in Mexico, and violence against women tends to be underreported since 82% of women who experience some form of violence do not report it. Furthermore, femicide is a major problem in Mexico. In 2003, 1205 women were murdered, and approximately 34% of women murdered in 2003 and 2004 were murdered in the home (Amnesty International, 2008a). In 2008, 28 of the states in Mexico enacted legislation that stated that women have the right to a life free from violence, but rates of violence remain high (Amnesty International, 2008b).

Women's susceptibility to violence can be exacerbated by lack of economic power. Economic dependence on men is a barrier not only to resistance to violence, but also to resistance to demands for high-risk sex. For example, a woman may be more willing to give in to the sexual demands of her partner to continue to gratify him and secure financial stability. Women also tend to be accepting of a partner's infidelity in order to ensure the financial stability of marriage. Women may be willing to remain in a high-risk relationship and to accept high-risk sexual behaviors because of fear of desertion and rejection (Blanc, 2001).

Women who leave a violent relationship may face economic hardships stemming from a loss of financial support from their partners. These women must find adequate housing and employment to provide for themselves and often their children. A woman leaving a violent relationship faces significant psychological barriers to finding a career or a job, especially when she has been economically dependent on a male partner and has little to no education or skill training (Morris, Shoffner, & Newsome, 2009).

Gender-Based Violence and Women's Health

Gender-based violence can affect women's health in multiple ways. The most obvious way is through direct physical harm to the body. Furthermore, repeated physical abuse can lead to long-term psychological problems such as depression and anxiety. Violent and/or coerced sexual attacks, including spousal/intimate partner rape, can also have a direct impact on women's health. Violent/coerced sex acts can lead to transmission of STIs, including HIV, as well as cause pelvic inflammation and chronic pelvic pain. There are also emotional effects of sexual violence (Blanc, 2001).

Gender-based violence can generate poor sexual health outcomes, such as risk for HIV infection, in the lives of marginalized women, including female sex workers. Experiences of violence can undermine a woman's ability to protect herself from STIs including HIV, as well as her ability to seek health services (Sanders, 2001; Ulibarri et al., 2010).

Violence Against Sex Workers

The relationship between a history of intimate partner violence and HIV risk among sex workers has been documented in other studies (Sanders, 2001; Ulibarri et al., 2010). Violence against sex workers has been classified in the research literature into three categories: physical, psychological, and sexual (Ratinthorn, Meleis, & Sindhu, 2009). Physical violence may include robbery, assault, battery, and murder. Psychological violence may involve harassment and verbal abuse during commercial sex work (CSW; Plumridge & Abel, 2001). Sexual violence may include rape and/or coercive sex and physical beatings during sexual interactions by customers, pimps/bosses/managers, and romantic partners. All forms of violence may be perpetrated by clients, pimps/bosses/managers, romantic partners, strangers, and even law enforcement agents (Ratinthorn et al., 2009). Ratinthorn et al. (2009) have identified three dimensions of threats pertaining to sex workers affected by violence: threats to life and health, threats to control of work and financial security, and threats to humanity.

Methods

Our study used a feminist constructivist grounded theory design. Data were collected from 2007 to 2009. The purpose of feminist constructivist grounded theory methodology is to develop theory grounded in the data through a systematic process of inductive analysis (Charmaz, 2006; Wuest, 1995) that simultaneously highlights the voices of women and other marginalized groups. The study was approved by the University of California, Los Angeles Institutional Review Board for the Protection of Human Subjects.

Site of Study

Tijuana is a border town in Mexico located just south of San Diego County, California. It is a relatively poor city whose economy relies greatly on tourism, including sex tourism. The sex work industry in Tijuana, where rates of gender-based violence are high and there is little protection for women, highlights gender inequalities, structural inequalities, and relationships among violence, CSW, and HIV risk. Previous studies among female sex workers in Tijuana have found that women who engage in sex work in Tijuana range in age from 18 to 80 years (Bucardo, Semple, Fraga-Vallejo, Davila, & Patterson, 2004; Strathdee et al., 2008).

In this study, we focused on establishment-based female sex workers. "Establishment-based female sex workers" has been defined as those women who work based out of a place of business that is not exclusively dedicated to sexual services. Sex workers who work on the streets are not generally included in this definition. The structured management of establishment-based sex work makes it different from street-based sex work, where women may work more independently or under a pimp rather than a business-based management. However, some women in our study reported that while they might have worked in a place of business as waitresses or dancers, they independently managed their sexual services. Furthermore, women in the study reported that working in a business setting offered them more security.

Laws and regulations regarding sex work in Tijuana, passed in 2005, revamped the registration process for CSW. In an attempt to regulate the sex industry in Tijuana, sex workers are required to carry a valid work permit at all times. For a permit to be valid, sex workers must attend the municipal clinic for routine health screenings for HIV infection and STIs. A permit will not be validated if a woman has a positive antibody test for HIV infection, and will be temporarily invalid in cases of other STIs (McKinley, 2005). A sex worker's health information is stored on a registration card that may be accessed by public health officials. The new regulations require establishments, such as bars/cantinas and brothels, that employ sex workers, to maintain a safe and healthy establishment. Although some may criticize this policy as extreme, research has found that some female sex workers endorsed the policy because it protects the lives and rights of women (McKinley, 2005).

Participants

Participants for our study were recruited in the waiting room of the municipal clinic dedicated to female sex workers in Tijuana. Men are not allowed in the clinic, except for health professionals who are employed by the clinic, which provided an atmosphere in which the women could speak more freely during the interview. The study participants were all registered sex workers.

The principal investigator approached women and offered verbal and written information about the study. Oral consent was obtained from all who agreed to participate. All 20 participants were self-identified as women, and all were Spanish speaking. They ranged in age from the early 20s to the mid-50s. All participants were working in the sex work industry at the time of the study, and 100% were registered as sex workers. The time that the participants worked in the sex work industry ranged from 6 months to over 10 years. Table 12.1 provides a summary of other characteristics of the sample.

Data Collection and Analysis

The principal investigator collected data using semi-structured in-depth interviews. The interviews included questions about participants' experiences working in the sex industry and questions that asked the participants to reflect on their social

Table 12.1 Description of the sample ($N = 20$)

Characteristic	Sample description
Children of the sex workers[a]	
Under the age of 18 years	16
Age 18 years or older	2
No longer living	1
No children	2
Place of origin	
Born and raised in Tijuana	3
From other regions of Mexico	17
Current relationship status	
In romantic relationship	6
Not in romantic relationship	14
Current place of work[b]	
Bars, gentlemen's clubs, night clubs	16
Hotels	2
Street	2
Interpersonal violence	
No former experience	3
No open discussion of previous experience[c]	3
Previous experience	14

[a] Some participants fell in more than one category

[b] Of the two participants who reported that they worked on the streets, one reported that she was a recovering alcoholic and did not want to work in an environment with alcohol, and the other stated that she was too old and could not get work in any bars or clubs. Both of these participants reflected on experiences when they did work in an establishment

[c] Some of the participants made general references to abuse but did not openly speak about their personal experiences (if any) with abuse

interactions with bosses/managers, clients, other female sex workers, families, and others who the participants identified as important and/or significant in their lives. The length of each interview ranged from 40 to 75 min. All interviews were conducted face to face in Spanish. Interviews were audio recorded with the participant's permission and then transcribed verbatim. All analyses were conducted in Spanish to preserve the voices of the participants. All quotes presented in this paper were translated from Spanish to English. An attempt has been made to preserve the idiomatic flavor of speech in the interviews even if this meant incorrect grammatical constructions in the quotes.

The principal investigator conducted data collection and data analyses simultaneously in accordance with the grounded theory method. Inductive approaches to data analysis were employed, and the constant comparative method was used (Charmaz, 2006; Glaser & Strauss, 1967). The first step in the iterative analysis process was phrase-by-phrase coding of each interview in which analytic codes were linked to each significant phrase. In vivo coding was sometimes used to preserve the language used by participants (Charmaz, 2006). The following step in the iterative process was focused coding, in which phrase-by-phrase codes were converged to form logical clusters (Charmaz, 2006). Focused codes were then analyzed and bundled to form categories. These categories were then dimensionalized through the process of axial coding (Charmaz, 2006). Theoretical coding was used to examine the ways in which categories and their dimensions were linked or related. This process fuelled the development of a theory grounded in the data rather than descriptive summaries or imposing preexisting theories onto the data (Charmaz, 2006).

Results

Five categories emerged in our inductive research study with regard to the experiences of violence for women involved in CSW: (a) abusive family life, (b) violence with romantic partners (i.e., presex work), (c) escaping violence, (d) violence in Tijuana, and (e) violence in the workplace. In the following subsections, we provide a discussion of each of these domains. Furthermore, data from this study support the notion that sex work is a choice for many women to escape violence.

Abusive Family Life

Some participants reported that their family lives have always been violent, and they reported a history of verbal and physical violence, especially at the hands of a father or stepfather. One participant recalled, "It was terrible for me, really too much, because I come from a family where my father was always aggressive, my father beat up on us all his life, that's one way of putting it…" Another participant stated that she just had to leave her home situation. She was involved in a disagreement with her stepfather over money, and her mother took his side. The lack of support from her mother made her feel betrayed. She shared:

> … I go to my mom to ask for some of my own money, and she says "it's that I don't have it, he [your step father] has your money," so I ask my stepfather "can I have some of my money?", and he replies "look you little free-loader, after I brought you here, after all I have done, and you being a constant burden…" I told him "I don't want anything to just be handed to me, I just want part of my own money…" Then he talked to my mom—he didn't reply to me directly, and he claimed that I said things to him totally differently, and all my mom did was say, "Let's just give her the money to get rid of the problem, then she can just go."

Violence with Romantic Partners

While some women had experienced violence in their parental homes, the most common violent experiences reported were with an intimate partner. A majority of the women who participated in this study had experienced interpersonal violence with an intimate partner at some point in their lives.

Social interactions with intimate (i.e., nonclient) partners were an essential part of the social worlds in which female sex workers lived. For most of the participants, the most significant intimate relationship(s) were with the father(s) of their children. One of the most commonly shared experiences among the participants was violence and abuse. Many participants reported several incidences of violence from intimate partners. One participant reported, "With my husband, the father of my girl, it was really ugly, that's the truth (there were) blows and abuse."

In some cases, the women reported not only physical abuse but also confinement of the woman herself or her children. One participant relayed, "Well, when I was with my first partner, it was a lot of abuse, lots of blows. I couldn't see my parents; he wouldn't let me see them. He locked me up." Another participant painfully elaborated:

> … Well, this time, I arrived with my son who was sick and he began to … (he) locked my kids in the bedroom … and then he took me out and grabbed me by the hair and began to beat me. He used boots. He gave me such a beating that you couldn't put a finger anywhere on my body that hadn't received blows. I was bleeding from the mouth, the nose.

In many cases, the incidences of violence and abuse were ongoing during their relationships. Furthermore, some women reported that the violence occurred either in front of their children or extended to the children themselves. A participant vividly described:

> It's just that I was married to a guy in the security force … we were married, but he got drunk a lot and beat me. He beat me a lot, and I had five children. He beat me and my children. He got drunk, got drugged out, whatever,—he would arrive really drunk or drugged out, I don't know. When we were sleeping, he would make me get up, beat me and my children with the butt of a pistol—it was horrible!

The abuse that these women experienced was not limited to physical violence; it also included emotional and psychological abuse. One participant explained, "He did whatever he wanted to me, physical abuse, emotional—in every way you can imagine." Another participant added, "It's a simple fact that it hurts you psychologically, it affects you … it really affects you that you're abused both verbally and by physical blows."

Issues of victimhood were also evident in how the women conceptualized their previous relationships. In this context, victimhood referred to an internalized self-perception that affects how one views one's self and how one internalizes that perception in the process of future social interactions (Anderson, 2002). Participants expressed the shattering nature of the relationships to their sense of self and to their livelihoods. For example, some women described how an abusive relationship can make them feel inferior. One participant relayed, "Well, for me, my worst trauma is if someone raises his hand because it makes me very afraid, it reminds me of many things, makes me feel really small."

Escaping Violence

No more tolerance. Violence can be very destructive to a woman's sense of self. Although many of these women remembered feeling lost and helpless at times throughout the abusive relationship, they also affirmed with pride that they eventually found the strength to escape. The participants reported that they could no longer tolerate the violence. One participant explained:

> There was no trust, that's all. There was abuse. He told me he was going to change … once there are blows, there will always be blows. Later after about 2 and a half months, I returned, but it was the same, and I said, no more!

Participants who were not in relationships at the time of the study stated that being single could be challenging and that having a good partner could make life better. However, the women expressed a desire to remain single rather than to be in a violent relationship. One participant shared:

> I'm not one of those women that [sic] likes to be tormented on all sides. I like to live fully and happily, so if he isn't for me, then goodbye. I'm not one of those who gets together today and tomorrow breaks up and keep on that way—no, I don't like the pain.

Another participant claimed, "I don't want a husband because I don't want to relive what happened with my first husband …" And another participant confirmed, "No, none of that—For me to have a boyfriend, it has to be all sugar because I didn't come into this life to suffer. I don't like being badly treated or told nasty things."

The participants described themselves as intolerant of violent relationships, perhaps as an indication that they did not want to experience another violent relationship and the need for assistance in avoiding future violent relationships. These reactions could be related to a desire for more independence and less vulnerability to intimate partner violence.

Most participants were adamant that they would not tolerate violence in a current or future personal relationship. Based on previous experiences, the women indicated a fear of abusive men and were aware that an abusive relationship would further destroy the sense of self. Participants placed high value on their agency and capacity to control their own lives.

Finding courage. The courage to escape a violent relationship was important for participants even if it meant losing financial or other means of support. One woman confided that she left her abusive partner even though she knew that she would be left with no means of support. Other participants explained that they eventually realized that they could not stay in a bad relationship just for the children to have a father. One participant commented, "… they say 'for the sake of the children', but if he's not a good partner, he's even less likely to be a good father."

The process of finding the courage to leave an abusive relationship was a critical juncture in the lives of participants. In many cases, separation from an abusive man symbolized rebirth as "a new woman" with a new sense of self. The examination of issues of support in significant relationships in the lives of these women was important because it affected their access to resources as well as their self-efficacy and capacity to make choices related to protecting and supporting themselves.

Entering Sex Work

The women who participated in this study conceptualized the search for stability and escape from violent romantic relationships as motivating factors for entering the sex work industry. One participant recollected:

> The only thing that mattered to me was being able to provide for my babies and in an honest way, but unfortunately here in Tijuana, it's not that easy to find a job that gives you enough to be able to spend time with your children, and gives them food, a roof over their heads, education, clothes, shoes, and more. The only route left for me is to sell myself.

Gaining independence from an abusive partner led many participants to perceive that sex work was their only option. The decision to enter the sex work industry stemmed from a search for independence. One participant acknowledged:

> More than anything, I think that almost all of us who work here are mothers who have their children without the fathers around, and [we] have to be daddy and mommy and so then work at this [sex work] for necessity … because I don't [like it], I do it for necessity. That's why I do it.

Some participants said that they needed to find work because they could not or would not want to depend on others for financial support. In some cases, they needed to feel independent and no longer wanted to depend on their families or partners. One woman shared, "… because of not wanting to depend on him after such a huge humiliation for me … Well, I decided to make the choice to work wherever, it didn't matter to me." Participants reported that they decided to work as sex workers out of necessity, even with fear of contracting HIV infection. One participant expounded:

> In what constitutes work, well, I protect myself—I protect myself because I've got a terrible fear of AIDS … Oh yeah, because I'm really, really scared. I'm not sure what made me so bold—I think it was mostly necessity at the time. I didn't even have clothes or diapers for my son … and felt really alone in the world, and there was when I started … but yes, I'm really scared.

Violence in Tijuana

Many participants said that they came to Tijuana because of the perception of better economic opportunities closer to the US-Mexico border. However, many participants also explained that there has been a recent surge of violence in Tijuana and that things were not the same as when they arrived. Because tourism had declined, there was less money coming into the city, which translated to fewer job opportunities and less money coming into the sex work industry. One participant said, "… and with all the violence in Tijuana, there is little money, and it's bad for everyone. Sometimes no, there's no work … you see? Right now, there is even less. Why? Because there's no tourism." Another participant explained how things had not been the same since the terrorist attacks of September 11, 2001:

> … it's very difficult because of stress and getting depressed. Look, I've been here for 10 years, and before the Towers fell, there used to be more work, more money, more tourism, and there weren't so many problems of violence in Tijuana. After 2001 for about 3 months, we almost died of hunger, almost like it is now. Unfortunately, one needs money every day—if it isn't for one thing, it's for another, and if there isn't any work, you get stressed out.

Life in Tijuana has served to empower and disempower women currently working in the sex work industry. As an empowering source, Tijuana has represented opportunity and a chance for women to provide a better life for their children. Conversely, the city has left many women disillusioned with a source of disempowerment. Many have left what they described as their peaceful hometowns only to experience danger and violence. One participant recollected:

> It's not like back home where it's very peaceful. There wasn't all this delinquency, so much drug addiction. You could walk around at any time of the day. Here, there are all sorts of things, lots of trafficking, contract killings, everything…

The danger and violence in Tijuana have affected the lives of these women in two basic ways. First, the increase in violence has had a profound impact on the tourism industry, which is an essential source of money for the sex industry in Tijuana. Second, these women no longer report that the city is a good place to live and many want to escape Tijuana to protect themselves and to ensure that their children are not exposed to such a violent environment.

Violence in the Workplace

Women who participated in this study frequently reported that CSW is a dangerous job and that there is insufficient security to provide for personal safety. Participants expressed particular concern with the need to protect themselves when they are at the hotel or in the private rooms providing sexual services. As the following quotes demonstrate, the women developed a plan for self-protection in the event that a client would become aggressive or violent, but they also had "buddy systems" with other women and could request help from security personnel in the establishment when available: "We always have to be really smart, astute, because there are bad people, and if you don't take care of yourself, who's gonna take care of you?"

"Yes, there have been [experiences of violence], for me … They … beat them [the girls] … it's that if I haven't seen a person around, I don't go [with him]. If I'm in real need, well, I'll tell a coworker to look out for me because I don't feel safe … You tell security to be there for you since the rooms are real close by."

Well, before going in you tell the client, "I'll be right there, wait a moment." And I go and tell someone, "Please be right there because I don't feel safe," and they tell me "Sure, fine," or you become friends with one of the cleaning people.

Most participants believed that the business was more concerned with satisfying customers than ensuring the safety of the sex workers. The women stressed the importance of protecting themselves regardless of the security options that were available to them at work because they had not been able to depend on others for protection. One participant explained:

> If you get into trouble, well, you have to get out. A lot of times if the client comes in drunk, he'll tell you that you're sulking, and they want you to give the money back, and there's every type of thing. You yourself have to get out of it because the truth is that there isn't camaraderie, and there isn't anyone to defend you. In this environment, you have to defend yourself alone… If they get violent? You alone have to get out of the problem.

The participants' concerns with self-protection reflected fear of being in an unpleasant or a violent situation, distrust in the establishment's interest in protecting the workers, and a desire to maintain control over the work environment and their bodies in the context of sex work. While many women shared similar experiences of fear of violence, several participants described the specifics of violent experiences during CSW. For example, one participant told a story about how she refused services to a male client because she feared that he would infect her with HIV, and he in turn threatened to kidnap her:

> It happened to me one time—I recall now that one person told me that above all, I should try to make the situation safe, that the condom is on, (and) that there's no contact with saliva because it's really risky. Unfortunately, the people who don't know what one could be exposed to, it's hard to tell them… It's not the same as interacting with a friend, a boyfriend—that's not risky. This person who, for example, I didn't want to have this exchange, he told me I'm going to "take you," that's like kidnap, and that terrified me, but I said, "This guy will get angry with me because I'm putting limits"—but he doesn't see that I'm protecting him, that I am in a way, well, doing good for society, because avoiding HIV infection makes for a better society. That's what I think.

Another participant related a story of how a client became aggressive because she did not want to continue engaging in sex with him because of his state of inebriation:

> Aggressive, um—well a while back, um, I had one guy who I told, "You know what? Time is money, let's use it because you're really drunk." And he told me, "No, you already stole my money, you took it from me," and I said to him, "Well, no. I'm saying that if you don't get it together, your time is going to be up, and I have to keep working." … I said, "Hey it's not me, what happens is that I charge you for providing a service, and if you can't or you aren't able for me to give you pleasure because you've got some problem in you, go see a doctor because I can't do anything. It's that I'm a sexual worker, not a witch, I can't make miracles!" And he got pissed off, he said, "Yeah well, now you're staying here your whole life, hopefully you're staying here," … Well, he was annoying, and right then I ignored him—I wasn't going to get involved in that, but yeah, he got really angry.

Additionally, other women observed that offering services outside of regular establishment settings increased the likelihood of potentially violent experiences with men. One participant recalled vivid details:

> Friday, I went to work as usual, I go to grab a taxi. It seems like the man was already there. I had seen him already. He says to me, "Well, let's go to my house." I tell him that I don't like to go to houses, but he seemed really decent. Believe me when I tell you he seemed really decent… He says go in, and I tell him to pay me. He says, "First go in." I tell him to pay me, and he says "How do I know you're going to do a good job?", and [I say], "How do

> I know you're going to pay me?" Right then, I see that he's closing the door, and I ask him why he's locking it … he tells me that he's not going to let me out. I get terribly scared, then I say, "Pay me." Then the man begins to undress, and I tell him to pay me, then he tells me he's only going to give me 100 pesos, and I told him that that's not how we left it … he began to grab me and try to kiss me and grab my flesh, grab my butt. He attacked me. He took out his pistol, and I told him, "Look," (crying)… He asks me, "You want to leave?" I told him yes, and he opened the door. When I was heading out the door, he hit me in the ass and I stumbled, but I was out on the street. I saw death close up.

Managing HIV Risk and Self-Preservation

Figure 12.1 depicts the multifaceted experiences of violence in the lives of establishment-based female sex workers in Tijuana. It shows that experiences of violence are not only from sex work clients but also violence had permeated these women's lives before they entered the sex industry. Prior to engaging in CSW, violence experienced by these participants had its roots in the family of origin and/or from intimate partners. Furthermore, it was found that sex work, for many of the women who participated in this study, was a choice they made to escape violence and that the process of escaping family or intimate partner violence was empowering. This does not mean that the women were free from violence once they entered into CSW. However, despite experiences of violence as sex workers, the participants were able to maintain a focus on their self-preservation and demonstrated agency in actively taking steps to prevent HIV infection.

Although preventing themselves from acquiring HIV was an important part of self-preservation, it was not the only element. In addition to protecting themselves by insisting on condom use with clients, the ways in which these women cared for themselves included escaping violent relationships, protecting themselves from the

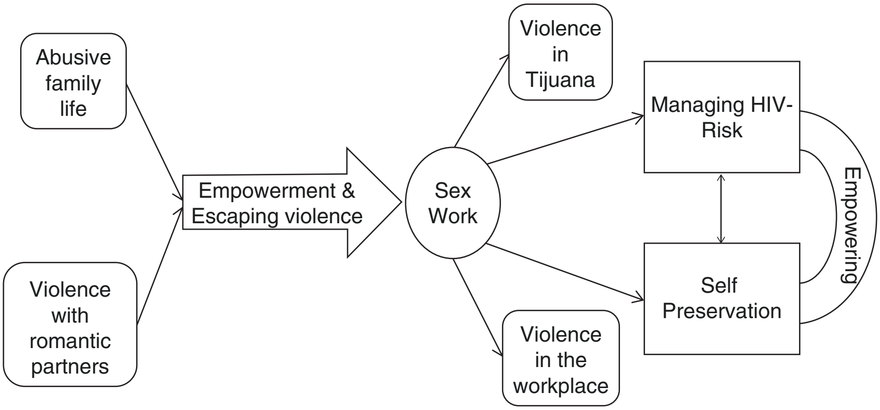

Fig. 12.1 Multifaceted experiences of violence

violent environment in Tijuana, protecting themselves from violence from CSW, and attempting to promote both their sexual and non-sexual health.

Many of the women working in the Tijuana sex industry have experienced interpersonal violence. These women were able to leave violent relationships in an attempt to provide a better life for themselves and their children. However, leaving a violent relationship did not guarantee a life free from other forms of violence. The environment in Tijuana was very dangerous. Women engaged in CSW in Tijuana had to constantly manage the sometimes violent and aggressive behavior of clients that made it difficult to consistently negotiate safer sex behaviors with their clients. Many women felt that there were not sufficient protections available to them from the CSW establishments where they were employed, so these women developed strategies to protect their safety and health while engaging in CSW.

These establishment-based female sex workers did not perceive themselves as helpless victims of violence either in the context of CSW or stemming from their past. Instead, they characterized themselves as empowered women who were independent of violent intimate relationships.

Discussion

Interpersonal Violence and Female Sex Workers

Interpersonal violence in the lives of female sex workers has been studied in other contexts, but the research has not been exhaustive. Wahab (2005) reported that the majority of literature on violence and sex work has focused on the experience of violence in the lives of street-based female sex workers and noted that rates of violence in the lives of female sex workers can range from 50 to 100%. In our study of establishment-based female sex workers, the rates would be comparable only if we included physical violence experienced prior to entrance into sex work. While our study was not quantitative and thus not conducive to exact percentages, most of the participants reported experiences of violence in the past with intimate partners, but none related violent experiences with current intimate partners. In the present study, the participants' greatest fear was physical violence at the hands of clients, but most talked of "close calls" and "narrow escapes" rather than actual experiences of violence.

Shannon et al. (2009) reported that environmental and structural factors contributed to a likelihood of violence against sex workers. Homelessness, inability to access drug treatment, criminalization of sex work, and enforcement-based approaches to sex work, such as assault by police and confiscation of drug-use paraphernalia, are examples of environmental and structural factors. None of the women in our study were homeless, and sex work is regulated, but not criminalized in Tijuana. The comparatively lower rate of violence observed in the lives of these establishment-based female sex workers provided additional supporting evidence for Shannon et al.'s (2009) findings.

Most studies of violence and sex work have concentrated on experiences during sex work employment. One exception was a study by Ulibarri et al. (2010) that focused on the association between child abuse and current experiences of interpersonal violence. Our study provided new information regarding the impact of violence from intimate partners prior to entering sex work. While children are relatively helpless to escape family violence, the women in this study who experienced violence at the hands of an intimate partner did exercise available options to end the violence, and this life choice made a profound difference in their self-image and capacity to resist violence.

Self-Preservation

In general, the women who participated in the study demonstrated high levels of concern with self-preservation. Many would like a more stable life with financial security, but most participants preferred to remain single and free of violence rather than entering into another relationship that could impact their sense of self-value. This notion of self-preservation in intimate relationships can be very empowering for women working in the sex industry.

Many of the women in this study moved to Tijuana from other areas of Mexico where violent crime was less prevalent. In most cases, the move to Tijuana, like the decision to enter sex work, was related to the need to find employment and leave a violent relationship. These women did not underestimate the violent atmosphere in Tijuana, a border city with a very high crime rate, but they believed that the alternative of accepting ongoing abuse from a partner would be worse than violence experienced during CSW.

For our participants, sex work was the best option to gain financial and emotional independence. The cost-benefit analysis for the women was that the risks of remaining in an abusive relationship far outweighed the risks of entering into sex work. This did not mean that the women were unaware of the risks of sex work. To the contrary, the participants emphasized the need for vigilance to maintain control over situations and protect themselves.

The women were very conscious of the interrelated dangers of violence and being pressured or force into high-risk sexual acts that could result in HIV infection during CSW. Many women expressed doubts about the degree of commitment of their bosses and managers to assure their safety. The women ultimately relied on themselves to avoid dangerous situations such as going to a client's residence or accepting a client with whom they felt uncomfortable, but they also used whatever security measures were provided by the establishment. Several women developed measures for personal safety such as asking the establishment security, cleaning personnel, or coworkers for assistance in the event that violence would occur. Findings from this study support data from ethnographic research that

Katsulis et al. (2010) conducted in Tijuana. They reported that workplace violence among female sex workers was embedded in a larger context of violence and was balanced and managed within a “hierarchy of risk” (Katsulis et al., 2010). In our study, we found that the women were aware of the multifaceted nature of the danger and violence they may experience and were conscious of the need to manage these dangers.

The findings from our study also support the findings of Nixon, Tutty, Downe, Gorkoff, and Ursel (2002) who reported that female sex workers were resourceful and resilient against violence, often adopting protective strategies such as carrying weapons, working with other workers, and reacting from instinct. The women in our study did not report the use of weapons, but they did rely on their own instincts and a “buddy system” with coworkers and other employees. Nixon et al. (2002) also pointed out that it was rare for women to leave sex work due to fear of violence in the workplace. Our findings support that conclusion.

Managing HIV Risk

Sex work, while an economic exchange, has been characterized by power and control, especially when it comes to the capacity to resist violence and refuse to engage in high-risk sexual behaviors. Having control over one’s life as a whole, as well as within the realm of sex work, is intricately linked to HIV risk. In the lives of women working in the commercial sex industry, having control is important to be able to manage their HIV risk. Cavanaugh, Hansen, and Sullivan (2010) suggested that women who experienced interpersonal violence from an intimate partner were at risk for HIV infection through engagement in high-risk sexual behaviors. Examples included having unprotected sex with partners who were infected with HIV or use of injected drugs or engaging in sexual behaviors with multiple partners.

Ulibarri et al.’s (2010) quantitative study on the prevalence and correlates of interpersonal violence with intimate partners among female sex workers in Tijuana and Ciudad Juarez, Mexico, clearly showed how the experiences of interpersonal violence contributed to HIV risk. The researchers reported that approximately one in three female sex workers in the sample had experienced interpersonal violence from an intimate partner in the previous 6 months. Female sex workers who reported interpersonal violence from an intimate partner were more likely to have also reported having partners with known HIV risk factors, such as injection drug use and multiple sexual partners, than female sex workers who did not report experiencing interpersonal violence with an intimate partner (Ulibarri et al., 2010).

Findings in other studies have documented that ongoing violence from an intimate partner is detrimental to a female sex worker’s ability to protect her health. Our findings also suggest that once women leave a violent relationship, prior experiences of violence do not necessarily undermine their capacity to protect themselves.

To the contrary, a clean break can contribute to a positive self-image and increased power to negotiate protection from violence in the workplace.

The women who participated in this study demonstrated resilience that assisted them in escaping violent relationships and finding new ways to support themselves, their children, and families. The women had learned that they could surmount negative experiences and take action to promote their independence. They also advocated for other women in their profession by asserting that women should not be expected to live with violence, which reinforced their sense of self-worth. Women who work in the sex industry who have left violent relationships reported personal strength that decreased their perceptions of victimization.

Self-Image and Agency

To manage HIV risk in the workplace, female sex workers must be able to prevent and avoid violence from clients and successfully negotiate services and condom use with clients. Participants believed that it was important to take responsibility for their personal protection because the establishment could not be trusted to prioritize sex workers' safety and health over customer satisfaction and money. Interactions with clients can degrade women working in the sex industry and can undermine a female sex worker's sense of value as a woman and her self-efficacy to protect herself from HIV and other STIs. Conversely, capacity to control interactions with clients and negotiate sexual services and condom use can contribute to the formation of a positive self-image.

In a previous paper based on our interviews with establishment-based female sex workers in Tijuana, it was noted that almost all of the women were committed to a policy of consistent condom use to protect themselves from STIs, particularly HIV. Because many were the sole providers for small children, the participants viewed consistent condom use as part of their duty to their children. Thus, they felt that condom use went beyond the narrow concept of self-preservation and established these women as responsible members of society (Choudhury, 2010).

Sex Work and Agency

Agency is the capacity to exert power and control in one's life (Wahab, 2005). The women who participated in this study clearly demonstrated that they had agency and experienced empowerment. The women reported that they chose sex work because it meant they could leave a violent relationship and be independent. However, if we overemphasize the agency and empowerment of sex workers, oppression experienced by these women is ignored (Wahab, 2005). In this study, while most women shared experiences of empowerment, many were still experiencing oppression and violence from CSW.

Clinical Implications

According to Sallmann (2010), healthcare practitioners should be knowledgeable about the issues experienced by women who engage in CSW. Healthcare practitioners have the responsibility to examine their own assumptions about sex work and the women involved, and assess for the ways in which their personal biases and stereotypes may inadvertently contribute to the continued stigmatization of these women. Study participants reported a lack of complete control of many situations experienced during CSW but rejected the notion that female sex workers were powerless. Furthermore, the desire to stay healthy and take active steps to negotiate condom use with clients demonstrated the need to reject the discourse of blame for spreading HIV infection that has often been placed on women engaged in CSW.

Practitioners who provide healthcare services for women in sex work should attempt to promote positive self-image and sense of agency among women protecting their own health. Interventions must be designed to build on the existing strengths of women by recognizing their achievements and providing them with additional tools and resources so that they are better prepared to manage potentially violent situations and actively protect themselves from violence, HIV infection, and other STIs.

Limitations

This study had a few limitations. The first was that the principal investigator who conducted all interviews was female, which may have had positive and negative implications. The participants probably felt more comfortable relating intimate aspects of their lives to another woman. On the other hand, it is possible that the participants overemphasized certain aspects of their experiences that they believed would favorably impress the principal investigator.

Second, experiences of violence and HIV risk among sex workers may be different for women who are employed outside of establishment-based venues. Women involved in sex work outside these establishments may be at even more risk for violence and HIV and may have different reasons for engaging in sex work. Therefore, the results of this study cannot be generalized to all female sex workers.

Key Considerations

- Nurses and other healthcare providers should become aware of their personal biases when working with marginalized women such as female sex workers and how these biases may affect the treatment they provide women working in the sex industry who also have a history of interpersonal violence.
- Nurses and other healthcare providers should stay vigilant to identify women who wish to seek situational changes, but at the same time not assume that exiting sex work is the only viable option for all female sex workers.
- Nurses and other healthcare providers who provide care for women working in the sex industry should not assume that all women who have experienced interpersonal violence are helpless victims and instead recognize and support their strengths.
- Clinics that provide services to female sex workers should expand their services to include more comprehensive social and mental health services such as career counseling and life transition counseling. These services are especially important for women with a history of interpersonal violence; nurses and other healthcare providers can help these women develop strategies to increase social support and increase self-efficacy.

Discussion Questions

1. Discuss the life-course perspective and how early experiences of violence may shape the trajectory of women's lives.
2. For many of the participants, sex work was viewed as empowering. Describe why.
3. The authors state that the participants demonstrated a high level of self-preservation and agency. Yet, they were still engaged in work that they conceded was very dangerous. Do you see this as a contradiction or as two issues that can coexist?
4. How might experiences of violence differ between establishment-based female commercial sex workers and those that are street based? How can interventions be designed to successfully meet the needs of these two groups?
5. How can women who have decided to leave an abusive relationship but are economically dependent on their partners be better supported so that they do not see sex work as their only option?

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Chapter 13
A Continuum of Severity of Sexual Intimate Partner Violence Among Black Women in the United States

Jamila K. Stockman and Kristin K. Gundersen

> *"Being a woman, you should never be pressured or [let] someone use physical violence towards you with having sex because to me that's like rape. It's no different than rape. Don't force me to do things I don't want to do. If I don't want to [have sex], I don't want to."*

Introduction

Prevalence of Sexual Violence in the United States

According to the 2011 National Intimate Partner and Sexual Violence Survey, in the United States (US), an estimated 19.3% of women (or more than 23 million women) have been raped during their lifetime, including completed forced penetration, attempted forced penetration, or alcohol/drug facilitated completed penetration. Approximately 12% of women experienced completed forced penetration (Breiding et al., 2014). Nationally, an estimated 1.6% of women (or approximately 1.9 million women) were raped during the past year (Breiding et al., 2014). Women of color are particularly affected with higher lifetime prevalence rates reported for multiracial women (32.3%), American Indian/Alaska Native women (21.2%), and non-Hispanic Black women (21.2%); while lifetime prevalence estimates for non-Hispanic white and Hispanic women are lower (20.5% and 13.6%, respectively) (Breiding et al., 2014). Specific to sexual coercion—defined as nonphysically pressured unwanted penetration—12.5% of women reported such experiences during their lifetimes and 2% of women experienced sexual coercion during the past year (Breiding et al., 2014). Overall, 45.4% of women with sexual violence experiences reported at least one perpetrator who was an intimate partner, whereas 74.1% of women with sexual coercion experiences reported at least one perpetrator who was an intimate partner (Breiding et al., 2014).

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A Continuum of Sexual Intimate Partner Violence

The US Centers for Disease Control and Prevention (CDC) determined that in order to monitor the prevalence of sexual violence and properly compare the problem across the United States, a consistent definition for sexual violence was needed (Basile & Saltzman, 2002). Furthermore, an original framework developed by the CDC outlined four defining characteristics of sexual violence (not specific to intimate partners): (1) lack of consent, (2) whether the act was completed or attempted, (3) type of force (i.e., physical or nonphysical), and (4) the type of sexual activity, ranging from noncontact sexual harassment to sexual penetration (Basile, Hertz, & Back, 2007; Breiding et al., 2014; Saltzman, Fanslow, McMahon, & Shelley, 1999; Bagwell-Gray, Messing, & Baldwin-White, 2015). More recently, Bagwell-Gray et al. (2015) proposed a new taxonomy of sexual violence perpetrated by an intimate partner, which is based on the levels of forcefulness and invasiveness. The level of forcefulness refers to the degree of physical force used, ranging from physical violence at the high end of physical force to nonphysical manipulation at the low end of physical force. The level of invasiveness refers to the invasiveness of the type of sexually abusive act, ranging from vaginal, oral, or anal penetration at the high end of invasive acts to unwanted touching at the low end of noninvasive acts. Degree of force and level of invasiveness are combined to create four distinct categories: (1) intimate partner sexual coercion (low force, high invasiveness), (2) intimate partner forced sex or sexual assault (high force, high invasiveness), (3) intimate partner sexual abuse (low force, low invasiveness), and (4) intimate partner forced sexual activity (high force, low invasiveness). This chapter will focus on sexual violence resulting in vaginal, oral, or anal penetration by a current or former male intimate partner. Therefore, further information on intimate partner sexual coercion and intimate partner forced sex (or sexual assault) is provided below.

Intimate partner sexual coercion is the use of nonphysical, controlling, degrading, and/or manipulative tactics to obtain (or attempt to obtain) unwanted oral, vaginal, or anal intercourse, including other penetrative acts such as sexual assault with objects (Bagwell-Gray et al., 2015). Nonphysical tactics include verbal manipulation (e.g., continual nagging, pressuring, making false promises) and withholding of resources (Bagwell-Gray et al., 2015; Stockman, Lucea, & Campbell, 2013). In this context, sexual violence is highly invasive, but with low levels of force (Bagwell-Gray et al., 2015). Women may submit to coercive sexual tactics and consent to unwanted intercourse out of a perceived obligation to an intimate partner or to avoid the negative outcomes of refusing sex (Bagwell-Gray et al., 2015; Basile, 2002). The overlapping nature of coercive behaviors and level of force provides an indication of the varying levels of severity experienced by some women (Stockman, et al., 2013). Predictors of sexual coercion perpetrated by men have been identified as sexual dominance—male behavior to obtain or maintain an impersonal sense of power and control—and sociosexuality—willingness to engage in sexual activity outside a committed relationship (Schatzel-Murphy, Harris, Knight, & Milburn, 2009).

Intimate partner forced sex (**or sexual assault**) has been conceptualized as forced vaginal or anal penetration through the use of actual or threatened physical force, in the context of an intimate relationship (Bagwell-Gray et al., 2015). Physical force refers to unwanted, rough sex; sex obtained through threats of a beating or threats with a weapon; physical coercion through holding down; or actual beatings prior to, during, or after unwanted sex (Stockman et al., 2013). Physical force also refers to the voluntary or involuntary administration of alcohol or drugs, resulting in lack of consent to sexual intercourse (Stockman et al., 2013). It is important to note that, historically, the following terms have been used to describe physically forced penetrative sexually abusive acts in the context of an intimate relationship: intimate partner sexual violence, forced sex, rape, sexual assault, sexual coercion, sexual aggression, sexual victimization, and being made to penetrate someone else (Bagwell-Gray et al., 2015).

Impact of Sexual Intimate Partner Violence on Black Women

Sexual intimate partner violence (IPV) has been associated with multiple adverse physical and mental health conditions and health risk behaviors among women of all backgrounds (Stockman et al., 2013; Stockman, Hayashi, & Campbell, 2015; Maman, Campbell, Sweat, & Gielen, 2000). Comprehensive reviews of physical health consequences of IPV collectively (i.e., physical and/or sexual IPV) report multiple health outcomes including chronic pain, cardiovascular problems, gastrointestinal disorders, and neurological problems (Coker, Smith, Bethea, King, & McKeown, 2000; Plichta, 2004; Dillon, Hussain, Loxton, & Rahman, 2013; Walton-Moss, Manganello, Frye, & Campbell, 2005). Reviews and studies specific to sexual IPV—most commonly measured as forced sex—consistently document increased risks of negative psychological outcomes including depression, posttraumatic stress disorder, low self-esteem, and suicidality (Bryant-Davis, Chung, Tillman, & Belcourt, 2009). Higher rates of these mental health outcomes have been found in Black women with sexual assault experiences, compared to White women with sexual assault experiences. The sexual and reproductive health impact of sexual IPV includes acute and chronic problems, such as vaginal and anal tearing, sexual dysfunction and pelvic pain, dysmenorrhea, pelvic inflammatory disease, cervical neoplasia, and sexually transmitted infections (STI), including HIV (Stockman et al., 2015; Maman et al., 2000; Coker et al., 2000; Campbell, 2002; Gielen, Ghandour, Burke, Mahoney, McDonnell, & O'Campo, 2007; Sharps, Laughon, & Giangrande, 2007; Campbell, Lucea Stockman, & Draghon 2013). HIV on its own disproportionately affects Black women compared to other racial/ethnic groups (Centers for Disease Control and Prevention, 2015). Sexual IPV intersects with HIV through multiple mechanisms including genital tearing and abrasions as a result of forced sex with an infected partner, limited or compromised negotiation of safer sex practices, increased sexual risk-taking behaviors, increased drug risk behaviors due to the adverse mental health effects of the violence, an increase in other STIs that accompany abuse and facilitate HIV transmission, and abuse-related immunocompromised states (Stockman et al., 2013; Maman et al., 2000; Campbell, Baty, Ghandour, Stockman, Francisco, & Wagman, 2008; Jones et al., 2015). Sexual IPV also contributes to unintended pregnancy, miscarriage, abortion, and decreased contraceptive use (Coker, et al., 2000; Pallitto, Campbell, & O'Campo, 2005).

While the health effects of nonphysical sexual coercion are understudied, one study found that verbal coercion by a dating partner was associated with reduced sexual functioning (Logan, Cole, & Shannon, 2007; Katz & Myhr, 2008). Another study found that women with larger numbers of verbal sexual coercion experiences reported larger numbers of anal sex partners, more frequent vaginal sexual intercourse after substance use, and stronger sex-related alcohol expectancies (Gilmore, Schacht, George, Davis, Norris, & Heiman, 2014). These findings suggest that verbal sexual coercion is associated with high levels of STI risk in women (Gilmore et al., 2014).

Black women, some of whom are immigrants, are more likely to have a low socioeconomic status and have less access to healthcare and other resources, which further exacerbates the health consequences of sexual IPV (Stockman et al., 2015). Some of these women may not be able to obtain the necessary medical care for fear of revealing the violence due to discouragement or threats by the perpetrator or lack of financial support (Bent-Goodley, 2007). In addition, cultural factors such as family secrecy, historical trauma, stigma, discrimination, and mistrust of formal support systems (e.g., medical institutions, law enforcement) can be barriers to disclosing sexual IPV and seeking help (e.g., counseling, support groups) (Bent-Goodley, 2007). Even more paramount, healthcare professionals often lack adequate training on IPV and the cultural competence needed to effectively care for Black women who are already dealing with underlying barriers to care (Bent-Goodley, 2007). Despite these barriers, some Black women are resilient and able to overcome the adverse physical and mental health effects of sexual IPV. That is, spirituality and social support have been identified as cultural strengths that work towards improving overall physical and mental well-being among Black women whom have been abused (Bent-Goodley, 2007; Hodges & Cabanilla, 2011).

Chapter Overview

Since sexual IPV lies at the intersection of sexual violence and IPV, it is often overlooked and research on the specific consequences of sexual violence committed by an intimate partner lags behind research on other forms of violence against women (Bagwell-Gray et al., 2015). Moreover, research on less severe forms of sexual violence, often classified as sexual coercion committed by an intimate partner, are virtually nonexistent in the literature. This chapter seeks to contextualize the experiences of sexual IPV along a continuum of severity among Black women. Through an in-depth exploration of these experiences, we are able to gain a better understanding of the overlapping nature along the continuum, including disclosure experiences, women's own perceptions of sexual violence, and the role of culture in the perceptions of the experiences. The few women who displayed high levels of resilience are highlighted, followed by recommendations for future practice and research.

The Black Women's Study

In 2012, the Black Women's Study was conducted to qualitatively characterize the continuum of intimate partner sexual violence and facilitators and barriers to help seeking behavior among a community-based sample of Black women in San Diego, California, USA. The Black Women's Study was designed and conducted by Jamila K. Stockman, PhD, MPH at the University of California, San Diego, School of Medicine, Division of Global Public Health and colleagues at the University of California, Los Angeles, David Geffen School of Medicine, Department of Psychiatry and Biobehavioral Sciences. The study obtained approval by the Institutional Review Boards of the University of California, San Diego, and the University of California, Los Angeles.

Eligible women self-identified as African-American or Black, aged 18–44 years, English speaking, residents of San Diego County, sexually active with a male intimate partner in the past year, and having experienced forced or coerced sex by a current or former intimate partner since the age of 18. Women were recruited through community outreach, newspaper advertisements, and flyer distributions at bus stops, social services agencies (e.g., WIC distribution centers), and drop-in centers. Eligible women were screened into the study and invited to complete the study at a private study office that was centrally located and easily accessible via public transportation. Participants provided written informed consent, then completed a brief demographic survey and a 45–60 min in-depth, in-person interview. The present research is an analysis of qualitative data consisting of 19 semi-structured interview transcripts from the women who graciously agreed to share their stories. Pseudonyms were assigned to women to protect participant identities.

Demographic characteristics of the study sample are presented in Table 13.1. As expected, sexual IPV occurred along a continuum of severity. All women who were interviewed reported being verbally pressured or "bullied" into having sex by an intimate partner. Eight women reported being verbally pressured and threatened into engaging in unwanted sex. Two women reported being both verbally pressured and physically forced into unwanted sex. Nine women reported experiencing verbal pressure, threats, and physical force as coercion tactics. In the next section, detailed accounts of these experiences are discussed within the continuum of severity of intimate partner sexual violence resulting in vaginal or anal penetration (i.e., verbal pressure, verbal pressure and threats, verbal pressure and force, and verbal pressure, threats, and force).

Table 13.1 Characteristics of African-American/Black women with experiences of sexual coercion, San Diego, 2012 ($n = 19$)

Characteristic	n	%
Average age (years)	35.15	–
Age range (years)	23–44	–
Average number of years lived in San Diego	22	–
Range of number of years lived in San Diego	1.5–44	–
Child under the age of 18 living in household	7	36.8
Military dependent	10	52.6
Lifetime illicit drug use	13	68.4
Lifetime history of healthcare use		
Ever had routine physical	14	73.7
Ever received mental health services	8	42.1
Ever had gynecological exam/pap smear test	5	26.3
Type of sexually coercive/violence experience[a]		
Verbal pressure and threats	8	42.1
Verbal pressure and physical force[b]	2	10.5
Threats and physical force	0	0
Pressure, threats, and physical force	9	47.3
Sexual coercion ≥18 years of age only	15	78.9
CSA and sexual coercion during adulthood	4	21.0

CSA childhood sexual abuse

[a] Since the age of 18

[b] Physical force is defined as being hit, held down, or use of a weapon

Verbal Manipulation

Intimate partner sexual violence through the use of verbal pressure—also known as intimate partner sexual coercion and classified as “sexual coercion”—was a common occurrence in these Black women’s relationships. The women often described engaging in unwanted sex because it was their perceived sexual responsibility. Specifically, some women discussed feeling that they owed their male partner sex as part of the relationship contract, despite their own desires to refrain, which was described as a “wifely duty.” This could include the male partner overtly reminding the female partner that she owed him sex. However, it also included the female partner’s own sense that she owed sex as a part of the relationship, with or without the male partner’s reminding. Most of the women who reported experiencing this type of coercion described being in serious, long-term relationships. Alexis described the following:

“You know where he would want sex and I really, really wouldn’t but I just like did it anyway to kind of shut him up you know but he was never like physically forceful…at all. It was mostly you know like we were married and it was like you know my wifely responsibility and that whole thing.”

Alexis's description highlighted the sexual expectations and normative perceptions of what it means to be a "wife" or a "long-term partner" for some of these women, whether officially married or not. These normative perceptions are often an indication of an underlying, unequal distribution of power within a relationship, in which men's voices and desires are given supremacy over women's desires.

Women also experienced unwanted sex as a result of verbal cues by their intimate partner. Women described men pressuring, pestering, or repetitively harassing them for sex. For example, several women stated that men would pester them with phrases, such as *"Come on baby. You know I love you,"* as a means to convince them to have sex, despite the women's desire not to engage in any sexual activity.

Many women also described men using negative verbal strategies, which included "bullying," bluntly stating a desire for sex, and accusations of being unfaithful. "Bullying," a term specifically used by one woman, included the male using intimidation strategies to coerce the female into sex. Bullying also included types of verbal abuse, such as degrading the female partner in public and private settings (i.e., "you're worthless"). Several women described their partners accusing them of cheating, or the fear that their partners would think they were cheating, as a means to pressure them into having unwanted sex. The male partners rationalized that when their female partner was not engaging in sex with them, they were being unfaithful.

Tamara recalled a time she and her partner at the time were arguing over her reluctance to have sex:

"I didn't want to and he was basically, you know, going off on me because I didn't want to have sex with him. 'Well, you know, what are you doing? Are you out there seeing somebody else?'"

In addition, a woman's perceptions of how their male partner—in the following case, a Black male partner—would be perceived if the incident was disclosed to medical professionals or law enforcement often skewed their perception of intimate partner sexual coercion. Suzette described how she elected not to disclose a sexual coercive incident, despite medical professionals asking specifically about "unwanted sex":

"I know that they asked me if I've ever had unwanted sexual intercourse. I always assumed that that meant unwanted penetration and I didn't… even though it had happened the second time and maybe it's because I watch too many TV dramas but I didn't think that was something significant enough to tell them that it happened because he didn't, like he kept coercing me but he wasn't rough you know afterwards. I wasn't you know too hurt. I didn't feel like… I felt like if I told them they would take it out of context."

When asked about her level of concern regarding potential repercussions, she shared the following:

"Well I know for Black males they tend to blow that up and so I didn't want to say 'Yes. He coerced me into having sex with him. He kept pushing the issue' because I don't want them to think that he raped me or that he did something, you know, like he threatened me or anything like that."

In Suzette's eyes, unwanted sex must involve physical force, and she was concerned that her partner would be unnecessarily punished.

Verbal Manipulation and Threats

Verbal pressure to engage in unwanted sex also occurred in the context of threats, which indicated a slightly higher level of severity than verbal pressure alone in regard to intimate partner sexual coercion. Among the eight women reporting such incidents, some did not feel as though they had the option to say "no" because of their partner's threats to leave the relationship. These incidents occurred frequently, to the point where many women would just submit to sex in order to avoid conflict or threats. When asked what would happen if Tiffany were to say "no," she shared:

"Let's see, arguments, he threatens to leave. A few times he would just make me do it you know. [This happened] maybe ten times. Pretty frequent so I just stopped saying no because I just didn't want to go through it if that makes any sense."

Tiffany then described coming to terms with this pattern of coercion:

"It was like, like nothing. Like nothing at all. Like business as usual. Like he didn't see it as he forced me to do something that I didn't want to do. He saw it as he convinced me so he just went about his normal day and I was just like, well I guess this is what I have to do to keep my relationship."

Tiffany did not want to report the incidents, since the perpetrator was her boyfriend. She believed that perpetrators who were intimate partners versus strangers were not committing a crime, warranting different reporting procedures. She stated:

"You don't file a police report on your man. You know, that just didn't make sense to me. That wasn't something that you did. I mean I didn't see it as a criminal offense like if someone raped me on the street, yeah but I didn't associate those two things at the time so I didn't do anything."

In other instances, women were threatened with injury if they did not give in to sexual intercourse with their partner. Lisa was in a relationship with a man who she originally thought was a "good guy" and a "normal person." However, he threatened to kill her if she did not have sex with him. This severe threat was all it took for her to get away from him and end the relationship. She shared:

"He told me that if I didn't have sex with him that he had a carpet laying on the side of his wall and he told me, he's like, 'I'll slit your throat and roll you up in the carpet' and that seriously scared me."

Karen also experienced threats of injury in addition to verbal pressure. She described dating a man she met through a friend. On their fourth date, she invited him to her apartment for drinks, where she described her forced sexual encounter:

"I just told him I really wasn't ready for that [sexual intercourse] right now and he couldn't take no for an answer, you know, and men have a lot more strength than a female does. I was focused on telling this person, 'No. I don't want to do anything,' and they took it anyway, you know, and threatened to hit me."

Although Karen was threatened with physical injury, this threat in the context of forced sex by her date was somehow construed as a consensual sexual encounter. Despite encouragement by medical personnel to report the incident, Karen held a strong belief that law enforcement officials would classify her experience as consensual sex. This reason may be two-fold: (1) women who experience sexual IPV typically do not feel they will be believed by law enforcement, since most incidents are considered "he said, she said," and (2) historically, distrust of law enforcement is highly prevalent in Black communities.

Verbal Manipulation and Force

In some instances, intimate partner sexual coercion extended beyond verbal pressure to also include physical force. Tina described her husband at the time overtly stating that she owed him sex as part of the relationship. Her husband's coercive strategies eventually increased in severity and led to the use of physical force:

"It was my wifely duties he would say and um when I didn't want to do it was just only once that he…he held me down and we had sex. He just put it in there and was pumping on me and we had sex. And then when he was done he got up and left me alone. It was just that when he was ready too because it was my wifely duty but I didn't want to have sex. You know what I mean? Sometimes I just didn't want to have sex."

Stacy was pressured and forced into oral sex by her partner. Stacy, who had never had oral sex and did not have the desire to have oral sex, experienced forced oral sex twice during her relationship. She described the first incident as "violent and severe" whereas she considered the second incident "more mental in nature":

"He would keep telling me, 'Come on baby. You know I love you.' and all of this stuff. One night, he had a little bit to drink and you know, he just forced, you know, my head. He's like, 'Alright. You're going to do it... So [he] kind of forced me to do it and I just did it…The second incident was more kind of a mental [thing] because I didn't want to fight."

Stacy endured the second incident in part due to the advice she received from her boyfriend's sister who shared the common belief that engaging in sex, regardless of whether or not a woman wants to, is expected in a relationship:

"I was talking to his sister and she was saying that, you know, 'Oh it's a normal thing. Girls do it to guys all the time, you know.' She was kind of like encouraging me like, 'Go ahead. You're his girlfriend. That's your job.'"

Her boyfriend's sister's comments prompted her to stay in the relationship despite her discomfort with the situation.

For Jackie, sex—especially violent sex—came as a shock to her. She was raised with the belief that you should be married before you have sex with a man. Her first sexual encounter was forced through verbal manipulation and subsequent physically forced acts:

"With this guy it just seemed like he wanted to start abusing you because you don't want to sleep with him…I think he started talking first about it. Why I didn't want to sleep with him. Next thing you know he started tearing off my clothes and I don't like that…He started hitting on me. That's like forcing yourself on me to tear down my clothes. If I don't want to, I don't want to. It doesn't mean that I'm sleeping with somebody else."

Jackie experienced this form of sexual IPV by her boyfriend three times before leaving the relationship of two years.

Women also described sexual expectations within their relationship that were reinforced through verbal pressure and sometimes escalated to physical force. Margie described her past partner's beliefs:

"If you're dating them, you're supposed to have sex [with them], even if you don't want to, like that's the role. Like one of them was like, 'a lady's role is to have sex with the man whenever we want to.'… I was forced to give him sex because it was my wifely duties he would say and, um, when I didn't want to was just only once that he…he held me down and we had sex."

She further explained that after consistently being reminded of her "wifely duties," she lost a sense of normalcy and came to expect coerced sex within subsequent relationships. Thus, it appears that some women feel the pressure of fulfilling the expectation of the role of a wife—justified by the man—whether they were legally married or not.

Verbal Manipulation, Threats, and Force

Intimate partner sexual violence can occur along the entire continuum of severity (i.e., verbal pressure, threats, and force). When the entire continuum of severity is prevalent in incidents of sexual violence, it often involves severe behavior such as choking, the use of weapons, and administration of alcohol and/or drugs. Tamara, who was introduced in the section on verbal pressure, also experienced threats and force in the same relationship. As previously mentioned, her husband at the time thought that if she did not want to have sex with him, this meant she was sleeping with someone else.

"Even when I didn't want to do it, I would basically have to force myself to do it with him in order not to hear his mouth or get in a physical altercation with him or him start accusing me of sleeping with other men and seeing somebody else."

Not only did Tamara experience intimate partner sexual violence with her husband, but she also experienced severe incidents during her relationship with the father of her son, which preceded her first marriage.

"He like choked me out and then we had sex after that…He was getting loaded and he was just very, very abusive. He gave me a black eye. He choked me, I almost passed out because I didn't want to be with him and he told me he would kill me if I wouldn't so I ended up being with him…He put his arm around my neck in the kitchen and started lifting me. I came up off my feet. He had me, such a tight hold on me, telling me, 'I'll kill you if you don't be with me' and so I got scared and then we end up being together. I ended up just giving in and staying together and it was just abusive after that and he always wanted sex so, there you go."

Incapacitated forced sex involves the perpetrator administering drugs to the woman without her knowing, both the woman and partner being under the influence of alcohol at their own will, or the perpetrator being under the influence of alcohol and/or drugs at the time of the incident. Sandra described an example of the first scenario: She and her live-in boyfriend at the time were both drug dealers and drug users. Sandra was making more money selling drugs than her partner, which was a consistent source of arguments between the two. One day, she came home and he poured her an alcoholic drink, which was not out of the ordinary. After what happened next, she realized that he slipped at least two "la rochas"—strong muscle relaxants—in her drink.

"I was debating if I should drink it or not but I just didn't want to move [to get up and pour my own drink] so I drank it and I passed out on the bed and I woke up. His friend was standing right here and he was on top of me…and I couldn't move. I mean I could say stuff but couldn't move. I passed out. So my body was in a sleeping state when the pills kicked in so I was like…I could watch him. He started beating on me and his friend got up. I guess they were finished. I don't know. But his friend got up and started hitting me too and I just lay there bleeding. That's all I could do. They weren't hitting me with their fists. They were hitting me with like these stick things, like back scratchers, like the little bamboo one with the little roller things and little claws."

Sandra realized that she had experienced forced vaginal intercourse. Following the incident, she lied there for a few hours because she could not move. Due to her incapacitated state, she was vulnerable to another attack:

"So I was laying there, just laid out. I was sprawled out and he came back, him and the same dude, did whatever they wanted to do. I couldn't feel anything because it's a muscle relaxant. But he did stick his dick in my mouth and I bit it of course. And then that's when he hit me again with the damn things. They just left me there. The friend spit on me in my face. A (initial for her ex-boyfriend) told me, 'I don't want you no more' and then just walked out the house. They never came back. I was in that house for like three days."

Sandra remained in the house because of shame, her numerous physical injuries, and since her partner and his friend had stolen all of her money. She did not call the police because of her drug use. While in the house for three days, she used all of the drugs she had brought home the day of the incident. After this incident, her drug use intensified for a number of years. In fact, it took a drug overdose to change Sandra's life. Sandra's story shows that women who experience incapacitated forced sex may use drugs as a way to cope with the adverse mental health effects of the incident(s).

For Corrine, incapacitated forced sex occurred while both she and her boyfriend at the time were drinking alcohol. She described her first and only encounter with this partner:

"I'm just an occasional drinker. We were both drinking, you know. He might have drank maybe a little bit more than I did…He couldn't take no for an answer […] men have a lot more strength than a female does, you know, so they're going to, you know […] I was drinking at the time, but I wasn't no heavy drinker but I didn't know that I was focused on telling this person, 'No. I don't want to do anything' and they took it anyway and threatened to hit me. That scared me […] and I felt so defenseless."

Corrine believed that she deserved someone who respected her and treated her like a woman. She immediately sought medical care and ended the relationship.

For Stacy, she experienced two types of sexual IPV. First, she reported that she experienced verbal pressure by her boyfriend at the time, as she wanted to wait until she was married to have sexual intercourse. He was an alcoholic and did not share this desire, so he continued to pressure her to have sex. His consistent pressuring led to the first incident, which was unwanted oral sex. Second, he perpetrated incapacitated forced sex, specifically the type of sexual IPV in which only the perpetrator was under the influence of alcohol and/or drugs at the time of the incident. The second incident occurred after he had been excessively drinking alcohol and occurred with the use of weapons:

"He penetrated me anally and took a knife and I was fighting and I wouldn't stop fighting. And so he took his knife and started cutting all my legs and that [genital] area. So he did vaginal and penetrated anally and was physical like that. Physically it [the second incident] was worse because he used the knife. And so when this happened, you know, it kind of really just changed me."

Stacy described how she went home instead of seeking medical attention:

"I just went home and it was terrible. I mean because I have never, like even the whole anal thing. It was intense. So I got really sick, you know, sick to my stomach and stuff like that. My body just went into shock. But I just went home and took a shower and then just…you know, I wanted to just wash everything. I know you're supposed to go straight to the emergency room and stuff like that. But you know, this was my best friend for four years. I didn't even see it coming."

The incidents went unreported due to Stacy's lack of trust in the police. Years later, Stacy sought medical care for chronic pain, in which she attributed to the forced sex incidents.

For some women, abuse also increased in severity over time. Behaviors that began as verbal pressure led to threats of terminating the relationship, accusations of infidelity, and eventually escalated to physically forced sex. Patty enjoyed being choked during consensual sex. She believed that because of this, her boyfriend translated this level of power and control into abusive acts later in the relationship:

"He was great and then it's like one day he just snapped. Like it started becoming verbal and I'm like ok. Then it, you know, became more mean, then it became physical, then it became like violent and just extra violent…I never really understood but he was like, 'I've had enough of you.' [Later in the relationship] He would choke me until I blacked out and then he started like physically beating me and just taking it [sex] whenever he wanted to. That's why it took me six months to get away from him…He would always tell me, 'If you leave me I'll kill you. If you leave me I'll find you. You can never get away from me.'…The more aggressive he got, the more violent he got."

Although Patty ended the relationship after six months, it had a lasting effect on her and would affect her selection of partners in the future. She went on to endure severe physical and sexual IPV re-victimization in two subsequent relationships.

Resilience

Resilience is referred to as the phenomenon of a dynamic developmental process encompassing the attainment of positive adaptation within the context of significant adversity (Cicchetti, 2010; Davydov, 2010; Domhardt, Munzer, Fegert, & Goldbeck, 2014). It is important to recognize that, for some women, it was critical that they shared how they have become more resilient in the aftermath of experiences of sexual IPV.

Corrine, who experienced a single incident of incapacitated forced sex by her ex-boyfriend, sought immediate medical attention and ended her abusive relationship. Through a referral provided by the medical professionals, she received counseling services to help her deal with her psychological distress. However, she did not report the incident to the police because, since both she and her partner had been drinking, she felt as though it would be her word against his.

Corrine's decision to seek medical attention and counseling was a strong decision to make on her own, as she was not raised to seek professional services. Her family members did not believe in therapy; rather, they believed *"that you should try to handle the problems yourself unless there was something seriously, physically wrong."* In fact, Corrine did not receive counseling for the sexual abuse she experienced during her childhood given her family's beliefs. In the current situation, her focus was on herself despite her upbringing. It was the experiences of sexual IPV in her adulthood that was the catalyst for her to seek counseling. This in turn allowed Corrine to also deal with the psychological effects of her childhood sexual abuse experiences and process how that has affected her to this day.

Stacy, who experienced verbal pressure and incapacitated forced sex by the same partner, had a deep spiritual background. Even though she did not seek medical or professional care immediately after the two sexual IPV experiences, it was her spirituality that got her through. Specifically her church group became her source of social support in the aftermath.

"I was really connected to the church and so I went there. It was really good 'cause they were praying for me and all that stuff. [The church] was my support system. When I went, I got prayer through prayer meetings."

At one of the prayer meetings, Stacy was introduced to someone from the church's Christian counseling center. This provided an additional layer of support to help her deal with the trauma experienced.

"The Christian counseling center helped me too. He [Christian counselor] really tried to help with the flashbacks. They did EMDR, kind of like a hypnosis thing, where he would take me back to the event and then try and lessen the severity."

Tamara, who experienced severe forms of sexual IPV in multiple relationships, expressed the importance of being very cautious in choosing her partners. It was her spirituality that allowed for her to know her self-worth and that helped her to select the right man for a relationship:

"Just basically the ladies just keep their heads up and […] just know that they're worth something today and no man is worth our dignity, our respect, and that God created us all equal for us to be loved and cherished because we are queens."

Jackie—who experienced verbal manipulation and physically forced sexual IPV during the course of a two-year relationship—did some soul-searching after her relationship ended. As time progressed, she became more empowered and confident in how women should be respected:

"Growing up and the older you get, the more wiser you're supposed to be […] That being a person, being a woman, you should never be pressured or [let] someone use physical violence towards you with having sex because to me that's like rape. It's no different than rape. Don't force me to do things I don't want to do. If I don't want to [have sex], I don't want to."

These experiences suggest that women with experiences of sexual IPV may overcome not only the actual violent incident, but also become aware of the signs of an abusive relationship. Thus, women gain hope that they have the ability to enter into healthy, future relationships that are completely free of sexual IPV.

Conclusions

Although empirical research has accumulated over the last 30 years regarding Black women and IPV, many questions remain about Black women's perceptions of the continuum of sexual IPV (Bent-Goodley, 2007; Bent-Goodley, 2004; Amar, 2008; Draughon, Lucea, Campbell, Paterno, Bertrand, Sharps et al., 2015; McNutt, van Ryn, Clark, & Fraiser, 2000; Stockman, Campbell, & Celentano, 2010; Wingood & DiClemente, 1998). It has been recognized that there is a need for qualitative research that focuses on consistent definitions and measurements to expand the behavioral specific measures and language used in order to quantitatively examine the prevalence and incidence of sexual coercion and violence (Hamby, 2014).

The findings from the Black Women's Study provide greater insight into the context of sexual IPV within a continuum of severity. That is, confirming the importance of expanding the use of behavioral specific measures to effectively characterize the epidemiology of sexual IPV among Black women. The findings also concur with recent qualitative inquiry that examined college women's subjective experiences with sexual coercion, documenting that physical violence need not be present for sexual coercion to be harmful, as many women experience guilt, anger, sadness, and self-blame (Jeffrey & Barata, 2016).

Normative expectations, such as that of "wifely duties," were consistent with prior research, confirming that relationship status contributes to uncertainty in defining incidents of coerced sex by intimate partners as rape or a criminal offense, increasing reluctance to disclose the incidents to others (Basile, 2002; Wadsworth & Records, 2013). The reluctance of some women to label their experiences of physically forced sex as "rape" or a criminal offense may be a possible coping mechanism for not wanting to confront forced sexual experiences. There is often a pervasive normalization and acceptance of nonconsensual sexual activity with women not labeling these actions as rape or assault (Fantasia, 2011). Women in this study viewed incidents of sexual IPV as unwanted sex in varying degrees. Women responded by clearly saying no, subtly implying no, and eventually ceasing to actively resist their partner's attempts at unwanted sex—responses that map onto the continuum of sexual IPV.

This study has significant implications for interventions designed to reduce experiences of sexual IPV and increase disclosure of such incidents. Given the pervasiveness of Black women engaging in unwanted sex since sex is considered a "wifely duty," not resisting unwanted sex to appease the partner and reducing disclosure of these incidents, culturally tailored strategies are needed at the individual, peer, community, and structural levels.

At the individual level, approaches should focus on self-empowerment methods for women and provide education for men on understanding the varying degrees of sexual IPV. Recent approaches to increase disclosure of sexual IPV have utilized mobile technology methods (i.e., cell phone applications) to offer women, with such experiences, information about their options in a discreet manner, and tailored to their specific comfort level. Similar applications can be culturally tailored and modified for men who are invested in understanding how such behaviors affect their partners, and who want to learn about such methods to reduce the related behaviors. Moreover, there is a need for gender-transforming interventions targeting men themselves, and more specifically, to target the norms of masculinity that promote sexual IPV (Gutzmer, Ludwig-Barron, Wyatt, Hamilton, & Stockman, 2016).

At the peer level, peer-based responses and peer-led interventions are another avenue that may prove useful in primary and secondary prevention efforts to address sexual IPV. Peer-based education strategies can be beneficial in changing individual perceptions and norms related to sexual IPV. Bystander education, comprised of bystanders or individuals known or unknown to the victim who can intervene to prevent sexual IPV and respond appropriately to victims in the aftermath, has proven successful in sexual assault prevention and intervention (Amar, Tuccinardi, Heislein, & Simpson, 2015). Participation in bystander education programs results in decreased rape myths and increased knowledge, self-efficacy related to bystander behavior, and increased likelihood of engaging in bystander behaviors (Amar et al., 2015). Additionally, since Black women often prefer disclosure to informal support networks (i.e., friends, someone close to them), it may be beneficial to develop a social support networking system where women with experiences of sexual IPV can reach out and help other women in need. Social networks can influence overall health directly (Katerndahl, Burge, Ferrer, Becho, & Wood, 2013), as in the case of dissemination of sexual IPV information to be informed of the signs of abuse and safety planning strategies and indirectly through the transmission of social norms and values that influence health behaviors. The use of social networks through peer influence or peer-led health promotion which involves like-minded people who have overcome the adverse experiences of sexual IPV can result in the spread and sustainability of new norms surrounding sexual IPV.

At the community level, Black women may benefit from interventions that address social stigma associated with sexual IPV and attempt to improve trust and confidence in medical institutions and law enforcement agencies. Providing education—on a community level—to women about psychological abuse and empowering assertive responses to sexual coercion may confront the views of verbal pressure and sexual obligations in relationships as acceptable (Stockman, Ludwig-Barron, Lagare, & Wyatt, 2012). This could be accomplished through the use of social media campaigns, billboard advertisements, and community forums. Finally, it is important to encourage Black women to capitalize on the strength of spirituality, which has been identified as a successful coping mechanism that helps women empower themselves and find solutions to end the violence in their lives (Bent-Goodley, 2007).

At the structural level, interventions for law enforcement and health professionals are urgently needed (Gutzmer et al., 2016). In the Black community, there is a longstanding distrust of the police, resulting in reluctance among Black women to view law enforcement as a positive resource in terms of disclosing sexual IPV, further exacerbating a complex and abusive relationship. Additionally, in light of highly publicized police-involved shootings of unarmed Black men, there is even more of a reluctance to view law enforcement as a positive resource in terms of disclosing sexual IPV (Gutzmer et al., 2016). Equally important are programs designed for health professionals that account for issues of medical mistrust in the Black community. Medical professionals in the emergency room setting are often first responders for women with severe experiences of sexual IPV. As such, ensuring that there is a first point of contact, such as a community/peer advocate in the emergency room setting, may serve to bridge the gap between victims of sexual IPV and receiving short- and long-term assistance from health professionals and social workers. Collectively, the development of culturally tailored interventions and programs at multiple levels will not only facilitate reductions in new and ongoing abusive relationships, but also break the generational cycle of abuse for Black women.

Discussion Questions

1. Please think about a case of sexual violence that you heard about through media, friends, or family. Based on the continuum of severity of IPV how would you classify this case? Why? Is your classification different than what was reported or told to you?
2. Based on your background or experiences with other cultures, how are the cultural factors that shape Black women's decision to disclose sexual IPV similar or different to women of other ethnic backgrounds in the United States? How about in low- and middle-income countries?
3. Describe a multilevel primary prevention intervention to prevent sexual IPV that targets the individual, peer/relationship, community, and/or the societal levels? How would this intervention be different from a secondary prevention intervention to address sexual IPV?

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Chapter 14
A Conceptual Framework and Intervention Approach for Addressing Intimate Partner Violence in Pregnancy: The Safe & Sound Model in South Africa

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Introduction

One-third of women globally experience intimate partner violence (IPV) (Devries et al., 2013). IPV encompasses any "behavior within an intimate relationship that causes physical, sexual, or psychological harm, including acts of physical aggression, sexual coercion, psychological abuse and controlling behaviors" (WHO, 2010). Estimates of the prevalence of physical abuse during pregnancy vary from 1–10% in North America and Western Europe (Bacchus, Mezey, & Bewley, 2004; Daoud et al., 2012; Gazmararian et al., 1996; Hedin, Grimstad, Moller, Schei, & Janson, 1999) to 2–57% in sub-Saharan Africa (Shamu, Abrahams, Temmerman, Musekiwa, & Zarowsky, 2011). South African studies of pregnant women estimate that 25–35% pregnant women report recent (past 12 months) exposure to physical or sexual IPV (Dunkle et al., 2004; Groves, Kagee, Maman, Moodley, & Rouse, 2012; Hoque, Hoque, & Kader, 2009; Mbokota & Moodley, 2003).

IPV in pregnancy is detrimental to both maternal and infant health (Shah et al., 2010). Among pregnant women, it is associated with increased risk of miscarriage and premature labor (Campbell, 2002; El Kady, Gilbert, Xing, & Smith, 2005; Huth-Bocks, Levendosky, & Bogat, 2002; Rodrigues, Rocha, & Barros, 2008; Silverman,

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Gupta, Decker, Kapur, & Raj, 2007). Women who experience physical and/or sexual IPV in pregnancy are more likely to experience antepartum hemorrhage, vaginal bleeding, high blood pressure, and intrauterine growth restriction, obstetric problems (Audi, Segall-Correa, Santiago, & Perez-Escamilla, 2012; Janssen et al., 2003; Moraes, Reichenheim, & Nunes, 2009; Silverman, Decker, Reed, & Raj, 2006). A large body of literature suggests that women who experienced violence in pregnancy have increased odds of reporting postpartum depression (Beydoun, Beydoun, Kaufman, Lo, & Zonderman, 2012; Urquia, O'Campo, Heaman, Janssen, & Thiessen, 2011). Physical assault around the time of pregnancy is associated with maternal death and in some settings partner homicide is the greatest driver of maternal mortality (El Kady et al., 2005; Horon & Cheng, 2001). While no data exist around IPV and maternal mortality in South Africa, the rate of intimate partner femicide is five times the global average (Abrahams, Mathews, Martin, Lombard, & Jewkes, 2013).

Despite strong evidence for the poor health outcomes associated with IPV in pregnancy, the health sector has few proven ways to prevent violence or mitigate its risks. A limited number of interventions have demonstrated efficacy, but all have been conducted in high-income settings. In a study conducted in Hong Kong, Tiwari et al. (2005) found that empowerment counseling in pregnancy significantly reduced minor violence during the period from pregnancy leading up to the first six weeks after delivery. Another study in Washington D.C. randomized 306 women to an empowerment counseling intervention comprised of four to eight cognitive behavioral sessions and safety planning. The proportion of women experiencing violence at any time point up to postpartum follow-up was lower in the intervention group (23.3%) than in the control (37.8%, $p = 0.006$) (Kiely et al., 2010).

However, few interventions to address IPV around the time of pregnancy have been tested in low- and middle-income settings. A recent review of interventions to address IPV in pregnancy identified only four existing models in low- and middle-income settings (Ritter, John, & McCleary-Sills, 2016), suggesting an urgent need for stronger evaluations of such programs. In this chapter, we describe the model for Safe & Sound, a program in urban South Africa that aims to reduce IPV in pregnancy. We also present the conceptual framework for Safe & Sound, in recognition that articulation of program theory is a necessary first step for developing efficacious IPV interventions.

The Safe & Sound Intervention

The Safe & Sound intervention is based on a nurse-led "empowerment counseling model." This model has been tested through randomized controlled studies in antenatal care and shown to be effective in improving women's safety, coping, and violence in the United States and Hong Kong (McFarlane, Soeken, & Wiist, 2000; Tiwari et al., 2005). The empowerment model assumes that male perpetration of IPV aims to control the behavior of female partners and that by increasing a woman's sense of control over her life, she can better develop strategies to reduce violence in her relationship. This model includes two complementary components—(a) improving women's safety and protection, while (b) enhancing her decision-making and problem-solving ability in her relationship.

Conceptual Framework

The theoretical model for the Safe & Sound intervention is drawn from Kennedy et al.'s Conceptual Model of Help Attainment for women experiencing violence (Kennedy et al., 2012). This model extends beyond previous theoretical frameworks in three important ways. It frames women's responses to IPV within the broader community and social context. It acknowledges that mental health of women is dependent not only on personal volition to seek help, but also on the usefulness and supportiveness of the resources that are available. The Kennedy Model takes into account the woman's stage in her life course (in our case, pregnancy) and highlights the role of interventions in facilitating help attainment.

We adapted the Kennedy Model (Fig. 14.1) by including a reduction in the severity or frequency of IPV as a possible endpoint of help attainment, since this has been shown as an outcome in similar trials (Parker, McFarlane, Soeken, Silva, & Reel, 1999). However, we are also aware that ending violence altogether is a long-term, complex process (Khaw & Hardesty, 2007; Landenburger, 1989), and this final goal of ending violence altogether may not be attainable through a brief intervention.

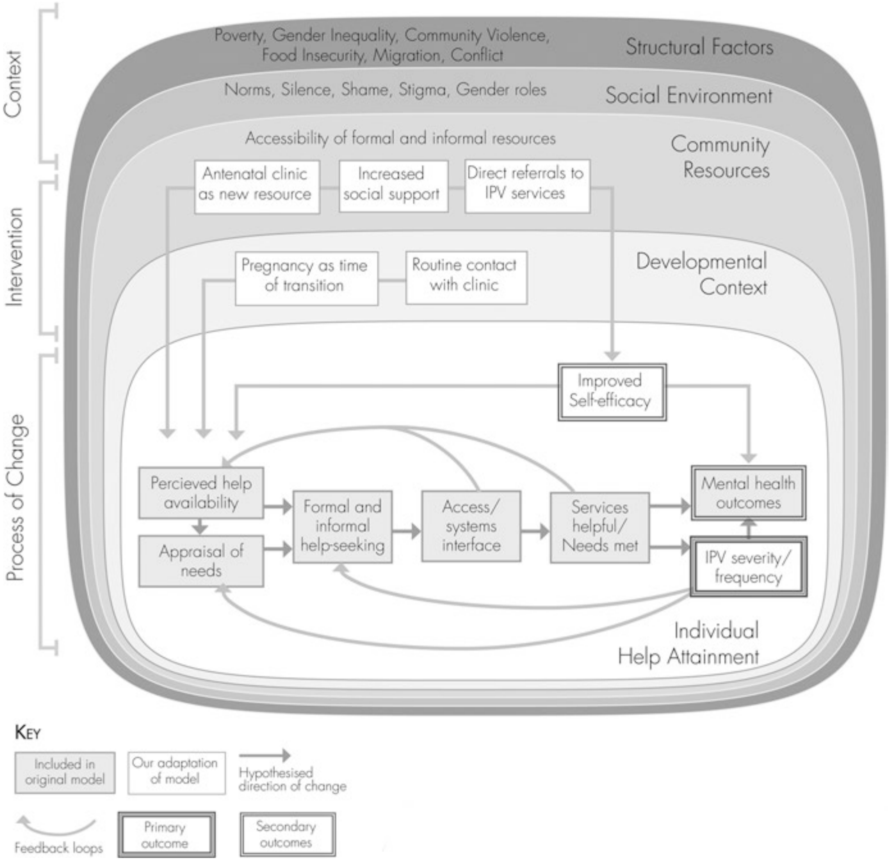


Fig. 14.1 Theoretical framework for addressing intimate partner violence in pregnancy

Thus, our secondary outcomes are improved mental health of women, their ability to cope through improved self-efficacy, and help-seeking behaviors around IPV. A tertiary outcome that will be explored through a nested study is retention in care (for the subsample of women who are HIV positive).

In the following sections, we will briefly summarize the literature in line with Kennedy's theoretical model. Starting with structural and social factors, we identify key considerations for the context of an intervention in the South African setting. Next we identify how the intervention will work, in light of community resources and a woman's developmental stage. We then outline the theorized mechanisms for change. Lastly, we highlight other IPV theoretical frameworks that have informed our approach, but will not comprise the central theory of change for the intervention.

Intervention Context

Structural and Social Factors

Broader societal factors, such as poverty, gender inequality, and levels of community violence, are drivers of IPV. Research has shown that exposure to societal violence (Gupta, Reed, Kelly, Stein, & Williams, 2012), neighborhood violence (Raiford, Seth, Braxton, & Diclemente, 2012), and neighborhood poverty (Cunradi, Caetano, Clark, & Schafer, 2000) all predict IPV perpetration. Witnessing violence within the home or community is a significant predictor of future perpetration of IPV (Roberts, Gilman, Fitzmaurice, Decker, & Koenen, 2010). Lack of support for gender equity is likewise associated with perpetrating IPV (Gomez, Speizer, & Moracco, 2011).

Although the Safe & Sound intervention is not structural in nature, nurse researchers engaging with participants are alert to the ways that structural factors shape IPV. The nurse researchers are responsive to how social pressures, norms, and experiences shape the decision of participants to seek help for IPV. This responsiveness to the holistic context of participant lives has been shown to be an important aspect of successful IPV interventions in the past (Dienemann, Glass, & Hyman, 2005; Hathaway, Willis, & Zimmer, 2002).

Community Resources

The intervention adds a new resource for coping with effects of IPV—the antenatal clinic. Although not traditionally viewed as a resource for women experiencing IPV, this setting is nevertheless highly accessed (uptake of antenatal care in South Africa is over 90%) (Day & Gray, 2006), trusted, and often geographically accessible to women in urban areas (Silal, Penn-Kekana, Harris, Birch, & McIntyre, 2012). Formative, qualitative research in this setting suggested that pregnant women were interested in talking about IPV at the antenatal clinic, so long as providers were empathetic, well trained, and nonjudgmental (Hatcher, 2016b). Direct referral to resources outside the health setting is seen as a key component of successful IPV interventions (Kirst et al., 2012). Safe & Sound nurses were trained to make referrals to trusted service providers, all of whom were visited for an introductory meeting and brief service assessment prior to the trial start. Acceptance of referrals by participants is often closely linked to the supportive approach taken by the healthcare provider (Krasnoff & Moscati, 2002; McCaw et al., 2002), so nurses were trained to offer onwards referrals in a reassuring manner.

Social support buffers the deleterious mental health effects of IPV (Coker et al., 2002; Escriba-Aguir et al., 2010; Mburia-Mwalili, Clements-Nolle, Lee, Shadley, & Wei, 2010), and decrease the risk of re-victimization (Bybee & Sullivan, 2005; Sanchez-Lorente, Blasco-Ros, & Martinez, 2012). Indeed, support from others can increase awareness that alternatives to IPV exist and that others are willing to help a woman take steps towards safety (Chang et al., 2010). Disclosing IPV to a trained nurse offers validation, information, and additional services (Feder, Hutson, Ramsay, & Taket, 2006; Phelan, 2007). By providing holistic, patient-focused attention (Sullivan & Bybee, 1999a), the Safe & Sound nurse serves as a new form of social support, and encourages women to access informal and formal sources of support.

Situational Context of Pregnancy

Based on the Life Course Theory (Elder, 1998), this portion of the theoretical model posits that life stage influences the process of accessing help for IPV. Life Course Theory has been increasingly applied to how women respond to IPV, in recognition that certain "turning points" or periods of transition influence help-seeking (Khaw & Hardesty, 2007). Pregnancy is a unique time in the developmental life course of women. Women use medical services more frequently during pregnancy than any other time (Gazmararian et al., 2000). This places healthcare providers in a position to build ongoing relationships with pregnant women, a prerequisite for identifying and supporting women experiencing IPV (Anderson, Marshak, & Hebbeler, 2002).

Because pregnancy is a transition period, it may be a time of increased receptivity to healthy changes and interventions (Hatch, 2005). This is especially true since children seem to influence mothers' decisions to leave violent relationships (Davis, 2002; Meyer, 2010, 2011). As participants in the intervention have heightened awareness of the effects of IPV on unborn children, they may be willing to consider help-seeking in a new way.

Mechanisms of Change

Individual Process of Seeking and Obtaining Effective IPV Help

Based on Andersen's Behavioral Model of Health Services Utilization (Andersen, 1995), this portion of the theoretical framework posits that the pathway to IPV services uptake is informed by participant needs, as well as predisposing and enabling factors that shape decisions. Moving from left to right in the figure, individuals tend to start by appraising needs and assessing the perceived level of help. They move onward to formal and informal help-seeking. Depending on whether the access and interface with help systems are responsive, they make an assessment of whether the services were useful. If services are useful and supportive, both improvements in mental health and reductions in IPV can be expected.

However, the help attainment process itself is not linear, but builds upon the quality of experience in seeking help. Feedback loops from poor services or a low-quality interface with help systems can make women return to the first step, and assess the perceived level of help as lower than before the negative experience.

Appraisal of Needs and Help Availability

Women tend to appraise their need for help based on the costs and benefits of seeking it out (Liang et al., 2005). Therefore, a start point of the intervention is a brief appraisal of needs by a trained Nurse Researcher that highlights the potential benefits and acknowledges the costs of seeking help. Women experiencing IPV are supportive of the idea that health workers should start with the woman's perspective (McCauley, Yurk, Jenckes, & Ford, 1998; Zink & Jacobson, 2003). A realistic cost-benefit analysis made together with the health worker may be a form of shared decision-making, also valued by IPV survivors (Battaglia, Finley, & Liebschutz, 2003).

One step of this appraisal of needs is to conduct a safety assessment. A safety component of interventions is seen as highly desirable by women (Gerbert, Abercrombie, Caspers, Love, & Bronstone, 1999; Nicolaidis, 2002), and adheres to Parker and McFarlane's original intervention design. The safety assessment in this setting helped participants explore concrete actions to assist them in staying safe in situations of escalating violence. Since the safety of the fetus is often at the forefront of women's minds during pregnancy, safety planning contained a specific focus on protecting the well-being of one's children.

Process of Formal and Informal Help-Seeking

Informal and formal sources of support are both crucial for help-seeking after experiencing IPV. This is because participants in an urban, African setting (and other settings (Fanslow & Robinson, 2010; Kiss et al., 2012; Liang et al., 2005)) tend to prefer informal modes of help-seeking, such as family or neighbors. Typically, IPV survivors have poor help-seeking behaviors because existing resources have failed them repeatedly, are confusing to access, or offer undesirable outcomes (such as jailing one's partner) (Fanslow & Robinson, 2010; Fugate, Landis, Riordan, Naureckas, & Engel, 2005; Goodkind, Gillum, Bybee, & Sullivan, 2003). Positive reframing of the help-seeking experience may assist women in coping with their situation, and in reaching out to future resources.

One theory that underpins the process of change for women is the Trans-theoretical Model (TTM), which posits that women move through a series of stages in preparation for taking action around IPV (Khaw & Hardesty, 2007). However, the TTM is not without challenges. Because the process of ending IPV occurs in a nonlinear way, scholars have suggested that a linear version of the TTM (moving from precontemplation—contemplation—preparation—action—maintenance) may be less appropriate for IPV since women often describe moving back and forth between the stages frequently (Chang et al., 2006). It is important to note that help-seeking often happens at a slow pace, and may not be recognizable if health workers are hoping to see sweeping changes (Cluss et al., 2006). Nurses can be trained to recognize the participant's own pace of making changes, since autonomy is a key component of how women want to be treated by a health provider (Feder et al., 2006).

Increasing Self-Efficacy

The counseling process is theorized to improve the self-efficacy of participants to respond to IPV in pregnancy. Based on Dutton's Empowerment Model, used in other IPV interventions with pregnant women (Parker et al., 1999), Safe & Sound aimed to increase self-efficacy through two elements: (a) increasing the woman's safety; and (b) enhancing problem-solving in decisions about the relationship (Dutton, 1992). Self-efficacy and empowerment have been found to improve mental health of IPV survivors (Frazier, 2003; O'Neill & Kerig, 2000; Wright, Perez, & Johnson, 2010).

Mental Health

No evidence-based treatments exist primarily for addressing mental health issues in the context of ongoing IPV (Warshaw & Brashler, 2009b). However, a small number of intervention studies targeting safety show efficacy in reducing mental health symptoms among women still living with violence (McFarlane et al., 2002; Sullivan & Bybee, 1999b) and those who are no longer in violent relationships (Johnson & Zlotnick, 2006; Kubany et al., 2004).

The Safe & Sound intervention is framed by Trauma Theory, which means that it views individuals as resilient survivors whose symptoms serve as adaptive responses to intolerable experiences when real protection is unavailable and coping mechanisms are overwhelmed (McCann & Pearlman, 1992). Trauma-focused interventions typically aim to help survivors to recognize their own strengths and skills, with a strong emphasis on psychoeducation regarding biological and emotional responses to traumatic events (Friedman, Keane, & Foa, 2009). Trauma-focused intervention is underpinned by collaborative therapeutic relationships with health providers—a condition that can assist the process of healing because providers are aware of how their own responses affect the person seeking help (Pearlman & Courtois, 2005).

Feedback Loops—Mental Health and Severity of IPV

Mental health has strong relationships with help-seeking behaviors. Both depression and post-traumatic stress may longitudinally worsen the re-victimization of women (Krause, Kaltman, Goodman, & Dutton, 2006; Tsai, Tomlinson, Comulada,

& Rotheram-Borus, 2016). One reason that poor mental health may hinder women's help-seeking behavior is that it can be challenging to access support if anxiety or depressive tendencies are overwhelming one's life. Another important feedback loop is the way that severity of IPV influences a woman's needs appraisal and help-seeking process. For example, previous studies have shown that more severe forms of abuse tend to increase women's uptake of supportive services (McFarlane & Wiist, 1997). However, in our South African setting, it is possible that severity of violence makes women more likely to stay quiet out of fear of shaming their family or themselves (Morgan et al., 2016).

Intervention Delivery

The Safe & Sound intervention was delivered by nurses who had no previous experience with addressing violence. These bachelor-level health professionals received a 30-h training using a formal curriculum. The training was developed and led by a team of two clinical psychologists, a social worker, and a social scientist. The training included technical aspects of understanding and responding to IPV, as well as key inter-related issues around mental health, HIV, and child safety (Table 14.1). Multiple "soft skills" around working with clients were addressed through specialized sessions on counseling, emotional safety, and self-regulation. Given the high likelihood of vicarious trauma in delivering this type of intervention, it was important to proactively address skills like containing emotions and responding to clients in crisis, to protect the well-being of clients and nurses (Sexual Violence Research Initiative, 2015).

The 30-h training was followed by professional mentorship by one of the developers of the empowerment counseling model (Dr. Judith McFarlane). Thereafter, supervision and team debriefing occurred during a series of weekly team meetings. These were comprised of 2 h sessions detailing the progress during the week, highlighting one to two challenging cases, and discussing new methods for addressing violence and managing professional boundaries. Similar to a social work approach, the team learning was done collaboratively, with an emphasis on creating a safe emotional space for expressing doubts, concerns, and areas of the intervention where clarity was lacking. Through initial process evaluation work, we learned that the mentorship and supervision aspect of Safe & Sound was essential to intervention delivery, since much learning around addressing IPV occurs on the job while new cases are being treated (Hatcher et al., 2015).

Nurses also received job aids (see Fig. 14.2) that detailed each element of the intervention. These served as training references—to spark memory of the intervention elements—as well as visual cues for clients.

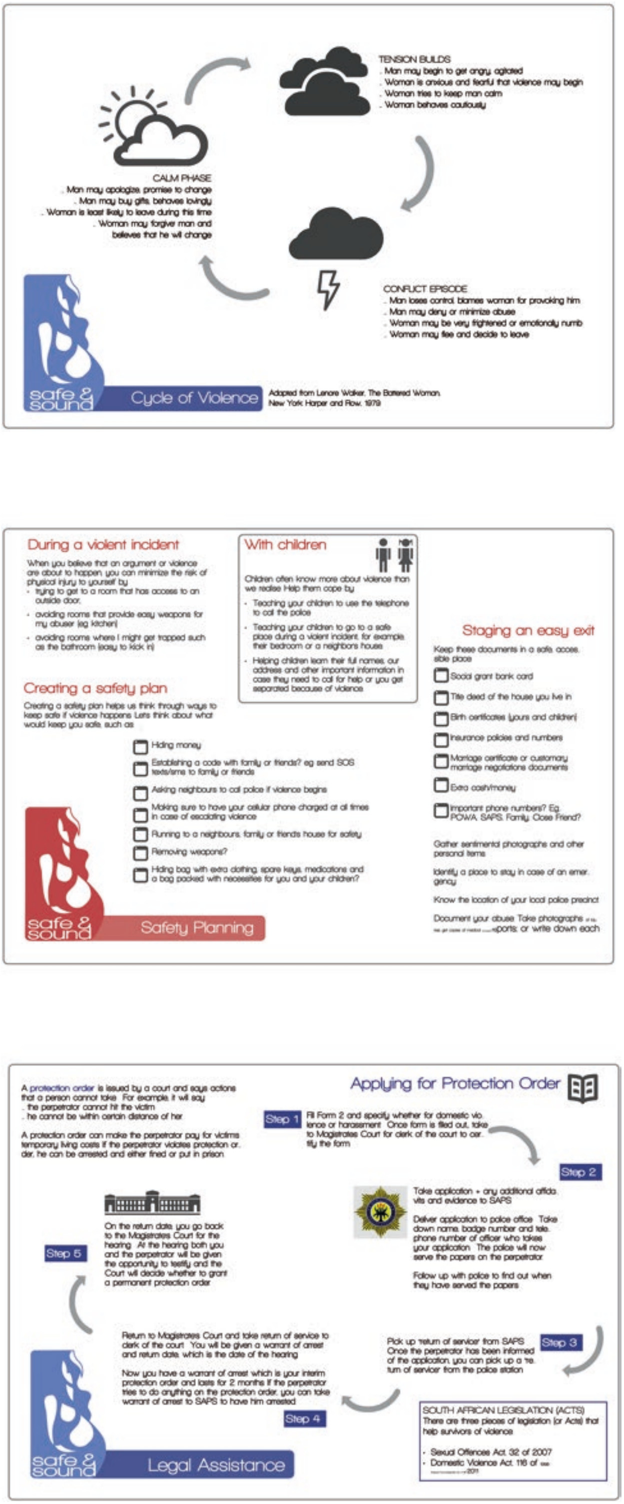
Table 14.1 Nurse training agenda

	Module	Topic
	Introduction	Getting to know each other
		Clarifying values
A	IPV Knowledge	Types of IPV
		IPV Prevalence & Impact
		Why doesn't she just leave?
		Cycle of violence
B	Mental Health Knowledge	HIV, Violence, and Mental Health
		MH and IPV
		Child considerations
		Suicide protocol and referrals
C	Pregnancy & HIV	IPV in pregnancy
		Prevention of mother-to-child treatment (PMTCT) Navigation
		PMTCT procedures
D	Intervention Context	Formative Findings
E	Counseling Skills	Behavior change
		Supporting change in clients
		Client-centered approaches and crisis management
		Empathic listening & validation
		Communication skills
F	Referral Skills	Theory of change
		Practical navigation skills
		Referral meetings
G	Rights-based Skills	Mandated reporting (children)
		How to safety plan
		Legal Assistance
H	Self-care Skills	Self-care techniques
		Burnout, vicarious trauma, stress
		Calming techniques

Intervention Components

The Safe & Sound intervention is comprised of two 30-min sessions with a trained nurse. Each session covers a combination of the following elements that are individually tailored depending on women's experience and her readiness to change:

- *Empathetic Listening*: Safe & Sound is provided by a nurse researcher trained in counseling and empathetic listening. Based on Roger's client-centered therapy model (Rogers & Koch, 1959), nurses use techniques of empathetic listening, a crucial component in other IPV interventions (Tiwari et al., 2005). Empathic understanding incorporates listening and accepting the woman's perceptions and feelings, with the goal of raising self-efficacy and self-awareness



TENSION BUILDS
- Man may begin to get angry, agitated
- Woman is anxious and fearful that violence may begin
- Woman tries to keep man calm
- Woman behaves cautiously

CONFLICT EPISODE
- Man loses control, blames woman for provoking him
- Man may deny or minimize abuse
- Woman may be very frightened or emotionally numb
- Woman may flee and decide to leave

CALM PHASE
- Man may apologize, promise to change
- Man may buy gifts, behaves lovingly
- Woman is least likely to leave during this time
- Woman may forgive man and believes that he will change

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Cycle of Violence

Adapted from Lenore Walker, The Battered Woman, New York Harper and Row, 1979

During a violent incident

When you believe that an argument or violence are about to happen, you can minimize the risk of physical injury to yourself by
- trying to get to a room that has access to an outside door,
- avoiding rooms that provide easy weapons for my abuser (eg kitchen)
- avoiding rooms where I might get trapped such as the bathroom (easy to kick in)

With children

Children often know more about violence than we realise Help them cope by
- Teaching your children to use the telephone to call the police
- Teaching your children to go to a safe place during a violent incident, for example their bedroom or a neighbors house
- Helping children learn their full names, our address and other important information in case they need to call for help or you get separated because of violence

Creating a safety plan

Creating a safety plan helps us think through ways to keep safe if violence happens Lets think about what would keep you safe, such as

☐ Hiding money
☐ Establishing a code with family or friends? eg send SOS texts/sms to family or friends
☐ Asking neighbours to call police if violence begins
☐ Making sure to have your cellular phone charged at all times in case of escalating violence
☐ Running to a neighbours, family or friends house for safety
☐ Removing weapons?
☐ Hiding bag with extra clothing, spare keys, medications and a bag packed with necessities for you and your children?

Staging an easy exit

Keep these documents in a safe, accessible place

☐ Social grant bank card
☐ Title deed of the house you live in
☐ Birth certificates (yours and children)
☐ Insurance policies and numbers
☐ Marriage certificate or customary marriage negotiations documents
☐ Extra cash/money
☐ Important phone numbers? Eg. POWA, SAPS, Family, Close Friend?

Gather sentimental photographs and other personal items

Identify a place to stay in case of an emergency

Know the location of your local police precinct

Document your abuse Take photographs [illegible] reports; or write down each

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Safety Planning

Applying for Protection Order

A protection order is issued by a court and says actions that a person cannot take For example, it will say
- the perpetrator cannot hit the victim
- he cannot be within certain distance of her

A protection order can make the perpetrator pay for victims temporary living costs If the perpetrator violates protection order, he can be arrested and either fined or put in prison

Step 1
Fill Form 2 and specify whether for domestic violence or harassment Once form is filled out, take to Magistrates Court for clerk of the court to certify the form

Step 2
Take application + any additional affidavits and evidence to SAPS

Deliver application to police office Take down name, badge number and telephone number of officer who takes your application The police will now serve the papers on the perpetrator

Follow up with police to find out when they have served the papers

Step 3
Pick up return of service from SAPS Once the perpetrator has been informed of the application, you can pick up a return of service from the police station

Step 4
Return to Magistrates Court and take return of service to clerk of the court You will be given a warrant of arrest and return date, which is the date of the hearing

Now you have a warrant of arrest which is your interim protection order and lasts for 2 months If the perpetrator tries to do anything on the protection order, you can take warrant of arrest to SAPS to have him arrested

Step 5
On the return date you go back to the Magistrates Court for the hearing At the hearing both you and the perpetrator will be given the opportunity to testify and the Court will decide whether to grant a permanent protection order

SOUTH AFRICAN LEGISLATION (ACTS)
There are three pieces of legislation (or Acts) that help survivors of violence
- Sexual Offences Act 32 of 2007
- Domestic Violence Act 116 of [illegible] 2011

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Legal Assistance

Fig. 14.2 Job aids for addressing intimate partner violence in pregnancy for participants without judgment. This skill involves therapeutic techniques of containment and active listening. The Safe & Sound approach to empathetic listening is informed by trauma literature, which focuses on creating an environment of "emotional safety" that prioritizes client choice and self-determination (Reynolds, 2007; Warshaw & Brashler, 2009a).

- *Cycle of Violence*: The nurse researcher discusses how abusive relationships often follow predictable patterns in which abuse might subside for a period of time, only to resume again later. She also highlights possible warning signs that could indicate that a renewed phase of violence might be imminent. By better understanding these patterns, the woman should be better prepared to prevent subsequent violence by utilizing safety behaviors and to predict signs of increased danger.
- *Assessing Risk*: Assessing immediate danger and ongoing safety risks is an important part of the clinician's role. This step helps the woman take stock of her own situation and can frame further conversations around safety planning. The most important element of assessing risk is to start the discussion in a place that is physically safe and confidential. Often, antenatal clinics can provide this type of physical and emotional safety, but given the busy nature of many clinics in South Africa, it took our team additional work to secure a quiet, private space. The provider approach while assessing risk should be free of judgment and supportive. Merely offering a safe space can give abused women a renewed sense that others can be trusted, an important step in the healing process (Pearlman & Courtois, 2005). A validated tool, such as the Danger Assessment, can be used during this process. However, we found that brief questions around important immediate safety risks were useful in identifying women who required urgent help (and could not ethically be randomized to an intervention):

  - *Suicidality* can be assessed after asking screening questions on IPV. We assessed this using a two-step process: (1) *inquiring whether the woman had thoughts of ending her own life*; (2) *inquiring whether the woman had plans to end her own life within the next 2 days*. The rationale for restricting suicidality to the two-day timeframe is to ensure that women with imminent threat to safety access immediate assistance. A direct referral should be established to the emergency room at the nearest hospital or to a specialized psychiatric treatment hospital.
  - *Homicidality* should also be assessed. Risks of homicidality increase as certain male behaviors increase: stalking, sharp increase in physical violence, estrangement, presence of guns, or mental illness (Campbell & Glass, 2009). Estrangement is particularly important when assessing danger, since women are often most at risk of severe violence or homicide when they have moved away from their partner during the past year (Campbell et al., 2003). This finding underscores the importance of letting clients decide what action they want to take—it may be strategic for them to stay with a partner until a moment when they can safely leave. We asked a single item: *Do you believe your partner may kill you in the coming 2 days?* If homicidality seems imminent, a direct referral to the nearest police station should be established. Women may require escort to the police station to ensure they receive the help they need.

  - *Child safety risk* is important to identify, given that children in homes with IPV are much more likely to be physically abused or neglected (Edleson, 1999). We asked a single item: *Do you fear that your partner may harm your child in the coming 2 days?* In settings like South Africa, it is a legal requirement that health providers report on cases of child abuse (Republic of SouthAfrica, 2005). Therefore, our team underwent training specific to mandatory child abuse reporting and follow-up. It is important to note that this step of reporting on a client, with whom you may have already established a therapeutic relationship, is fraught with challenges. Child safety is one area of assessing risk that requires ongoing supervision from a trained manager, such as a clinical psychologist, to ensure it is done in an ethical and responsive manner.

It is useful to note that we used a 2-day timeframe to determine "imminent" risk. This was due to the fact that fears around suicidality, homicidality, and child harm were likely to be high in our setting and could mean that a large portion of women were deemed ineligible to take part in the trial. Outside of a trial setting, these suicidality, homicidality, and child safety criteria could be expanded in order to assist women dealing with danger over a longer timeframe, say the coming month.

- *Pregnancy Changes*: Based on early piloting of the intervention which suggested women have concerns around relationship and sexuality changes in pregnancy, nurses can choose to lead an open-ended discussion of pregnancy. The aim of this discussion is to highlight the shifts in relationship dynamics, financial needs, or sexual drives that couples might experience. The approach is to "contain" a woman's feelings around these changes and to provide empathetic listening to her concerns. Containment in this context means emotionally supporting and de-escalating distress, a technique commonly used by mental health providers to ensure emotional safety of participants. Health considerations (such as perceived danger of sexual intercourse during pregnancy) can be clarified at this stage. In our setting, this component of the intervention also included discussion around HIV and how to prevent transmission to one's infant.
- *Safety Planning*: The nurse help the woman to develop a safety strategy tailored to her situation and based on culturally appropriate actions for increasing personal safety of herself and her children. These strategies include developing a code with family and friends to indicate increased risk, alerting neighbors to the situation and seeking support from them in the case of an abusive incident, and having a bag and documents ready in case of the need to flee with children in the event of imminent danger. The nurse researcher helps the woman identify those behaviors and strategies that she can best implement. One central element of safety planning is the emphasis on giving women themselves choice over the strategies they employ. This is a crucial technique to help women feel "in control" of their own situation, and to empower them to choose options that fit well in their own lives. One clinical challenge of this approach to safety planning is that clients may choose to retreat in what seems like a "submissive" or "passive" phase (Grigsby & Hartman, 1997). Rather than pushing clients forward into more active safety plans, the nurse should recognize that violence survivors demonstrate strategic ingenuity in how they attempt to relieve their abusive situation. Sometimes, passivity actually represents a strategic approach to reduce immediate danger. One example within Safe &

Sound was the attentive decisions that women made not to disclose their HIV-positive status—a form of strategic safety assurance that they navigated with great skill (Hatcher et al., 2016a).

- *Legal Steps*: Women who are prepared to take legal steps to protect themselves from IPV are given step-by-step instructions for obtaining a protection order. In practice, this process is a complex one requiring many visits to the magistrate court and police. A “job aid” was developed with input from a local legal organization specializing in IPV. If needed, nurses refer women to legal aid who can support them practically or emotionally to complete the protection order. This component of the intervention was challenging to deliver because very few clients are at the stage of desiring legal action against partners (at least in our South African setting). The job aid and legal instructions can be adapted to various settings, and this process takes time in advance of delivering the intervention. To develop the job aid, a legal assistance organization or skillful family lawyer can advise on the appropriate steps women should take for key legal action, such as protection orders or pressing charges.
- *Referrals*: Based on the findings of our team’s formative research (Hatcher et al., 2016b), Safe & Sound participants are given a list of onwards services available locally. These services included help with the psychological, legal, social, shelter, or health-related needs resulting from violence. Prior to being included on the referral list, all agencies were sensitized to the intervention and demonstrated capacity to serve as referrals. This means that they were in a position to take on additional clients, would answer the phone (also called a “warm referral”), and were capacitated to respond to new client requests. This assessment of service capacity needed to be evaluated every few months to ensure that referrals were still active. The nurses had a choice of giving women a written, verbal, or telephone referral to the external organizations, depending on the preferences of the woman. Interestingly, this was one element that nurses felt truly empowered to deliver, and they were satisfied with the sense that they were providing new information that clients appreciated. This finding aligns with literature that suggests violence-related interventions can benefit from taking an “advocacy” stance (Warshaw & Brashler, 2009a). Advocacy in the case of Safe & Sound means actively assisting clients to know their options, navigate community resources, and use their own strength to mitigate further violence problems. In a return to the trauma-informed literature, health providers using this advocacy approach need to be aware of the many barriers that clients face in engaging with referral systems, partly because of the natural traumatic response that makes it difficult for abused women to fully trust new systems (Pearlman & Courtois, 2005).

Conclusion

We developed a theoretical framework that positions IPV-related health within the broader context of community resources, the woman’s stage in life, her social environment, and key structural factors. By creating an enabling environment during antenatal care, the Safe & Sound intervention may reduce a woman’s experience of

IPV and increase her actions to seek help (including accessing community resources, safety planning, HIV-related treatment uptake), resulting in improved physical and mental health. Our conceptual framework can inform future health sector approaches by simultaneously fostering women's response to violence and strengthening the health system and its linkages to other community services.

The Safe & Sound model is being tested using a randomized control trial design (Pallitto et al., 2016), with results available in 2017. However, several studies that compared the results of a health sector intervention with another form of aid for women, such as providing referral information, found no significant difference between the intervention and control group (McFarlane, Groff, O'Brien, & Watson, 2006; Parker et al., 1999; Sullivan, Campbell, Angelique, Eby, & Davidson, 1994; Tiwari et al., 2010). In the United States, McFarlane et al. randomized 329 women to brief empowerment counseling, targeted outreach with a mentor mother, or a control condition with a wallet-sized referral card. Empowerment counseling and outreach reduced mean rates of physical violence over time, but not significantly compared to the control condition (McFarlane et al., 2000). A key reason for McFarlane et al.'s null trial finding was that the control condition involved giving women a slip of paper with referral information and may be, in itself, a way to improve violence-related outcomes.

Another potential reason for the mixed and null findings about the efficacy of health sector interventions is that the theoretical or therapeutic underpinnings of these interventions have not, to our knowledge, been clearly articulated. The public health field has increasingly learned that trials should focus on interventions with explicit theories of change rooted in the social and behavioral sciences (Briscoe & Aboud, 2012; Michie et al., 2013). However, notwithstanding important exceptions (Jack et al., 2012; Whitaker, Hall, & Coker, 2009), theory-based approaches have largely been absent in IPV research. In this chapter we aimed to fill this gap in the literature by exploring the theory behind Safe & Sound and articulate how it informed a novel intervention model that is among the first to address IPV in low- or middle-income settings.

Two other ongoing studies that anticipate results in 2017–2018 are exceptions to this gap in evidence. In Kenya, a pilot program aims to address maternal, paternal, and child health by providing couples a series of three home visits comprising information on infant development, HIV, and partner dynamics including IPV (Turan, Bukusi, Kwena, Hatcher, & Darbes, 2015). In South Africa, a clinic-based series of three group sessions and three couples counseling sessions aims to improve HIV outcomes for mothers and infants (Jones et al., 2014). Both in-progress studies, however, exclude couples experiencing severe partner violence for ethical reasons. This is consistent with many couples studies and presents complex questions about how to engage partners already in violent relationship in such intervention trials.

Much more needs to be done to ensure that lessons from individual projects like these are scaled up to reach the multitude of women who experience violence in pregnancy. Promising models from resource-rich settings can be applied and tested in low- and middle-income countries. For example, the home visiting program led by the Nurse-Family Partnership in the United States (Olds, Hill, O'Brien, Racine, & Moritz, 2003) has demonstrated marked improvements in maternal and infant health in South Africa (Tomlinson et al., 2016). Just as the U.S. program has incorporated IPV screening and care into routine home visits (Jack et al., 2012), so too should South Africa and other African settings consider adapting efficacious IPV interventions during the perinatal period. It will be essential for health providers to be trained and supported to deliver perinatal IPV interventions if we are to ensure the physical and mental health of women and infants globally.

Discussion Questions

1. Explain how intimate partner violence impacts on the health of women in pregnancy. List the ways that it can influence the health of the fetus or infant.
2. How would you describe the current state of evidence for addressing IPV in pregnancy in low- and middle-income countries? Why do you think some settings, such as low- and middle-income countries, have access to fewer efficacious interventions than high-income settings?
3. Thinking about your own life, are there moments that you found yourself with high “readiness to change” a health-related behavior? What were the circumstances that helped you feel ready to change? Did you feel that real change was an easy process, or did it take time? Consider how this might apply for a pregnant woman who is experiencing IPV, given that the health behavior in question is her partner’s use of violence and she may not be able to fully control it.
4. How might pregnancy be a “turning point” for women who are experiencing IPV? Describe how the “turning point” framing applies to interventions in the health sector.
5. List three aspects of assessing IPV risk that are crucial for health providers to be aware of.

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Chapter 15
Invisible Survivors: Causes and Consequences of Violence Against Older Women and Promising Solutions

Jennifer McCleary-Sills, Cailin Crockett, and Bergen Cooper

> *"Older women face greater risk of physical and psychological abuse due to discriminatory societal attitudes and the non-realization of the human rights of women. Some harmful traditional and customary practices result in abuse and violence directed at older women, often exacerbated by poverty and lack of access to legal protection."*
>
> *Source: United Nations (2002). Political Declaration and Madrid International Plan of Action on Ageing, Paragraph 38. New York.*

Introduction

Violence Against Older Women as a Development Challenge

The global population of people aged 60 and above is expected to reach 1.4 billion in 2030 and 2 billion in 2050. The majority of this population will be women living in low- and middle-income countries, who continue to outnumber men as they age (UN DESA, 2013a). In fact, women account for more than half of the global population aged 60 and older (UNGA, 2013). Across the globe, nearly one-quarter

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(23.6%) of the female population is of age 50 and older (UNGA, 2013). Yet we know very little about what happens in their lives after age 49. This knowledge gap reflects the fact that globally comparable data sets, such as the Demographic Health Surveys (DHS), collect data only from women of reproductive age (15–49 years old) (WHO, 2013).[1] As a result, information about older women's sexual health, their economic activity, and their experiences of violence is severely limited. It also means that older women are rarely given proper credit for their role and potential as change agents and drivers of development.

This evidence gap reflects a missed opportunity to bring more attention to the lived experiences of older women, including documenting the specific forms of abuse and violence they face. Violence against older people has been addressed through the frame of elder abuse, which the World Health Organization (WHO) defines as "harm to an older person (aged 60-plus years) through any single or repeated act—physical, psychological, sexual, emotional, or financial—including neglect and abandonment" (WHO, 2015). This definition of (elder) abuse lacks a specific gender lens in that it does not distinguish the forms of violence experienced by any older adult from those experienced only by older women. Furthermore, it does not recognize older women's unique vulnerability to abuse, including intimate partner and sexual violence from non-partners. This definition also excludes women who are beyond reproductive age but not yet considered "old" in their cultural context.

In line with the WHO, this chapter defines "violence against older women" here as "any act of gender-based violence (GBV) that results in, or is likely to result in, physical, sexual or mental harm or suffering" to women aged 50 and older "including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life" (WHO, 2014). This can also include financial abuse, exploitation or deprivation of resources, neglect, and abandonment. This definition recognizes that as women enter older age, they can become vulnerable to acts of violence from a wider range of possible perpetrators, including intimate partners or spouses, family members, and caregivers.

There is an unfortunate array of harmful practices that disproportionately affect older women. While distinct in form and nature, all these acts of violence stem from strict gender norms and culturally embedded values that place a premium on youth and women's role as childbearers—in some cases, the harmful assumptions that older women are "useless" once they are past reproductive age (UNGA, 2013). This creates an overlapping vulnerability to violence fueled by both ageism and sexism.

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[1] While some data sets have included women aged 50 and older in surveys on lifetime prevalence of intimate partner violence (IPV), there is very limited data on IPV prevalence among women aged 50-plus in the previous 12 months. Some researchers caution that expanding the age range for women included in 12-month IPV prevalence surveys would reduce average prevalence estimates. WHO cautions that lack of data should not be interpreted as evidence that older women experience lower levels of partner violence, but rather that less is known about patterns of violence among women aged 50 years and older, especially in low- and middle-income countries.

This chapter underscores that integrating the prevention of, and response to, violence against older women into health and development programs requires an understanding of the legal, social, and epidemiological context.

State of the Evidence: Violence Against Older Women

A recent global study revealed that over 35% of women worldwide have experienced physical or sexual partner violence or non-partner sexual violence (WHO, 2013). That is at least 818 million women—almost the total population of sub-Saharan Africa (Klugman et al., 2014). However, these figures are largely based on studies with women aged 15–49, and do not reveal the true magnitude of the violence experienced by women across their life course. Yet we know that aging is not a defense against intimate partner violence (IPV) or sexual violence outside of relationships; women can be subject to multiple forms of violence throughout their lives.

- The limited available research on violence against older women comes predominantly from developed countries. In a 2013 WHO study on violence against women globally, women aged 50 and above comprised less than 6% of the sample; less than 1% of women aged 50 and above included in the survey came from low- and middle-income countries (WHO, 2013).
- Still, these studies offer useful insights into understanding violence against older women in lower income and developing countries. A recent study in five European Union countries found that 28% of women 60 years of age and older reported experiencing some form of abuse in the previous year—this included sexual and physical violence as well as other forms of abuse (neglect, emotional, financial, and/or "violation of rights") (Luoma et al., 2011).[2] Emotional abuse was the highest reported category, with 24% prevalence of this type of abuse in the home in the previous 12 months. As is the case with younger women, the most common perpetrator of this violence is a spouse or an intimate partner, underscoring the fact that IPV remains a problem for women across the life course (Luoma et al., 2011).[3]
- Recent research from the United States revealed that sexual violence against older women is almost never reported to the police. Non-partner sexual assaults committed against women aged 65 and older are reported 15.5% less frequently than sex-

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[2] The DAPHNE Abuse and Violence against Older Women (AVOW) study included data collected from Austria, Belgium, Finland, Lithuania, and Portugal; it measured the prevalence of older women experiencing violence or abuse in their homes in the previous 12 months. Overall rates included neglect: 5.4%; emotional abuse: 23.6%; financial abuse: 8.8%; physical abuse: 2.5%; sexual abuse: 3.1%; violation of rights: 6.4%; and overall abuse: 28.1%.

[3] For financial abuse, the spouse/partner was the most common abuser (33.7%); this was closely followed by the category comprising daughter, son, and son/daughter-in-law (28.7%). The most prevalent category of abuser for neglect was daughter, son, and son/daughter-in-law (40.6%).

> ual assaults committed against younger women (between the age of 25 and 49) (Morgan & Mason, 2014). Another study from the United States found that women remain at a fairly constant risk for IPV regardless of age when psychological abuse and controlling behavior are included (Mezey, Post, & Maxwell, 2002).

In addition to IPV and non-partner sexual violence, older women can be subjected to harmful practices that vary by regional and local contexts. These include practices of widow burning (Solotaroff & Pande, 2014),[4] wife inheritance (Nyanzi, Emodu-Walakira, & Serwaniko, 2011),[5] and forms of violence and stigma related to accusations of witchcraft (Alston, 2009).[6] A perpetrator might choose to exploit an older woman's vulnerability in terms of physical ability, social status, availability of financial resources, or all of the above (UN DESA, 2013b). One form of psychological/emotional abuse that is of unique risk to older women is the denial of access to sacred sites or participation in faith activities, a practice most likely to occur in cultures with strong spiritual and religious traditions. Older women also experience financial exploitation or economic abuse through the illegal or improper use of their money, property, or assets. This may be perpetrated through the use of threats, intimidation, and/or force to take control of their resources. Intentional neglect is also a form of violence that older women are acutely at risk of experiencing. This can include desertion or abandonment, and failure to provide essential support such as food, clothing, shelter, and health and medical care (UN DESA, 2013b). Across all of these estimates and models, it is also critical to note that the figures are almost certainly underestimates of true prevalence given the social and structural factors that serve as barriers to reporting for the majority of women who experience violence (Klugman et al., 2014).

Impacts of Violence Against Older Women

The most common settings for this violence are in women's homes and in their communities. The pervasive and intimate nature of this violence makes the deleterious effects more salient and damaging. Such violence can have serious consequences for survivors' physical and mental health; a substantial body of research

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[4] Widow burning, or "sati," in India, in which a Hindu widow sacrifices herself on her husband's funeral pyre, is illegal but continues (albeit rarely) in parts of South Asia. Not all widows are older women, but tend to be in their 40s and above.

[5] Widow inheritance is a widespread cultural practice in sub-Saharan Africa that allows a designated male to assume responsibility for the social and economic support of a widow upon the death of her husband. Often, widows are expected to fulfill the sexual demands of the new husband and perform a subordinate role in the household.

[6] The harmful practice of accusing older women (typically widows) of witchcraft is often a tactic to remove them from their land holdings, and is also exercised by communities as an explanation for sudden deaths from HIV/AIDS. The practice has been recorded in regions of Africa, South Asia, and the Pacific.

demonstrates that trauma stemming from abuse throughout the life course has a devastating impact on older women. Further, the significance of older women's economic contributions, both as unremunerated caregivers and labor force participants, suggests that families, communities, and economies also suffer from lost productivity resulting from abuse.

For older survivors of sexual assault, the health consequences and resulting injuries are often more severe. Data from the United States reveal that older adults are more likely to sustain injuries that require hospitalization or urgent care following an assault compared to younger individuals (Burgess, 2006; Eckert & Sugar, 2008). Research with physicians in the United States indicates that postmenopausal women experience more frequent and more severe genital injuries from sexual assault than younger women (Poulos & Sheridan, 2008), and older women with a history of repeated experiences of sexual assault have a two- to threefold risk of arthritis and breast cancer compared to older women without a history of assault (Stein & Barrett-Connor, 2000). In Burkina Faso, a survey of older women accused of witchcraft reveals the profound mental health implications of community rejection. More than one-half (55%) of women surveyed disclosed that their immediate thought upon being accused was to commit suicide (HelpAge International, 2010).

Beyond the incalculable social and emotional impacts of this violence and abuse, there are significant economic costs. In the United States, the direct medical costs associated with violent injuries to older adults stemming from interpersonal abuse are estimated to add over $5.3 billion to the annual national health expenditures (Mouton et al., 2004). This model does not, however, calculate the human and economic burden of the forms of neglect that are so common among older women. While a growing body of literature is offering quantified estimates of the costs of VAW, no studies have yet looked specifically at the economic costs of violence against older women. Researchers have established that VAW reduces employee productivity, and the ability of survivors to maintain stable jobs, and in severe cases forces survivors to miss work (Duvvury, Carney, Callan, & Raghavendra, 2013). The same may be true when violence is experienced by older women workers, whose labor force participation has increased since 1990 in all regions of the world (UN DESA, 2010). Worldwide, violence and abuse undermine older women's ability to be resources to their families, who depend on them to be primary caregivers for grandchildren while parents are at work. A study of Bolivian migrants in Spain found that more than two-thirds (69%) left their children at home, usually with grandparents. In rural China, grandparents care for more than one-third (38%) of children under 5 years of age whose parents have migrated to cities for work (UNFPA & HelpAge International, 2012).

Risk Profile

Data on violence against older women in vulnerable settings or from marginalized populations are very limited. However, empirical studies, complemented by observations from development practitioners working with older populations, have identified factors that can magnify older women's risk for violence and abuse (Acierno, Hernandez-Tejada, Muzzy, & Steve, 2010; Cooney, Howard, & Lawlor, 2006; Cooper et al., 2009; Kwatra, 2012; UN DESA, 2013c; Wiglesworth et al., 2010; Yan & Kwok, 2010). These include isolation, cognitive decline and dementia, disability and care dependency, and prior history of interpersonal violence (Fisher, Zink, & Regan, 2010; UNGA, 2012; WHO, 2012).[7] It is also important to recognize that older women are not a monolithic group, but rather include women from all countries, ethnicities, sexualities, gender identities, professions, and health statuses. Those from marginalized populations continue to be at greater or unique risks for violence throughout their life span and in older age (Agence France-Presse, 2015; Bartels, VanRooyen, Leaning, Scott, & Kelly, 2010; Cook, Dinnen, & O'Donnell, 2011; Grossman et al., 2014; Guruge & Kanthasamy, 2010; UN DESA, 2013b). These overlapping forms of discrimination and risk are of particular salience for immigrant and ethnic minority women, sexual and gender minority women, indigenous women, sex workers, women living with HIV, and women in contexts of fragility and violence (D'Augelli & Grossman, 2001; Deering et al., 2014; Dunkle & Decker, 2013; Fawole & Dagunduro, 2014; Hao et al., 2014; Hontelez et al., 2012; Nerenberg, 2004; Reed, Gupta, Biradavolu, Devireddy, & Blankenship, 2010; Silverman, 2011).[8]

Health status, disability, care dependency, and HIV status are also characteristics that can intersect with age- and gender-related identities and thus influence one's experiences, social expectations, and societal roles (World Bank, 2013). Intersectionality is specific to each context; however, in many societies, this intersection can increase older women's disadvantage and vulnerability to violence. For many older women, poor health and disability are manifestations of gender disparity across the life span. Research on the social determinants of health shows that health status in later life is linked to the conditions and activities of an individual throughout the life span. In countries or cultures where son preference is common, girls may have lesser access to adequate food and nutrition in their developmental years, increasing the risk of disease in old age (WHO, 2007). In many countries, older women have lower levels of education than older men due to gendered expectations and norms that privilege boys' education (IFES, 2010).[9] In low- and middle-income countries, nearly twice the proportion of women aged 65-plus are illiterate compared with men of the same age group (58% compared to 34%) (UN Women

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[7] A systematic review by the WHO on violence against adults with disabilities found that overall they are 1.5 times more likely to be a victim of violence than those without a disability.

[8] *An analytical cross-sectional survey and in-depth interviews with female sex workers working in brothels in Abuja, Nigeria, found that older female sex workers experienced significantly more sexual violence than their younger counterparts.*

[9] The gender gap in access to primary and secondary education in low- and middle-income countries has decreased over the past three decades, but a gap remains. Progress in increasing access for girls to attend school correlates with historic and persistent gender disparities. For example, 87% of women aged 65 and older in Morocco have no formal education, compared with 16% of women and girls aged 14–24.

Coordination Division, 2012).[10] Further, complications during pregnancy and childbirth remain a leading cause of death and disability among women in many countries. According to the World Bank, 15–50 million women per year are injured or seriously disabled during childbirth, suffering from conditions such as severe anemia, incontinence, damage to the reproductive organs or nervous system, chronic pain, and infertility (World Bank, n.d.). These conditions can worsen in later life, leading to greater dependence, lower quality of life, and increased marginalization and vulnerability.

In both developed and developing countries, older women are more likely than their male counterparts to be poor (UN Women Coordination Division, 2012). Living in poverty augments older women's vulnerability to violence, reducing their ability to leave an abusive partner or household due to limited economic independence (Kidd, 2009; UN DESA, 2010). This additional vulnerability is due to a host of common factors that disproportionately affect older women, including limited access to pensions and other government assistance, unpaid caregiving responsibilities, and obstructed land rights (HelpAge International, n.d.; UNFPA & HelpAge International, 2012; UNGA, 2012).

Essential Services for Older Survivors

In addition to the economic disadvantages older women often grapple with, there is significant evidence that older age impacts women's health-seeking behavior and access to services, which in turn furthers the cycle of violence. This includes access to essential services for survivors of violence—health, social service, and access to justice. In light of the sensitive nature of collecting such data, there are globally accepted ethical guidelines that must be adhered to when collecting data from survivors about their experiences of violence, which prioritize the safety and agency of survivors (Gennari, McCleary-Sills, Arango, & Hidalgo, 2014). There are specific considerations that must be taken into account when studying or providing services to older women, who are infrequently screened for violence in healthcare settings and are largely ignored by research on violence. For example, it is critical to ensure confidentiality and anonymity of respondents/participants, particularly in contexts in which the abuser is a caregiver or family member. While it should not be assumed that older women have physical or cognitive disabilities, researchers and service providers should support the equitable participation of women with such disabilities.

Equally important, women past reproductive age continue to have sex. In part based on the focus on women of reproductive age, the sexual health of older women

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[10] According to UN Women, "average levels of illiteracy for women aged 65 or over are as high as 78% in Africa and 53% in Asia, compared to 58% and 29% respectively for men in these regions."

is often ignored, marginalized, and stigmatized, impeding access to preventive services and care for interpersonal violence and sexually transmitted infections, including HIV. While many primary care providers avoid talking to their patients about sexual health (due to a range of reasons such as time constraints, lack of resources, training, or perceived ability) (Dyer & Das Nair, 2013), they are even less likely to inquire about the sexual activity of older patients (Moreira et al., 2005). The Global Study of Sexual Attitudes and Behaviors surveyed 27,500 men and women aged 40–80 and found that only 9% had been asked about their sexual health by a provider in the past three years, even though 49% of women had reported at least one sexual problem in the past 12 months. These included, among other problems, lack of desire, inability to climax, lack of lubrication, and physical pain during intercourse. More than one-third (41%) of women surveyed believed that providers should spontaneously ask about sexual problems as a part of routine care (Moreira et al., 2005). This lack of communication is problematic since it is known that sexual problems can negatively impact a person's quality of life (Fugl-Meyer, Lodnert, Bränholm, & Fugl-Meyer, 1997; Laumann, Paik, & Rosen, 1999; Morokoff & Gilliland, 1993).

A report by the Joint United Nations Program on HIV/AIDS (UNAIDS) emphasizes that "health communication and health services are not geared towards people aged 50 and older living with HIV" and that "clinicians are less likely to be trained on the specific needs of people 50 and older living with HIV" (UNAIDS, 2014). Studies in the United States show that older women are uniquely at risk of not knowing whether they have HIV, as they are extremely unlikely to ask for an HIV test without first being prompted by a provider (Durvasula, 2014). Given the increasing degree to which successful GBV interventions are combined with programming for HIV testing, services, and care, it is problematic that older women are excluded from most of these settings (Cooper & Crockett, 2015).

Solutions: Preventing and Responding to Violence Against Older Women

Preventing and responding to violence against older women require an understanding of the legal, social, and epidemiological context of this violence and what structures and systems are in place to meet the needs of survivors (Crockett, McCleary-Sills, Cooper, & Brown, 2016). It is also critical to understand how age and gender discrimination combine to deny older women access to health care and social service provision (Sleap, 2015). Such exclusion undermines the development of protective factors against violence and heightens their risk for violence and abuse. There is a growing body of evidence on successful practices to better meet the needs of older women and of older survivors of violence in particular.

Only a small minority of survivors of violence willingly report the crime or seek help from formal service providers (Palermo, Bleck, & Peterman, 2014). Thus, it is essential that healthcare personnel, social workers, traditional or community healers, and law enforcement be trained to recognize and respond to the (unique) situations of violence, abuse, and neglect that older women face. The example below summarizes a promising approach used in Europe to improve the health and social service sector response to violence against older women.

Example 1 Raising Providers' Awareness of Violence Against Older Women in Europe

Across the European Union, efforts are under way to raise awareness among social services and health providers working with older women on violence and abuse in later life. The European Commission financed the two-part project "Breaking the Taboo" and "Breaking the Taboo II" with the aim of providing required support services to survivors of violence. Central to this initiative was capacity building for professionals working with older adults to recognize violence against older women and to provide required support services to these survivors (Edthofer & Bammer, 2010). Through "Breaking the Taboo," nurses, home health aides, social workers, and physicians received targeted training on how to detect violence against older women in the home by their families. "Breaking the Taboo II" utilized a train-the-trainer approach to develop providers' skills in recognizing and responding to violence against older women within the family. This training targeted public health and social service professionals, as well as advocates in mainstream domestic violence shelters. It included peer-led workshops, and an online curriculum available in Bulgarian, Dutch, English, German, Portuguese, and Slovenian.

An evaluation of the first phase found that the project made the issue of violence against older women visible and charted a path forward for coordinated action across European health and social service systems. These findings underscore the critical role healthcare professionals play in the detection of violence against older women, particularly as they are often the only source of outside contact for older persons living at home with their families. This evaluation revealed that many health and social service organizations working with older adults do not have designated procedures for reporting abuse and referring to support services. As a result, the second phase trained organizations in developing protocols for identifying older survivors and providing assistance; this included additional capacity building for health professionals to engage in strengthening networks among community victim service providers (Edthofer & Bammer, 2010; UN DESA, 2013b).

Solutions can also be community based, targeting the root norms that perpetuate ageism, sexism, and other forms of discrimination. This may involve engaging community members, notably religious and other leaders, to stimulate change in the prevailing attitudes that contribute to the maltreatment of older women, such as unreported violence or accusations of witchcraft fueled by superstitions and traditional beliefs. The example below presents a successful model from Tanzania.

Example 2 Involving Communities to Change Social Norms and Combat Gender-Based Ageism in Tanzania

In the Sukumaland region of Tanzania, older women joined forces with local spiritual leaders and traditional healers to conduct community workshops to prevent violence targeting older women. This initiative aimed to break down stereotypes that contribute to violent accusations of witchcraft and killings of older women (UNFPA & HelpAge International, 2012).[11] From 2001 to 2007, the Sukumaland Older Women's Program sought to address the causes, symptoms, and effects of the murder and victimization of older women due to witchcraft allegations in a number of districts throughout Tanzania (Mengele, 2007). The program comprised four principal components: (1) social norm change; (2) empowerment for older women; (3) a series of structural and service-based interventions; and (4) capacity building. The first component challenged harmful beliefs and practices by winning understanding and support in the communities (both allies and potential opponents) and organizing and conducting a series of sensitization meetings at the very local level. The second component increased older women's access to basic rights by providing opportunities for community-based discussions on discriminatory gendered social norms, such as sexism and ageism, jointly facilitated by volunteer committees comprised of older persons to support one another as a means of self-advocacy, and partner staff from the local affiliate of HelpAge International in Tanzania. The interventions under component three included an intentional focus on those problems identified as key correlates to witchcraft allegations, including improved shelter, greater community awareness of the risks for HIV/AIDS, and fuel-efficient stoves that do not irritate eyes and lungs (as a means to ease prejudice toward older women experiencing redness in the eyes as a result of smoke from cooking and accused of appearing "possessed"). The fourth and final component offered capacity building for a wide range of community stakeholders. As a result of these trainings, traditional healers agreed to ban the practice of divination, which was responsible for a large proportion of witchcraft allegations. The result was a significant reduction in the number of murders of suspected "witches" in the region, which had previously totaled close to 100 per year (Mengele, 2007).

Recognizing the intersecting vulnerabilities of older women is a critical step toward providing protection from violence and abuse. The socioeconomic vulnerability underscored above is a central risk factor for economic violence in particular. A promising solution is to ensure older women's property rights, including their ability to own, use, occupy, transfer, sell, inherit, and distribute land and other

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[11] Police reports from eight regions in Tanzania between 2004 and 2009 show that 2585 older women were killed after being accused of witchcraft.

property. This may eliminate traditional widowhood practices that deprive women of property and inheritance rights and in some cases can lead to their death or forced marriage.[12] The example below illustrates how a program in Vietnam had effectively identified and addressed these challenges for older women.

Example 3 Protecting the Land and Property Rights of Older Women in Vietnam

Vietnam's centuries-old tradition of men receiving preference in land ownership and inheritance is not supported by national laws. Rather, the legal framework affirms women's equal right to own, inherit, and pass on land. Yet in practice women own a very small proportion of land—only 14% in 2014 (Sproule, Kieran, Quisumbing, & Doss, 2015). Gaps in awareness and in the implementation of national laws have limited the effect of these positive policy changes for rural women, and emerging evidence suggests that this may be a particular challenge for older women. *Land Access for Women (LAW)*: Vietnam is a 2-year pilot intervention that aims to close these gaps. Implemented by the Institute for Social Development Studies and the International Center for Research on Women, with funding from the United States Agency for International Development, the centerpiece of the program is the mobilization and training of 60 community volunteers for gender equality advocacy (CVGEAs) to raise awareness of land rights and provide legal counseling in two provinces.

In 2015, CVGEAs advised 1800 women, nearly half (44%) of whom were 50 or older. Project monitoring data show that the most common concerns raised by the older women stemmed from land boundary disputes and loans. Requests from younger women, on the other hand, centered more on domestic violence and inheritance rights (Alvarado et al., 2015). Among the oldest women in the program (those aged 60 and above), more than 21% sought counsel from CVGEAs on "land grabbing"/boundary matters, another 18% on inheritance rights, 9% on obtaining land use certificates, and 7% on writing a will. Success stories from this project illustrate the life-changing effects of the LAW program for older women, demonstrating that programs like this can help women—especially widows and older women who are often at greatest risk of "land grabbing" and property rights violations—to claim their rights. They can also provide the impetus for erasing long-standing gender inequalities, as well as promoting economic stability and empowerment, for millions of women around the globe.

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[12] Recommendation adapted from HelpAge International. A new convention on the rights of older people: A concrete proposal. Retrieved from http://www.helpage.org/download/5591235a62a92

Conclusion

Global development discourse and action on gender equality and women's empowerment have centered on women and girls of reproductive age, leaving older women in the shadows of the critical dialogue that informs development programs and investments, and depriving them of the benefits that are derived from them. Fortunately, the new era of global development policies ushered in with the Sustainable Development Goals (SDGs) shows promise for greater inclusion of older women in the movement to end VAW. Through a commitment to "leave no one behind," the SDGs include indicators to measure the prevalence of intimate partner violence and non-partner sexual violence among women aged 15 and older, thus intentionally including experiences of women beyond the age of 49. Without measuring this violence as a distinct development challenge, we cannot understand the full magnitude of its effects on the individual women who experience it, or on their families and communities.

It is time for the global community to capitalize on the momentum offered by the SDGs by (1) investing in expanded data collection and building the capacity of national statistical commissions to collect data on women older than 49; (2) including older women's voices and needs in national plans of action on VAWG and strategies to remedy gender disparities; and (3) training providers to break down ageist biases that can impede older survivors' access to essential services.

These three strategies are reflected in emerging innovative practices that promote social inclusion and essential services for older women, including resources for gender-based violence and sexual and reproductive health. These promising approaches offer learnings about how to dismantle the social and gendered norms that render older women invisible, ensure their protection in formal and informal legal systems, and also recognize the valuable contributions and continued capacity of older people to be change agents in their communities and productive members of society. Such lessons, as illustrated by the examples above, can be adapted and applied to a wide range of contexts and across development sectors.

Since the adoption of the 2030 Agenda, increased attention by governments and multilateral organizations to inclusive development policy that underscores the impact of lifetime gender disparities is steadily emerging. Reinforcing the principles reflected in the projects discussed in this chapter, several policy initiatives from the US Department of State and United Nations have been recently launched. The first-ever State Department Strategy for Women's Economic Empowerment, launched in June 2016, includes more than nine separate references to older women, aging, or life course dimensions of financial security, and is prefaced by the statement: Increasing women's economic participation *throughout their lives* (emphasis added) strengthens prospects for economic growth, and benefits families, communities, and countries …[and] enhancing women's economic security and inclusion is key to breaking the cycle of poverty for families and *preventing financial vulnerability in older age* (emphasis added) (US Department of State, 2016a). Similarly, the updated US Agency for International Development (USAID) and State Department

Strategy for Preventing and Responding to Gender-Based Violence Globally include an unprecedented definition of GBV that is intersectional, and articulates violence as a human rights violation experienced by women of all ages, with a mention of the particular vulnerability of older women, and widows (US Department of State, 2016b).

At the multilateral level, the United Nations Development Program (UNDP) has recently committed to taking stock of the reach of its programs across 170 countries to understand how they are benefiting older women, issuing a new policy brief on gender, aging, and SDGs and advocating for greater attention to GBV among older populations (Clark, 2016; UNDP, 2016). While this new policy guidance can be a powerful tool for promoting continued engagement of women as they age, success of these initiatives depends on raising awareness about older women's contributions and also ensuring more equitable mobilization of resources across all generations of women and girls as drivers of health and development outcomes.

Discussion Questions

1. How is old age defined in your culture? Is the definition the same for men and women?
2. How do data gaps affect development policy? How is that evident in the case of programs, laws, and policies regarding violence against older women?
3. How do multiple social norms and inequalities intersect to make older women vulnerable to violence and discrimination?
4. How do the intervention examples provided here address social norms? Would such an approach work in your community?
5. What policy recommendations would you make to improve efforts to prevent and respond to violence against older women?

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Suggested Reading

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Chapter 16
Women's Exposure to Sexual Violence Across the Life Cycle: An African Perspective

Lillian Artz, Talia Meer, and Alex Müller

Introduction

Women's health services have by and large been addressed through conventional reproductive health programs. We are, however, beginning to witness new approaches that extend beyond women's reproductive role to encompass women's health at every stage and in every aspect of their lives. This more holistic approach to women's health means that the determinants and responses to women's health consider not only strict biological or physiological concerns, but also the social, environmental, economic, and cultural factors that affect their health status (CHETNA, 2016). The Centre for Health Education, Training and Nutrition Awareness (CHETNA), a women's health organization in India, provides a helpful illustration of the range of health-related issues and discriminatory practices that affect women over the life course (Fig. 16.1).

Here CHETNA (2016) identifies gendered practices and experiences over the course of a woman's lifetime, from preconception to late adulthood. There are, however, other forms of sexual and gender-based violence (SGBV) and discrimination to be conscious of, including harmful initiation rites (for instance, female genital cutting), rape and other forms of sexual abuse and traumatic fistula (induced by particularly brutal sexual assaults), commercial sexual exploitation, economically coerced sex, early marriage, honor crimes, intimate partner (and general family) violence, intimate partner homicide, coerced pregnancy, sexual abuse in the workplace, sexual harassment, and the targeted abuse of women with disabilities, widows and the elderly, lesbians, and transgender people. While these harms against women are indeed experienced globally, they are arguably more pronounced in

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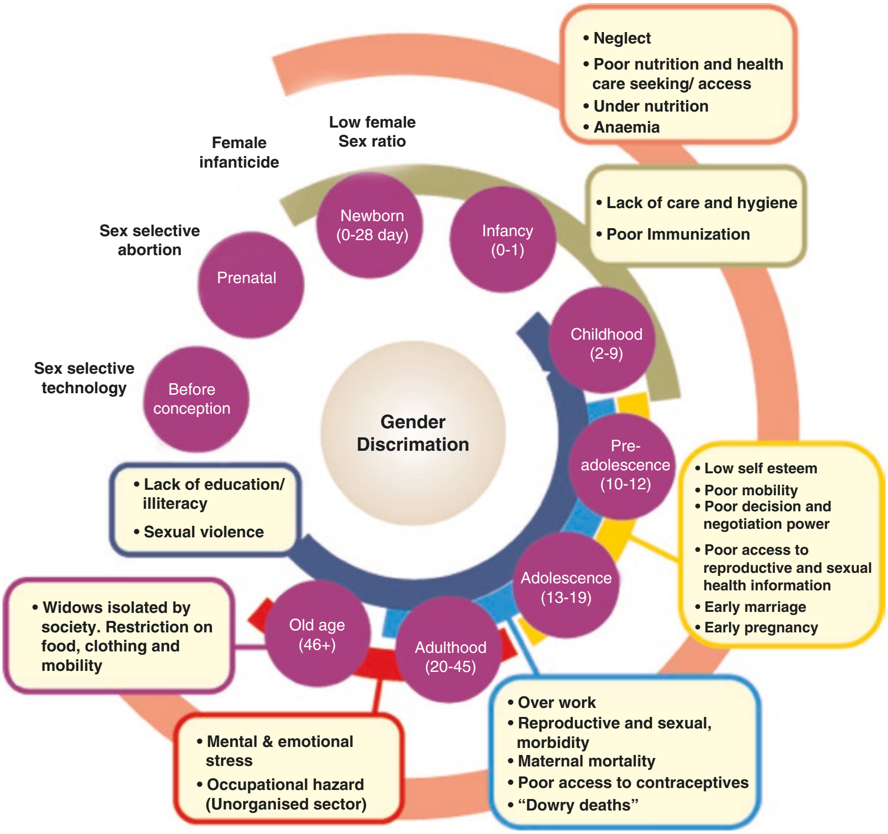

Fig. 16.1 Life course approach to sexual and other forms of gender-based violence

developing contexts, where SGBV remains unchecked due to unchallenged discriminatory laws and customs, the lack of protective legal frameworks, or as a result of the lack of implementation of existing ones.

In this chapter we explore exposure to sexual and other forms of gender-based violence (SGBV) over the course of a lifetime, delineating the life course into particular age cohorts: children aged 0–12, adolescents aged 13–18, adults aged 19–59 and older adults aged 60+. While we have chosen to use the term "older adults" for those 60 and older, this group is clearly heterogeneous. Among global north countries, and the middle classes of the global south, people tend to live longer, are healthier, and tend to be more mobile well into their 60s and 70s. As a result, an alternative to classifications based on fixed chronological age is emerging in the field of population aging that considers other characteristics including "remaining life expectancy, health, disabilities rates, cognitive functioning, and eligibility for a full public pension are also important for understanding population aging" (Sanderson & Scherbov, 2013, p. 1). However, these various factors that shape individual aging are dependent on socio-economic context. In the global south, life expectancy is lower, and the effects of poverty, limited access to quality health care, and exposure to violence all impact on aging (Dhemba & Dhemba, 2015).

Concerns about the appropriateness of chronological age categories are not limited to older populations. We therefore use age categories somewhat reluctantly, being mindful of the important critique that lifetime experiences of SGBV cannot be isolated into distinct age or developmental cohorts and that exposure to, and certainly the impact of, these forms of violence is cumulative, co-occurring, and enduring. We make use of age cohorts in this review because empirical studies on the prevalence and nature of SGBV predominately—and explicitly—use these demographic "identities" as central inclusion criteria or as control variables. We are cognizant, however, that emerging literature on the life course of women and their exposure to SGBV needs to advance a theoretical framework that views the intersections and co-occurrences of violence across the lifetime as the centerpiece of analysis, rather than age.

We begin by briefly framing the international, regional (African), and domestic (South African) legal and policy contexts which shape approaches to SGBV prevention, and, to some extent, inform the age categories set out above; these frameworks conceptualize what constitutes a "sexual violation," and offer different degrees of protection, based on these age demographics. While our domestic and empirical focus is on South Africa, our analysis has some application to other regions on the African continent, particularly Southern and East Africa. We also identify specific vulnerabilities affecting marginalized and minority groups, which has had scant attention in mainstream women's health literature on the continent.

Women's Health Across the Life Course: The Global Legal and Policy Environment

International health organizations such as the World Health Organization (WHO) have clearly indicated that the focus of women's health policy-making, interventions, and treatment responses requires a dedicated shift from the traditional narrow focus on reproductive health and the childbearing years to a more holistic human rights-based life cycle approach that considers the social, economic, cultural, and biological factors which influence woman's health from prenatal stage to late adulthood. These international policy-change efforts have been reinforced—and in some instances have been activated—by country-level ratifications of international conventions and declarations that frame global norms on the prevention of, and responses to, SGBV and discrimination in all spheres of life. One of the first, or at least most persuasive of these, was the *UN Convention on the Elimination of All Forms of Discrimination against Women* ("the Women's Convention"), adopted in 1979. This was later reinforced by General Recommendation No 19 (1992) by the Committee on the Elimination of Discrimination against Women, which connected SGBV and women's health, and made explicit reference to the prevention of violence against women and included the need to institute preventive and protective measures that unambiguously addressed SGBV (paras 24(a) and 24(b)).

The 1994 *International Conference on Population and Development* (ICPD) defined a nuanced rights-based approach to sexual and reproductive health (United Nations, 1994). The United Nations Fourth World Conference on Women, in 1995, endorsed a *Platform for Action* which reiterates the agreements reached at the 1994 IPCD, establishing five strategic objectives for further actions, and attempted to redirect health policy by taking on a holistic rights-based life cycle approach to women's health. A 10-year review showed that multiple challenges to reforming women's health policy still exist, and include insufficient statistical data, lack of expertise and resources for research, the trend to limit women's health policies to reproductive roles, insufficient funding, and socio-cultural attitudes (United Nations Economic and Social Council, 2000).

The African Legal Context and Policy Environment

There are several important regional instruments, such as the South African Development Community's *Protocol on Gender and Development* (the "SADC Protocol," South African Development Community, 1997) and the *Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa* (the "Maputo Protocol," South African Development Community, 2005), that have emerged as more contextually relevant instruments for the protection of women within the African context. The SADC Protocol has been the most plainspoken on the continent in imposing duties on states to eradicate SGBV at legislative, judicial, and service delivery levels. The Maputo Protocol, on the other hand, marked a milestone in the protection and promotion of women's rights in Africa by explicitly setting out the reproductive rights of women to medical abortion in cases of rape or incest or when pregnancy endangers the health or life of the mother (Art 14(c)) as well as the rights to control of fertility (Art. 14(1)(a)); the right to decide whether to have children, the number of children and the spacing of children (Art 14(1)(b)); the right to choose any method of contraception (Art. 14(1)(c)); and the right to self-protection and to be protected against sexually transmitted infections, including HIV/AIDS (Art. 14(1)(d)). In another first, the Maputo Protocol unequivocally called for the legal prohibition of female genital cutting (Art. 5(a)) and the prohibition of the abuse of women in advertising and pornography (Art. 13(m)). Like the SADC Protocol, it too makes specific reference to the prohibition of all forms of violence against women including unwanted or forced sex whether the violence takes place in private or public Art. 2(a).

The South African Legal Context and Policy Environment

Sexual offenses are governed in South Africa by four primary pieces of legislation: (1) the *Criminal Law [Sexual Offenses and Related Matters] Amendment Act No. 32 of 2007* (the "Sexual Offenses Act"), (2) the *Children's Act No. 38 of 2005,* (3) the

Children's Amendment Act No 41 of 2007, and (4) in the case of a sexual offense within a domestic relationship, the *Domestic Violence Act No. 116 of 1998*. These Acts provide detailed definitions of what legally constitutes rape and a range of other SGBV offenses, including a distinct range of offenses against adults, those with "mental disabilities," and children. Specifically, the Sexual Offences Act defines the age of consent to sex as 16[1], and provides clear statutory definitions of almost 60 new sexual offenses, with acts of rape separated into acts of *penetrative* (rape) and *non penetrative* (sexual assault) sexual offenses. Health-related responses can be found in the same Act, but largely focus on the provision of post-exposure prophylaxis (PEP) for rape victims and the compulsory HIV testing of alleged sex offenders, leaving out other crucial health and mental health treatment and support services (Section 27 and 28 of Chap. 5 of the "Sexual Offenses Act").

The only health-related policy document that contains any explicit commitment to providing "an integrated service using a life course approach" to women's health in South Africa is the *Strategic Plan for Maternal, Newborn, Child and Women's Health* (MNCWH) *and Nutrition in South Africa* (Department of Health, 2012), which acknowledges that socioeconomic conditions have a significant role to play in determining the health of women throughout their life course:

> In general those districts with the poorest socioeconomic indicators also have the poorest health status indicators and the highest maternal, new-born and child mortality rates. These districts often also have poor health coverage indicators. Improving socioeconomic conditions and improving coverage with priority MNCWH & Nutrition interventions can therefore be expected to reduce maternal, neonatal and child mortality. Empowering women to achieve greater gender equity is essential for promoting the health of women and children (p. 30).

Child Sexual Abuse and Maltreatment (0–12 Years of Age)

Every year in South Africa between 18,000 and 20,000 child sexual abuse (CSA) cases are reported to the police. In a recent 2013/2014 annual report of the South African Police Service (SAPS) it was reported that 18,524 cases of CSA were brought to the attention of the police (SAPS Strategic Management, 2014).This amounts to 51 *reported* cases of CSA every day. The SAPS claim that this rate dropped by 52.62% in the 2014/15 year, but there is deep skepticism of the plausibility of this drastic decline in reporting rates in such a short period of time (SAPS Strategic Management, 2015). Notwithstanding these disputed figures, it is commonly accepted that official police statistics are in any case seriously under-representative of

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[1] Until 2015, any consensual sexual contact between two adolescents aged 12–16 was also criminalized as statutory rape under the Sexual Offences Act. However, this was changed after a constitutional court judgment found that criminalizing age-appropriate, consensual sexual activity was not in the best interest of the adolescents involved. As a result, sexual activity between consenting adolescents aged 12–16, with an age gap of less than 2 years between partners, is now allowed. Any sexual activity with a child under the age of 12 is criminalized.

the actual prevalence of children's exposure to sexual violence. Prevalence studies have attempted to capture more accurate rates of CSA, but even these studies acknowledge critical levels of under-reporting and methodological challenges in securing national prevalence data. There are many reasons for this. Firstly, prevalence studies are often site specific and population specific (i.e., they take place in particular geographical areas or through particular institutions or agencies) and are therefore not nationally representative. The second and more obvious challenge arises from the ethical and methodological difficulties of conducting population studies on minors, on the subject of sexual abuse exposure, with the consent of legal guardians. Establishing accurate prevalence rates is also complicated by a wide range of other factors, such as the following: (1) preverbal children are unable to communicate abuse; (2) children are often victimized by those responsible for their care or for reporting suspected abuse; (3) children that report abuse, but are not believed or are thought to be exaggerating; (4) intimidation or threats by abusers; (5) nonabusive parents that are reluctant to report for fear of family impact of legal interventions, being accused of complacency, or the child being removed from the household; (6) the "threat" of losing household income if the accused is the main breadwinner; (7) nonabusive parents being made more vulnerable to domestic violence if sexual abuse is reported; or (8) children feeling ashamed or guilty about the abuse.

A national prevalence study in South Africa which involved both interviews and self-administered questionnaires with 9717 adolescents (ages 15–17), on lifetime exposure to sexual abuse and maltreatment, found that one in three young people (35.4%) had experienced some form of sexual abuse during their lifetime (Artz et al., 2016), commencing from the age of one year. The average age of first *exposure* to some form of sexual abuse was four years for girls and six years for boys. Risk factors included separation from biological parents, harsh parenting, presence of a step parent, frequent exposure to IPV, parental substance abuse, "sleeping density" in the home, and those who had parents with some form of mental illness or hospitalization due to illness. The prevalence data are relatively comparable to other regions on the continent. Artz et al. (2016) found that lifetime exposures to abuse are similar to other African contexts that have conducted national baseline and prevalence studies on CSA. For example, a study from Zimbabwe (2011) reported that 32.5% of females and 8.9% of males experienced sexual violence prior to age 18 (ZIMSTAT, 2013). Females also reported to be more likely to experience child sexual abuse in Kenya. In a 2010 national survey, the prevalence of females who experienced sexual abuse before age 18 was 31.9% and for males it was 17.5% (UNCF Kenya et al., 2012). It was also reported in this Kenyan study that sexual violence rarely occurred in isolation (only 5.5% of females and 0.9% of males' experienced sexual violence in childhood without reporting physical or emotional violence). A national household survey in Tanzania reported that 27.9% of females and 13.4% of males experienced at least one incident of sexual violence before the age of 18 (UNICEF Tanzania et al., 2011). This study further reported that more than eight in ten females and males experienced sexual violence prior to age 18, and also experienced physical violence prior to age 18.

In the health sector, practitioners are generally aware of their legal duties as they pertain to suspected child sexual abuse cases. However, in low-resource contexts within Africa, health care practitioners are generally reluctant to "screen and intervene" unless there has been a disclosure of a suspicion of child abuse, if injuries that the child presents with are clear indicators of abuse or if there are available child abuse support services in the area once the child is examined for abuse. Compounding these reporting barriers for children is the fact that access to treatment, support services, and investigative mechanisms is almost entirely dependent on a caregiver's ability to identify and subsequently report sexual abuse. This is complicated by abuse symptoms that present as seemingly innocuous general health complaints, such as abdominal pain or gastric complaints, learning difficulties or adjustment issues, unexplained injuries, fear, anxiety, aggression, self-destructive behavior, or sexually inappropriate behavior (Artz, 2013a; Richter et al., 2014). Despite the high levels of sexual abuse against children, the identification and treatment of indicated physiological and psychological responses to sexual abuse are regrettably underdeveloped.

Experiences and Prevalence of Sexual Abuse and Sexual Offenses in Adolescence (12–18 Years of Age)

Research shows that in adolescent sexual relationships, male coercion and violence are widespread (Harrison, 2008; Varga, 2003; Wood & Jewkes, 1997). While the law defines rape comprehensively in South Africa, including sexual violence from an intimate partner or family member, adolescents themselves may have a different interpretation of the term "rape." Research conducted in public schools in Cape Town found that among adolescents, the term "rape" is often reserved to refer specifically to the rapes by strangers and/or groups of men (King et al., 2004). This has clear implications for the under-reporting of rape by intimate partners or other perpetrators known to adolescents. Based on cases of sexual violence that are reported, data show that of all age groups, girls between the ages of 12 and 17 are at the highest risk for being raped (King et al., 2004; Petersen, Bhana, & McKay, 2005). Less than 30% of these rapes are perpetrated by strangers, where in the majority of cases, the adolescent knows the perpetrator, who is either a relative (in 14% of cases) or a friend, acquaintance, or neighbor (in over 40% of cases) (Mathews et al., 2015). Adolescence is thus the key risk age for first experiencing sexual violence. Surveys of adolescent sexuality have found consistently that a high proportion of young women describe their first sexual experience to be forced (Buga, Amoko, & Ncayiyana, 1996; Jewkes, Vundule, Maforah, & Jordaan, 2001). A recent cross-sectional, national prevalence study showed that the average age of a first sexually abusive *experience* is 14 years for girls and 15 years for boys, and that exposure to sexual abuse occurs over the course of a lifetime (*see* Table 16.1; Artz et al., 2016). Within this study, forms of abuse varied significantly between adolescent boys and

Table 16.1 Lifetime prevalence of sexual abuse from survey of schools

Experience of abuse	No. of times	Percentage (%)
Sexual abuse by known adult	1	59.4
	2	18.8
	3	11.5
	4+	10.3
Sexual abuse by unknown adult	1	91.4
	2	5.7
	3	2.9
	4+	0
Sexual abuse by a child or an adolescent	1	54.0
	2	24.1
	3	11.5
	4+	10.3
Forced sexual intercourse (actual or attempted)	1	72.9
	2	15.5
	3	4.7
	4+	6.9
Sexual harassment (verbal or written)	1	54.2
	2	18.8
	3	7.3
	4+	19.7
Sexual experience with an adult	1	39.1
	2	18.9
	3	13.9
	4+	28.1

Source: Artz et al. (2016). *The Optimus Study on Child Abuse, Violence and Neglect in South Africa*, p. 37

adolescent girls, where girls were more likely to experience *direct* or forced sexual intercourse/offences, while boys were more likely to experience *exposure-related* sexual offenses such as being forced to watch pornography, touch someone's genitalia or watch sexual acts between others. More than 15% of adolescents had had sexual experiences with someone over the age of 18.

These findings illustrate that while sexual abuse is slightly more likely to occur once in a young person's lifetime, there is a strong probability that it occurs more than once (40% of the time), with one in ten children experiencing sexual abuse by a known adult four or more times, by age of 17. Sexual abuse by an unknown adult, on the other hand, largely occurs only once in a young person's lifetime.

In South Africa, sexual violence also dramatically increases adolescents' vulnerability to HIV and other sexually transmitted infections. King et al. (2004) highlight the fact that adolescent girls have much higher levels of HIV prevalence, compared to adolescent boys, which serves as an indication of the impact of sexual assault.

Further, sexual violence increases adolescent girls' risk for pregnancy (King et al., 2004). In a study in a township of Cape Town, 30% of pregnant teenagers said that their first sexual encounter had been non consensual (Jewkes et al., 2001). These risks are significant in that they can hamper adolescents' access to and success in secondary education, with pregnant adolescent girls being less likely to finish secondary school because of child care responsibilities, social stigma of teenage pregnancy, and discriminatory school policies that do not allow pregnant learners to continue attending school.

System Responses: Age- and Vulnerability-Appropriate Approaches

While a number of youth-friendly clinics exist in the South African public health sector, they are unlikely to provide specialized medico-legal services. Similarly, medico-legal clinics, called *Thuthuzela Care Centres*[2] (TCCs), which offer specialized medico-legal services to survivors of sexual violence, do not have adolescent-specific programs or services. As a result of this, adolescents are sometimes reluctant to seek access services in the "wrong" place. Existing literature highlights the reasons for their concerns: many adolescents encounter barriers when accessing health services, especially when linked to sexual and reproductive health care and anticipate judgmental and moralized service provision from healthcare providers—based either on their own previous experience or through word of mouth from other adolescents (Wood & Jewkes, 2006). Research with healthcare providers shows that their services are discretionary, based on their own morals and values, and on their judgment of an adolescent client as "worthy" of assistance or not (Müller, Röhrs, Hoffman-Wanderer, & Moult, 2016). Significantly, healthcare providers in "general" clinics were often unclear about the legal framework, including provisions around sexual violence (Müller et al., 2016). While adolescent survivors of sexual assault are likely to be deemed "worthy" of accessing services, this might not apply to everyone. For example, anecdotal evidence suggests that adolescents from marginalized groups (for example, sexual and gender minority adolescents) experience secondary victimization in healthcare provision when accessing services after sexual assault (Sanger, 2014; Smith, 2015).

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[2] TCCs are typically located within state hospital settings and offer a range of services to victims of sexual offences, including acute or emergency medical care, medico-legal examinations of victims, post-exposure prophylaxis (or "PEP") for the prevention of HIV, treatment for sexually transmitted infections, emergency contraception and crisis counseling, and referrals to state and non governmental services.

Experiences and Prevalence of Sexual Violence in Adulthood (18+ Years of Age)

There are no recent nationally representative data that specifically describe the prevalence of rape and other forms of SGBV in adult women in South Africa[3], or other African countries for that matter, although we know more about the experiences of adults who experience sexual assault than any other age demographic. For the moment, national police crime statistics are the only source of national prevalence data, where women aged 18 and older were reported to be the victims of 29,928 sexual assault cases across 2012/2013 (SAPS Strategic Management, 2013). Police statistics from September 2015 show that in the previous year 2014/2015, 53,617 sexual offences were officially reported to the South African Police Services (SAPS), or 147 cases a day. Approximately 60% of these are committed against adult women. Gang rape is also relatively common in South Africa. In one study, 20% of men admitted to having been involved in a gang rape incident, either as perpetrators, supporters, or witnesses (Jewkes, Nduna, Shai, & Dunkle, 2012; Jewkes, Sikweyiya, Morrell, & Dunkle, 2009). As with children, it is difficult to accurately determine the prevalence rate of sexual offenses against women because of the high rate of under-reporting in the country. One provincial study indicates that as few as 1 in 25 women report rape to the police (Machisa, Jewkes, Morna, & Rama, 2011), but more conservative estimates are that 1 in 9 sexual offenses are reported to the police in South Africa (Jewkes & Abrahams, 2002).

One reason for under-reporting is that sexual violence most commonly occurs within intimate partner relationships and families, or through non violent coercion such as blackmail or threats, circumstances where the survivor is likely to feel the least confident about reporting (Jewkes & Abrahams, 2002). These circumstances not only deter reporting but also make it difficult to elicit accurate responses about prevalence in quantitative research with adult women. For example, Jewkes and Abrahams (2002) explain that poor recall about sexual violence may actually be an issue of identification of SGBV and "reflect the fact that most women have such low expectations of genuine sexual negotiation in relationships that being forced to have sex when men (husbands, boyfriends, or would-be lovers) want it, or provide it as a unit of exchange, is seen as 'normal'" (p. 1232).

Despite widespread acceptance that sexual intimate partner violence (IPV) is pervasive, in one study it was, unsurprisingly, the least reported form of SGBV, up to 18% in one South African province (Gauteng) reporting IPV but only 6.9% in another (Limpopo) (Gender Links, 2015). In a sample of men, the two most noted motivators of intimate partner rape were sexual refusal by the survivor and her perceived challenge to the perpetrator's authority (Abrahams, Jewkes, Hoffman, & Laubsher, 2004). Abrahams, Mathews, Martin, Lombard, and Jewkes (2013) found the rate of intimate partner rape homicide to be 0.6 in 100,000 in 2009. As relation-

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[3] The last national—but not nationally "representative" study—was conducted in 1999. *See* Bollen, S., Artz, L., Vetten, L., and Louw, A. (eds.) (1999). *Violence against Women in Metropolitan South Africa*. Pretoria: Institute for Security Studies.

ship power inequity and IPV increase the risk of incident HIV infection, the actual death toll of IPV is likely much higher in young South African women (Jewkes, Dunkle, Nduna, & Shai, 2010).

The international SGBV literature has long established a link between contemporary victimization and historical exposure to or experiences with violence (WHO, 2005). Given that a considerable proportion, indeed likely the majority, of sexual violence occurs within existing relationships, it is unsurprising that research evidence indicates that women who were previously exposed to violence, in childhood homes or other contexts, are at greater risk for future victimization. For example, experiences of childhood sexual assault are significantly associated with experience of IP and non-IP sexual violence in adulthood (Dunkle et al., 2004b; Machisa et al., 2011). Further, experiencing frequent childhood beatings and observing maternal IPV victimization place women at greater risk for later experience of IPV and non-IP sexual violence (Jewkes, Levin, & Penn-Kekana, 2002; Machisa et al., 2011). The reasons suggested for this are that women who were raised in a violent home are more likely to normalize violence and thus have a greater tolerance for IPV, and that women who are beaten during childhood often have lower self-esteem, which makes them less likely to leave a violent relationship (Jewkes et al., 2002). International findings also suggest a relationship between childhood sexual abuse and greater consensual adolescent and adult sex, which can in turn increase the risk for sexual assault, and childhood abuse and substance use, which increases vulnerability to sexual risk-taking behavior and future victimization (Arata, 2002).

South African studies also note the impact of substance use in increasing a woman's risk for sexual violence, particularly within the context of IPV (Abrahams, Jewkes, Laubscher, & Hoffman, 2006; Dunkle et al., 2004a; Mathews, Abrahams, Jewkes, Martin, & Lombard, 2009; Watt et al., 2012). Research has found that hazardous alcohol consumption was associated with experience of physical and sexual IPV. However, a limitation of the research on substance use and GBV is that it is unable to identify whether substance use precedes or follows victimization. Reasons offered for the relationship between alcohol and GBV include (a) the disinhibiting effect of alcohol causing conflict to become violent; (b) alcohol use increases a woman's vulnerability; (c) men perceive women who drink alcohol to be more likely to be unfaithful and IPV is used as a means of punishment; and (d) women's substance use is used to cope with the abuse and associated trauma (Abrahams et al., 2006; Jewkes et al., 2002; Mathews et al., 2009). The latter suggests that substance use is an outcome of IPV or that a possible bidirectional relationship exists between IPV and substance use.

Sexual violence by someone other than a partner was reported as high as 12% in one study, but experienced by only 5% of women in the remaining provinces (Machisa et al., 2011). Reaffirming concerns about under-reporting in general, men reported perpetrating non-IP rape more frequently than women reported experiencing it. Interestingly, a number of studies reported higher rates of non-IP sexual violence than sexual IPV (Jewkes, Sikweyiya, Morrell, & Dunkle, 2011; Jewkes et al., 2012). Abrahams et al. (2013) found the rate of non-intimate partner rape homicide in 2009 to be alarmingly high at 1.2 in 100,000.

Low socioeconomic status, which in South Africa is strongly associated with being a person of color, is also associated with sexual violence. Women with no post-primary education (Jewkes et al., 2002), and unemployed women (Hoque, Hoque, & Kader, 2009), were significantly more likely to have experienced all forms of IPV, including rape. Poor education can also increase the risk for sexual assault through increasing the likelihood of engagement in sex work, or other forms of transactional sex. A number of South African studies point to the vulnerability of sex workers (and indeed the homeless) to high levels of emotional, physical, and sexual violence, including from partners, clients, and the general public and sometimes hotel managers, security guards, and the police (Stadler & Delany, 2006; Wojcicki & Malala, 2001). Some sex workers describe abusing substances to help them cope with the fear of future victimization and the stressors of their jobs (Wechsberg, Luseno, & Lam, 2005), which in turn can increase their vulnerability to further abuse. Some reported abuse or being forced to pay bribes to police when they attempted to report instances of sexual violence (Wojcicki & Malala, 2001). As a result, participants were reluctant to report experiences of sexual violence.

Experiences and Prevalence of Sexual Violence Among Older Adult Women (60+ Years of Age)

In South Africa, population estimates from 2016 approximate that 8.0% (4.42 million) of the South African population is of 60 years or older; about 60% of this group are female and the average female life expectancy is 64.3 years (Statistics South Africa, 2016). While the *Older Persons Act* (No. 13 of 2006) recognizes the vulnerability of older persons, and provides a framework dedicated to upholding and protecting the safety and security of older persons and actively addresses elder abuse in South Africa, including the mandatory reporting of abuse (Mathiso, 2011), there is little other information about the status of older people in South Africa. Data on national violence exposure prevalence rates are lacking. Two small-scale studies give some insight into prevalence: Bigala and Ayiga (2014) found that 8.4% of their female sample experienced sexual abuse, and in an unpublished study of elder clinic attendees in a Durban Hospital, Phakathi (2011) found that 11.3% were sexually assaulted.

A small number of studies have investigated the living conditions and experiences of older persons. This reveals that in addition to the pervasive levels of IPV in South Africa, elderly women may be at a particular risk because of “older women are at particular risk of abuse or violence through physical weakness, and a lack of economic capacity to care for and protect themselves, and thus to resist violence” (Ferreira, 2005, p. 20). While poverty is pervasive across South Africa, older persons are disproportionately affected by it; due to HIV/AIDS they may have many dependents, and as, frequently, young adults go off to work or in search of work, older women may have little support or assistance (Ferreira, 2005; Mba, 2007). For example, of the 70 years and older age group, 54.7% of households are female headed, compared to the 37.5% of households that are female headed across the general population (Statistics South Africa, 2012).

In addition, cultural stigma, such as the belief that old women may be witches, and their blame for familial or community misfortune and the spread of HIV/AIDS in the community, makes elderly women vulnerable (Kohnert, 2003). As with children and women with disabilities, the belief held by some that sex with a sexually inactive person can cure HIV/AIDS has also been linked to some elder rapes (Frisoli, 2016, p. 17). Older persons may also be at risk from their children and extended families. There is evidence to suggest that sons and grandsons are frequently responsible for the sexual assault of older women (Keikelame & Ferreira, 2000; Kohnert, 2003). In an unpublished study of elder clinic attendees in a Durban Hospital, Phakathi (2011) found that 13.3% of participants reported that their relatives tried to rape them. The threat of rape is used to coerce money and assets from elderly women (Ferreira & Lindgren, 2008), to cure HIV according to the "celibate or virgin cure" myth, or when the son is assuming the role of his abusive father (Ward & Ernst, 2005). In one study, elder participants did not classify incestuous sexual intercourse as rape even if forced/non consensual, suggesting normalization of this kind of violence (Keikelame & Ferreira, 2000).

Compounding Vulnerabilities

There are numerous factors and intersections of these that make women particularly vulnerable to sexual violence over the course of a lifetime. We have already mentioned the particular vulnerabilities of children, of being in abusive relationships or households, living on or working from the street, substance abuse and of older adult women. There are other vulnerabilities that are important to mention, including girls and women who have physical or intellectual disabilities or mental illnesses, are orphaned or running child-headed households, and are refugees, undocumented migrants, or internally displaced persons due to conflict as well as sexual orientation and gender identity (Artz, 2013b). While we cannot address all these factors, we will speak in some more detail about sexual orientation and gender identities, disabilities, and migration to explicate the notion of compounding vulnerabilities.

Sexual Orientation and Gender Identity

There is scant literature on sexual orientation and gender identity as it pertains to youth specifically, but existing literature on sexual and gender minorities and violence does allow for some inferences to be made about vulnerabilities and responses to sexual violence for adolescents. Sexual violence targeted at sexual and gender-minority individuals is well documented in South Africa (Nath & Mthathi, 2011;

Sandfort, Baumann, Matebeni, Reddy, & Southey-Swartz, 2013). Confirming findings from adult sexual and gender-minority individuals, sexual violence against sexual and gender-minority adolescents diverges from sexual violence more broadly in that sexual minority adolescents are often targeted because of their (perceived) sexual orientation or gender identity (Graziano, 2004; Kowen & Davis, 2006). Such sexual orientation-motivated violence is often justified by adolescents' heteronormative environments, for example at school, where homophobic language and other, more subtle, forms of violence are tolerated, or condoned by teachers (Msibi, 2012; Sanger, 2014). In addition to sexual violence perpetrated by strangers, a recent quantitative study reported that sexual minority youth (69% of which were women) also experience higher levels of partner-perpetrated violence than heterosexual matched peers (Thurston et al., 2014).

Despite advanced legal protections in South Africa, sexual minority women (SMW) are especially at risk for non-IP sexual assault (Martin, Kelly, Turquet, & Ross, 2009; Nath & Mthathi, 2011; Sandfort et al., 2013). In a study of SMW, 31% reported forced sex, 14.9% by male perpetrators only, 6.6% female perpetrators only, and 9.6% by male and female perpetrators (Sandfort, Frazer, Matebeni, Reddy, & Southey-Swartz, 2015). Black SMW are at higher risk, and frequently perpetrators often made it clear that the motivation for sexual violence was to "cure" (perceived) lesbianism (Muller & Hughes, 2016). Race, class, and gender identity strongly shape such violence, with it mostly occurring in black townships, and targeting gender-non-conforming individuals, and masculine-presenting women (Nath & Mthathi, 2011). Violence against this group is associated with the perception that the SMW's sexuality, appearance, and behavior violate accepted religious, gender, and cultural norms (Nath & Mthathi, 2011), including the perceptions that homosexuality is "un-African" (Swarr, 2012).

There is also an increased likelihood of non reporting among this group (Nath & Mthathi, 2011). Reasons include a lack of information concerning rights and redress, a lack of support in reporting, previous negative experiences with prejudiced officials, and a lack of trust in the criminal justice system (Nath & Mthathi, 2011). There is also evidence of police discrimination and violence against SMW women (Martin et al., 2009; Nath & Mthathi, 2011). Similarly, SMW are often hesitant or avoidant of the healthcare system altogether due to a reluctance to disclose their minority status, a lack of providers' knowledge of minority health issues, structural limits on health insurance and healthcare decision-making, and negative past experiences with providers (Muller & Hughes, 2016). This can have severe consequences for post-rape treatment, especially where rape has resulted in STIs, HIV, or pregnancy.

Women and Disabilities

Although there are no South African population-level data, there is a consensus in the international literature that women with disabilities are particularly at risk for violence of all forms (Barger, Wacker, Macy, & Parish, 2009; Horner-Johnson &

Drum, 2006), and are exposed to violence for longer periods of time compared to those without disabilities (Ballan & Freyer, 2012; Plummer & Findley, 2012). As in other contexts (see, for example, Nosek, Foley, Hughes, and Howland, 2001), SGBV against women with disabilities seems to be normalized by pervasive stigmatization, including the general view that they are worthless, and the categorization of women with disabilities as asexual or hypersexual (Meer & Combrinck, 2015). In rural areas of South Africa, where disability is poorly understood, cultural myths and superstitions about disability being the product of cursing or demon possession can be widespread (Groce & Trasi, 2004; Meer & Combrinck, 2015). As a result there is pervasive acceptance of such violence and related under-reporting (Wazakili, Mpofu, & Devlieger, 2006). To compound the problem, limited knowledge about HIV and treatment and patriarchal indigenous healing practices have seen the spread of a "virgin cure" myth, which holds that HIV/AIDS can be cured by intercourse with a virgin. This puts children as well as people with intellectual disabilities at greater risk of rape due to the assumption that they are not sexually active (Groce & Trasi, 2004). While there is very little data, increased vulnerability to HIV through sexual assault has been highlighted (Hanass-Hancock, 2009; Wazakili et al., 2006). One small exploratory qualitative study concluded that women with disabilities are exceedingly vulnerable to GBV and face challenges in their access to support services and the criminal justice system following experiences of violence (Naidu, Haffejee, Vetten, & Hargreaves, 2005).

Migration, Immigration, and Displacement

Some have suggested that migrant women (including refugees and undocumented migrants) in South Africa may experience heightened IPV, including rape, because of a lack of social networks to buffer SGBV—including isolation of migrants in local South African communities—and the reluctance of involving formal justice mechanisms of violence for fear of arrest, deportation, or aggravating residency applications that are in process. Immigrant women may also sometimes be specifically targeted for sexual assault simply because they are foreign (Fuller, 2008). Targeted rape is a weapon of conflict and a form of xenophobia—a way of humiliating, shaming, and communicating power over migrant peoples (Fuller, 2008). There are also high rates of sexual violence against female migrants while crossing the border into South Africa (Naicker & Nair, 2000). Some immigrant women have also described being sexually harassed by government officials, with some individuals soliciting sexual favors in return for issuing documentation to enter or leave the country (Fuller, 2008). There is likely a high rate of under-reporting of xenophobia-related sexual violence. Their vulnerability is multitudinous, where reporting may not only result in a lack of—or an indifferent—response by criminal justice personnel, but may also result in xenophobic responses, forced relocation or deportation, and community stigma and aggression (particularly if a local resident is accused).

Conclusion

We briefly highlighted the prevalence and potential exposure to sexual violence over the life course of women in South Africa, but are mindful that these phenomena are experienced globally. The range of factors that collide, rally, and compound each other to make girls and women vulnerable to sexual violence over their lifetimes is difficult to portray succinctly or absolutely. We can provide risk and, to some extent, avoidance factors as well as set out resilience factors, but there are certain indefinable, labyrinthic social, structural, and environmental factors that cannot be easily categorized and charted when attempting to “come to grips with” women’s vulnerability to sexual violence. We can come some way towards comprehending the extent, nature, and consequences of this violence and that evidence of this pandemic has resulted both international and country-level legal reforms. While these are largely paper-based rights, we are beginning to see the public health sector engage more holistically with the health and mental health consequences of sexual violence, not to mention more specialized services for those who have experienced it.

Discussion Questions

1. Describe five key “moments” or phases in a woman’s life course that would make her vulnerable to sexual and gender-based violence (SGBV).
2. Discuss how various vulnerabilities to SGBV in South Africa might be similar or different to your country’s context.
3. Could the “life course analysis” be applied to other women’s health concerns? If yes, provide an example of how this framework could be used to understand these health concerns.
4. What are some of the key barriers for women in reporting SGBV?

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Part V
Beyond Reproduction

Chapter 17

Economic Empowerment to Improve Sexual and Reproductive Health Among Women and Girls

Elizabeth Reed, Brooke S. West, Marissa Salazar, and Ricardo Vera Monroy

Introduction

The economic empowerment of women and girls has become increasingly recognized as an important strategy to reduce gender inequities, including those related to health, between males and females across the globe. Gender inequities, largely attributable to societal norms promoting male dominance, involve the disproportionate allocation of resources, opportunities, and power in decision making that favors men over women. Gender inequities are experienced across all spheres of a woman's life, within their families, intimate partnerships, community, and worklife. The effects of gender inequities persist throughout all phases of women's lives and play a role in determining years of education, opportunities for career and employment, age at marriage, and number and timing of children (United Nation Sustainable Development, 2016). Consequently, gender inequities compromise the rights, safety, well-being, and health of women and girls.

Women and girls experience gender inequities across multiple contexts. Gender inequities are pervasive in access to education, employment, political inclusion, within the financial sector, as well as in the form of legal protections and authorizations, such as limitations for women to own or rent property. In most parts of the world, women are more likely to live in poverty, have lower rates of financial

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inclusion and employment, and earn less income compared to males (Razavi & Turquet, 2016; UNICEF Development, 2010). Globally, 75% of men compared to 50% of women of working age (15 and older) are in the labor force (UN Women, 2015). Among employed individuals, women are disproportionately among those who work in family businesses without any direct pay; almost two-thirds of these are women (UN Women, 2015). Relative to men, women also engage in greater levels of unpaid household work, including caretaking for children or other family members and other household responsibilities, even in places where employment rates among women are high (Lachance-Grzela & Bouchard, 2010; UN Women, 2015). Across the globe, women's wages are, on average, 24% lower than men's wages (UN Women, 2015). When examining country-specific wage differences, women's incomes are as low as 12 cents per every dollar men earn in Bangladesh, 34 cents per dollar of men's income in Ethiopia, and only 79 cents per dollar of men's income in the USA, for example (Proctor, Semega, & Kollar, 2016; World Bank, 2012). In addition to these forms of economic disenfranchisement, many women and girls also lack basic rights providing them freedom from violence and autonomy in decisions regarding marriage, sex, and family planning (UNICEF Development, 2010).

There are a number of ways in which gender inequities determine the health of women and girls. In some contexts, women have shorter life spans as a direct result of gender-based inequities and related discrimination. Social and economic constraints restrict women's access to health care and other needed resources that support health and well-being, including food, education, and/or employment (UNICEF Development, 2010). For example, low freedom of movement, such as restrictions for women to go to places on their own, limits women's access to health care in many global contexts (Upadhyay et al., 2014). In certain places, women live longer than men; yet, this does not always translate into living healthier lives (Jagger & Robine, 2011; Luy & Minagawa, 2014; UNICEF Development, 2010). Inequities in women's access to paid employment opportunities and higher rates of unpaid work among women also reduce women's access to health care through employer-based health insurance systems (Cook & Dong, 2011; UNICEF Development, 2010). Unpaid work further limits women's and girls' ability to reach their potential in education achievement and economic opportunity, leading to greater proportions of women being impoverished (Corcoran, 1998; Robinson, 1997). Furthermore, poverty itself has a negative impact on women's health and is associated with a number of poor health outcomes, including infectious diseases like HIV/AIDS as well as chronic health conditions like diabetes (Ackerson & Subramanian, 2008; Krishnan et al., 2008; Pascoe et al., 2015).

A number of policies, programs, and research using multidisciplinary approaches at the state, country, and worldwide levels have contributed to the promotion of gender equity. These efforts have largely sought to change the social norms (i.e., influential societal beliefs) that promote gender inequities as a way to address social and economic disenfranchisement as well as to improve health outcomes among women and girls. Increasingly, efforts have also *directly* focused on women's economic empowerment through increased financial inclusion for women, financial incentives for girls' education, and other programs aiming to increase economic autonomy and opportunity among women and girls, all of which can have an impact on health.

The purpose of this chapter is to (1) discuss how gender inequities create social *and economic* constraints that affect sexual and reproductive health, (2) provide an overview of women's economic empowerment programs, and (3) present research related to the effect of economic empowerment programs on sexual and reproductive health outcomes among women and girls.

Gender Inequity Leads to Poor Sexual and Reproductive Health Outcomes Among Women and Girls

Gender inequity has effects on sexual and reproductive health outcomes including unintended and adolescent pregnancy, as well as the incidence of HIV, and other sexually transmitted infections (STIs). Conditions such as pregnancy and childbirth confer health risks to women specifically, and thus require health care; yet, gender inequities may limit availability and accessibility to care for women (Shimamoto & Gipson, 2015; World Health Organization, 2009). Furthermore, gender inequities promote high rates of violence against women, also a primary factor contributing to poor sexual and reproductive health outcomes among women and girls (Miller et al., 2007; Silverman et al., 2006, 2011).

Social and economic constraints created by gender inequities lead to poor sexual and reproductive health outcomes in different but often intersecting ways. Both social and economic constraints can reduce sexual decision-making power in relationships with male partners, limit control over use of family planning methods, and increase vulnerability to other sexual risk behaviors, including unprotected sex and sex trade involvement (Adelekan, Omoregie, & Edoni, 2014; Ezeh, 1993; Ganle et al., 2015; Upadhyay et al., 2014; Wechsberg et al., 2013). Considering the intersecting influence of social and economic constraints on health outcomes is especially important for informing the development of effective programming. For example, the success of economic interventions may be limited in many contexts without also considering women's control over financial decisions in their households, particularly in decisions regarding how financial resources will be used. Economic interventions may also need to consider women's safety and threats of violence as a result of women gaining financial independence from male partners. Furthermore, economic interventions that focus on improving employment or promoting women as entrepreneurs may not be as effective without efforts to support women's freedom of movement in their communities, access to bank accounts, or ability to rent space/property on their own. Overall, economic empowerment approaches may need to also consider social constraints in women's lives. Below, we discuss social and economic constraints that are most relevant to sexual and reproductive health among women and girls.

Social Norms Promoting Gender Inequity

Ideologies and social norms regarding femininity and masculinity contribute to gender-based constraints on women, particularly with regard to family planning, HIV/STI testing, and medical care during pregnancy and childbirth. Several studies show that within intimate relationships with male partners, norms promoting women's submissiveness to men have been associated with reduced decision making in family planning, including contraceptive use (Adelekan et al., 2014; Ezeh, 1993). Restrictions on women's mobility, which stem from gendered power imbalances, also contribute to women's inability to access family planning services (Khalaf, 2009). Further, lack of access to medical care during pregnancy and childbirth is associated with high rates of maternal morbidity and mortality. In general, women's lower social status leads to lack of access to care, including emergency obstetric care when needed, resulting in limited use of family planning, high levels of maternal mortality, and poorer overall reproductive health outcomes. Moreover, norms promoting male dominance support the occurrence of girl child marriage, which has been linked to lowered contraceptive use before first childbirth, increased experiences of unplanned/unwanted pregnancies, rapid repeat childbirth, high fertility, pregnancy termination, pregnancy complications, as well as intimate partner violence (IPV) by husbands (Nasrullah, Muazzam, Bhutta, & Raj, 2014; Nasrullah, Zakar, & Zakar, 2014; Raj, Saggurti, Lawrence, Balaiah, & Silverman, 2010; Santhya, 2011).

Intimate Partner Violence (IPV)

Social constraints also include gender-based violence, a primary factor contributing to poor sexual and reproductive health outcomes among women and girls (Heise, Ellsberg, & Gottmoeller, 2002). Gender-based violence, including intimate partner violence (IPV), sexual violence, and sex trafficking, affects 23–49% of women across the globe (García-Moreno, 2013). Studies across every age group and global context have found that male-perpetrated violence against females is tied to gender norms promoting male dominance and control (i.e., beliefs in the inferiority of women and girls, and men's entitlement to control female partners) (Anderson, Simpson-Taylor, & Herrmann, 2004; Anderson & Umberson, 2001; Goicolea, Öhman, Salazar, Morras, & Edin, 2012; Murnen, Wright, & Kaluzny, 2002; Palma-Solis, Vives-Cases, & Álvarez-Dardet, 2008; Reed, Silverman, Raj, Decker, & Miller, 2011; Reed et al., 2008; Santana, Raj, Decker, La Marche, & Silverman, 2006; Zakar, Zakar, & Kraemer, 2013). Furthermore, population-based research has found that in countries where there is less gender equality—as measured by country-level data on civil liberties, political rights, and occupation of parliamentary seats by women—there are more deaths among women from male-perpetrated partner violence (Palma-Solis et al., 2008). Women and girls experiencing IPV and other forms of gender-based violence are more likely to report reduced control over sexual decision making, including the use of condoms and other forms of birth control (Silverman & Raj, 2014). Experiencing IPV has also been associated with reproductive coercion, which is the restriction of reproductive autonomy by male partners through coerced pregnancy and/or sabotaging contraceptive use or other family planning methods (Silverman & Raj, 2014). Notably, research on IPV has hypothesized that gender norms that promote male dominance and violence against women also promote other risky health behaviors, including sexual risk behaviors for HIV/STI among boys and men who report perpetration of IPV (Reed et al., 2011).

Economic Vulnerability

Gender inequities in education and economic opportunities are linked to women's reduced access to or control over economic resources, which promotes women's economic vulnerability. Economic vulnerability can result in economic reliance on male partners, which can restrict women's access to health care, contraceptive use, as well as sexual and reproductive decision-making power.

Economic reliance on male partners affects women's decision-making power in terms of deciding whether or how much of family resources will be spent on health care. In Ghana, women with no influence over financial resources within the household were the least likely to receive antenatal or delivery care compared to women who had influence over household finances (Furuta & Salway, 2006). Furthermore, among married women in India who did not desire pregnancy, those who had access to their own money were more likely to use family planning methods. This association was significant even when considering other factors, such as women's reproductive decision-making power in their households as well as their freedom of movement to seek health care (Reed et al., 2016). Economic reliance on male partners also affects women's decision-making power in relationships, including reduced power over decisions related to sex, contraceptive and condom use, pregnancy, and pregnancy timing (Biello, Sipsma, Ickovics, & Kershaw, 2010; Do & Kurimoto, 2012). Furthermore, economic reliance heightens vulnerability to IPV, limiting women's ability to leave abusive relationships when financially relying on male partners (Dalal, 2010; Deuba, Mainali, Alvesson, & Karki, 2016; Golden, Perreira, & Durrance, 2013; Rosen, 2004; Sanders, 2015). Notably, economic hardship has also been linked to increased IPV perpetration among males (Malcoe, Duran, & Montgomery, 2004; Reed et al., 2014; Sambisa, Angeles, Lance, Naved, & Thornton, 2011; Selic, Svab, & Gucek, 2014).

Although the majority of these studies have been conducted among adult women, preliminary evidence suggests that similar linkages exist among adolescent girls. Findings suggest a relation between economic vulnerability and sexual risks for adolescent pregnancy as well as HIV/STI (Boonstra, 2011; Penman-Aguilar, Carter, Snead, & Kourtis, 2013). Experiencing economic vulnerability at home, such as food insecurity or financial stress in the household, may increase girls' likelihood of seeking male partners who can provide economic security. Some work has shown that fatalistic expectations for future educational or career opportunities among girls living in poor households are also a determinant for girls seeking relationships with male partners who can provide for them financially (Boonstra, 2011; Penman-Aguilar et al., 2013). These partnerships often involve older males, further contributing to inequitable power dynamics and girls' risk for IPV and reproductive coercion by male partners. Greater risk for IPV among girls experiencing economic vulnerability also exacerbates the risk for HIV/STI and unintended or adolescent pregnancy (Miller et al., 2007; Silverman et al., 2006, 2011). Studies have also shown that early experiences of IPV interfere with girls' educational achievement and impede career development (Adams, Greeson, Kennedy, & Tolman, 2013; Davis, 2008), further promoting economic vulnerability and dependency on male partnerships.

In addition to risks associated with intimate partnerships, economic vulnerability among women and girls has also been linked to sexual risks for unintended pregnancy and HIV/STI through sexual relationships with males who provide some type of economic support, including paying clients in sexual transactions. Having sexual partnerships with males who provide economic support has been associated with reduced power in sexual and condom negotiations and greater risk for HIV/STI. For example, in sub-Saharan Africa, sexual relationships between girls and older male partners involving economic transactions are associated with risky sexual behaviors for HIV/STI, with girls having little control over condom use as well as other sexual decision making (Luke, 2003). While the reasons adolescent girls choose these types of relationships vary, receiving economic benefits has been documented as an important motivator to ensure economic survival or to secure long-term opportunities (Luke, 2003). Women working in sex work are also at greater risk for HIV/STI as a result of economic vulnerability. Economic vulnerability creates an urgency that reduces the capacity to negotiate safety from violence, such as the ability to refuse clients who have been drinking or using drugs and who may be more likely to become violent. Economic vulnerability also restricts condom negotiating power among women working in sex work, particularly if clients offer to pay more for sex without a condom (Reed, Gupta, Biradavolu, Devireddy, & Blankenship, 2010). Female sex workers (FSW) also cite economic hardship as a primary reason underlying their involvement in sex work (Vindhya & Dev, 2011) and women without support from male partners or family end up as primary caretakers and financial breadwinners for themselves and their children. Studies among FSW in Mexico suggest that adolescent pregnancy often creates economic vulnerability that underlies entry to sex work (Servin et al., 2015). Financially supporting children is especially difficult for girls and young women with limited opportunities for education and employment.

Overall, unequal access to education and economic opportunities results in food insecurity, economic hardship, and economic reliance on male partnerships, which in turn leads to a range of poor health outcomes for women and girls globally including IPV, adolescent or unintended pregnancy, and HIV/STI.

Economic Empowerment Programs

Movements to support women's empowerment have been at the forefront of improving the social status of women across the globe. These efforts have focused on promoting women's political inclusion, increasing their freedom of mobility in their communities, improving decision-making power within their households and families, and changing policies or norms that constrain women and girls' educational and employment opportunities. Empowerment programs also aim to decrease gender-based violence, including intimate partner violence, sex trafficking of women and girls, and sexual violence and harassment. Economic empowerment programs, for example those that provide women with access to their own money or improved employment opportunities, may offer some reprieve, and be of particular importance in contexts where gender norms may be slow to change.

Economic empowerment interventions are designed to reduce poverty and promote economic independence which, in turn, affects decision-making autonomy, power within relationships, and changes in a woman's ability to control her sexual and reproductive health (Dworkin & Blankenship, 2009; Mahmud, 2003). By promoting economic independence, such interventions can help women and girls reduce financial reliance on male partners and strengthen their relationship decision-making capabilities, including negotiating condom and other contraceptive use, as well as making it possible for women and girls to leave abusive partnerships (Biello et al., 2010; Do & Kurimoto, 2012; Postmus, Plummer, McMahon, Murshid, & Kim, 2011). Increasing economic resources may also provide greater opportunities to access sexual and reproductive health services by providing money required for transportation to such services or to privately purchase contraceptives or condoms (Reed et al., 2016). Although the mechanisms by which economic empowerment interventions have an impact on women and girls' health vary, these programs have shown promise in improving health behaviors, including use of preventive services and improved outcomes related to sexual and reproductive health (Khalaf, 2009; Pettifor, MacPhail, Nguyen, & Rosenberg, 2012).

Types of Economic Empowerment Programs

Economic empowerment programs have primarily focused on reducing poverty through cash transfers (CTs) or in-kind transfers for services (vouchers), vocational training, and microfinance. CTs are either provided with or without conditions, wherein payments may be conditional on behaviors such as educational enrollment, attending antenatal and post-birth checkups, or HIV/STI testing (Ranganathan & Lagarde, 2012). The concept behind CTs is that the provision of cash may directly improve access to resources, such as food, education, and health care, and thereby promote improvements in health behaviors and health outcomes. Similarly, in-kind transfers, including vouchers, provide free or low-cost health services and can promote the use of such services (Razavi & Turquet, 2016).

Other economic empowerment programs focus on the promotion of self-generated income through vocational training or the development of small-scale businesses. Vocational training programs involve skill training and other activities such as linkages to employers to promote employment opportunities. Microenterprise programs involve the development of a small-scale business with the support of a sponsoring organization (Midgley, 2008). Microcredits, which finance microenterprises, are small loans available to populations who have not had access to traditional financial organizations, often due to inability to prove credit through traditional means, such as inability to provide a paycheck receipt or collateral. Women from economically disenfranchised communities are the primary recipients of microcredit programs and represent the majority of owners and operators of microenterprises (Ssewamala, Han, Neilands, Ismayilova, & Sperber, 2010). Group loans are often used as the preferred way of offsetting the risk implicit in providing loans to people in poverty (Kennedy, Fonner, O'Reilly, & Sweat, 2014). Microfinance is the industry that is developed to meet the demand of financial services for unrepresented or underrepresented groups of people in traditional financial institutions. The microfinance field encompasses financial services such as savings, loans, fund transfers, and insurances among other services.

Findings from the Evaluation of Economic Empowerment Programs: Family Planning and Unintended Pregnancy

A growing body of literature has found that economic empowerment programs have the potential to reduce unintended pregnancy and improve access to and decision-making power related to family planning. Economic empowerment programs may be especially important among women and girls living in contexts where endorsement of early marriage and early first birth is prevalent, as well as in regions where freedom of movement may constrain access to family planning services.

Cash transfer (CT) programs are perhaps the most widely used economic programs to improve reproductive health outcomes. The majority of CT programs to improve reproductive health outcomes have been conditional on education or health care visits. CT programs have been associated with increased antenatal visits, increased institutional deliveries, and reduced maternal mortality (Dongre, 2012; Glassman et al., 2013); however, these studies have not been rigorously evaluated or tested via randomized controlled trials. Furthermore, there have not been any studies to support the effects of CT programs on reductions in fertility and findings related to increased contraceptive use and reductions in unintended pregnancy have been inconclusive (Glassman et al., 2013). One of the early CCT programs that focused on unintended pregnancy among adolescents was the “Dollar-a-Day” program. Implemented in two states (North Carolina and Colorado), the “Dollar-a-Day” program included peer support and education about sexual and reproductive health with a monetary incentive that involved paying girls a dollar a day for not being pregnant (Brown, Saunders, & Dick, 1999; Stevens-Simon, Dolgan, Kelly, & Singer, 1996). Preliminary studies following 65 girls in North Carolina over 5 years attending the "Dollar-a-Day" program found that only 15% of participants had repeat pregnancies (Brown et al., 1999). However, findings from a larger randomized controlled trial of almost 300 adolescent girls showed no difference in repeat pregnancies between intervention and control conditions (Stevens-Simon, Dolgan, Kelly, & Singer, 1997; Stevens-Simon et al., 1996).

More recently, CTs have focused on underlying economic constraints that contribute to unintended pregnancy. For example, Mexico's *Oportunidades* program provides cash to impoverished families, contingent upon children staying in school and accessing health care. Although enrollment in *Oportunidades* was associated with increased educational attainment, it did not directly increase contraceptive use or decrease unintended pregnancy among adolescent girls. Instead, *Oportunidades* had an indirect effect on sexual and reproductive health through improvements in educational attainment (Darney et al., 2013). Other studies support findings that programs providing monetary compensation as an incentive to stay in school can reduce adolescent pregnancy (Baird, Chirwa, McIntosh, & Özler, 2010; Baird, Garfein, McIntosh, & Özler, 2012; De Brauw, Gilligan, Hoddinott, & Roy, 2014; Duflo, Dupas, & Kremer, 2015; Todd, Winters, & Stecklov, 2012). Overall, CCT programs focused on education attainment appear to reduce adolescent pregnancy, but more work is needed to rigorously evaluate CCTs on other reproductive health outcomes.

Microcredit programs were among the first economic interventions implemented to increase access to family planning services and contraceptive use. The goal of microcredit programs is to increase women's access to financial resources, thereby improving women's access to and control over decisions related to family planning, including birth spacing and contraception use. While many microcredit programs have been implemented, rigorous evaluation of these types of programs is lacking. Existing evaluation studies in low- and middle-income countries have found that microcredit programs are associated with reduced fertility and increased contraceptive use among women; however, none of these studies employed randomized controlled trials (Amin, Hill, & Li, 1995; Amin, Li, & Ahmed, 1996; Schuler & Hashemi, 1994; Schuler, Hashemi, & Riley, 1997; Steele, Amin, & Naved, 1998).

Voucher programs seek to improve access to family planning services by defraying the cost of care. Several studies, which evaluated voucher programs that provide women and girls with free or low-cost sexual and reproductive health services, found increases in contraceptive use (Meuwissen, Gorter, Segura, Kester, & Knottnerus, 2006) including long-acting reversible contraceptives (Azmat et al., 2013; Secura, Allsworth, Madden, Mullersman, & Peipert, 2010). Studies providing vouchers for a discounted cost, rather than the free provision of care, have had less success (Chin-Quee, Wedderburn, Otterness, Janowitz, & Chen-Mok, 2010). A systematic review of voucher programs concluded that these programs increase utilization of reproductive health services (Bellows, Bellows, & Warren, 2011); however, there is a need to further evaluate their impact on other health outcomes such as unintended pregnancy.

Vocational training programs to reduce unintended pregnancy are less common than other types of economic interventions, but have had some promising results. By increasing women's opportunities for educational attainment and employment, these programs aim to increase women's career aspirations, delay marriage and childbirth, and decrease economic reliance on male partners. Vocational training studies in Liberia and India have demonstrated increased employment and earnings among women (Adoho, Chakravarty, Korkoyah, Lundberg, & Tasneem, 2014; Jensen, 2012), delayed marriage and childbearing, reduced fertility intentions, and increased education and career aspirations (Jensen, 2012). Although these studies did not measure unintended pregnancy specifically, they provide some evidence of the potential impact of these programs to address unintended or mistimed pregnancy, particularly in contexts with high fertility. In addition, given the promising results of the program in India, future implementation of vocational training programs may need to be broadly implemented within communities or incorporate other ways to create buy-in, particularly in places with high levels of endorsement of social norms restricting women's employment opportunities (Jensen, 2012).

These studies suggest that different economic interventions may be used to have an impact on different health outcomes: CT programs may address adolescent pregnancy, vouchers impact the use of family planning services, and vocational training programs may delay marriage and childbearing in contexts where early marriage and first birth are emphasized. Since much of this research has been conducted in Africa and Asia, there is a need for more work in other contexts. More work is also needed that employs rigorous evaluation, particularly of the impact of microcredit programs on reproductive health outcomes. Further, most programs focused on reproductive health outcomes have not reported findings related to IPV, which may represent a missed opportunity. Overall, many of these programs, particularly CT programs and vocational training, appear to foster improvements in reproductive health outcomes by altering the structures that constrain women's and girl's reproductive autonomy.

Findings from the Evaluation of Economic Empowerment Programs: HIV/STI Prevention

Economic interventions implemented for HIV/STI prevention, and the reduction of risky sexual behaviors for HIV/STI, have commonly included cash transfer or microfinance programs. HIV/STI economic interventions have most often been conducted with young or adolescent women. Additionally, a subset of economic interventions have been designed specifically for women in sex work in order to address the unique vulnerabilities that heighten HIV/STI risk among this population. Overall, these interventions have varied impacts on health behaviors and outcomes. Types of outcomes assessed have included HIV testing, HIV/STI-related risk behaviors, and sex work activities that increase women's vulnerability to both HIV and STI.

Cash transfer programs aimed at reducing HIV/STI have involved the provision of incentives to reduce risky sexual behaviors by altering conditions associated with poverty, gender inequality, or other structural determinants of HIV/STI. A number of studies have suggested that cash transfer programs that do not focus specifically on sexual behavior can have an impact on both risk behaviors and HIV/STI prevalence. The majority of this work has been conducted in developing countries, particularly African settings where HIV prevalence is high. Cash transfers among adolescent girls in Africa have been found to be associated with significant reductions in the prevalence and incidence of transactional sexual engagements (Cluver et al., 2013), as well as reductions in HIV and other STIs (Baird et al., 2012; Karim, 2012). Additionally, a study with low-income adolescent females in Nicaragua found that the distribution of vouchers for free-of-charge access to sexual and reproductive health care increased the use of contraceptive and STI testing and treatment services (Meuwissen et al., 2006). Among adults, research in Tanzania has shown that cash incentives provided upon testing negative for STIs were associated with reductions in risky sexual behaviors for HIV/STI and STI incidence (De Walque, Dow, Medlin, & Nathan, 2014; De Walque et al., 2012). While not traditional CTs, there is also some evidence that lotteries (opportunity for participants to be provided with a high reward conditional on negative STI test results from periodic screenings) are associated with decreased HIV incidence among adult populations (Bjorkman Nyqvist, Corno, De Walque, & Svensson, 2015). Overall, while more work is needed, cash transfer programs designed to reduce HIV/STI, either indirectly by addressing structural factors or directly through the incentivization of safer sex, show promise for HIV/STI prevention among women and girls (Pettifor et al., 2012; Taaffe, Cheikh, & Wilson, 2016).

Microfinance programs, which address structural drivers of HIV/STI through income generation activities, also show promise for risk reduction, especially among high-risk women. One of the most well-known microfinance interventions for HIV/STI prevention, the IMAGE (Intervention with Microfinance for AIDS and Gender Equity) study, integrated gender and HIV training with microfinance initiatives in a cluster randomized trial among adult women in rural South Africa (Kim et al., 2009; Pronyk et al., 2008). This study demonstrated that microfinance programs led to reductions in HIV risk behavior and IPV, as well as improvements in economic well-being and empowerment (Kim et al., 2009; Pronyk et al., 2008). Other studies suggest that microcredit and/or vocational training programs in combination with HIV prevention intervention may promote economic security while reducing risk; however, findings are mixed (Dunbar et al., 2010; Kennedy et al., 2014; Rosenberg, Seavey, Jules, & Kershaw, 2011; Spielberg et al., 2013; Swendeman, Basu, Das, Jana, & Rotheram-Borus, 2009). Evidence for the effect of microfinance on HIV prevention has also been demonstrated among women working in sex work (Cui, Lee, Thirumurthy, Muessig, & Tucker, 2013). In particular, microenterprise programs among FSW provide alternative sources of income, reducing economic vulnerability, and increasing women's control over sex work activities. Such economic interventions with FSW have shown significant reductions in sexual risk behaviors. Studies in India and Mongolia have found that a microenterprise intervention was associated with a lower number of clients per month (Sherman et al., 2010) as well as reduced sexual risk behaviors with paying partners (Witte et al., 2015). While not a randomized controlled design, another combined microenterprise and peer-mediated HIV intervention study with FSW in Kenya found reductions in numbers of regular nonpaying sexual partners and increased consistent condom use with regular partners (Odek et al., 2009). Overall, systematic reviews of income generation interventions indicate that microfinance/microenterprise programs may be a viable way to reduce HIV/STI by decreasing sexual risk behaviors, in particular among FSW; however, more research is needed to determine how to integrate income generation and HIV prevention most effectively (Kennedy et al., 2014).

Interventions that integrate a combination of economic empowerment approaches have also shown promise for reducing HIV/STI. For instance, in one such study among FSW in Mongolia, researchers examined the efficacy of a savings-led microfinance intervention with the goal of increasing economic empowerment and reducing sexual risk behaviors (Witte et al., 2015). The intervention implemented a matched savings program, where savings could be used for business development or vocational education, and provided financial literacy and business development training alongside an HIV prevention intervention, which resulted in reductions in the number of paying sexual partners and an increase in consistent condom use (Witte et al., 2015). The JEWEL (Jewelry Education for Women Empowering Their Lives) study, on the other hand, combined vocational training in the form of making, marketing, and selling of jewelry with an HIV prevention risk reduction intervention for illicit drug using women who engage in sex work in Baltimore, Maryland (Sherman, German, Cheng, Marks, & Bailey-Kloche, 2006). This study demonstrated that an integrated income generation and training intervention can reduce the number of sex trade partners and may also have an impact on receiving drugs or money for sex and drug use patterns (Sherman et al., 2006).

Collectively, economic interventions to reduce HIV/STI have been implemented in diverse settings and in diverse ways. Economic strategies, which include cash transfer, microfinance, and vocational training programs, may have broad impacts on both HIV/STI sexual risk behaviors and economic and other empowerment indicators. Importantly, these studies suggest that economic interventions may operate directly to shape health behaviors and indirectly to alter the context in which women and girls live and work.

Conclusions and Future Directions

Economic empowerment approaches seek to address issues arising from the intersection of gender inequities, poverty, and health among women and girls. Findings from the evaluation of economic empowerment programs highlight that changes at the structural level (i.e., addressing economic constraints) can improve sexual and reproductive health outcomes among women and girls, often without directly promoting specific health behaviors. Structural level change likely creates a broader impact across populations by reducing economic and social constraints that limit engagement in healthy behaviors and that increase exposure to health threats.

Next steps for this work will require continued efforts to evaluate the effect of economic empowerment programs using rigorous evaluation methodologies (e.g., including randomized controlled designs) on a comprehensive list of sexual and reproductive health outcomes. Notably, many of the health behaviors and risk factors for HIV/ST, including unprotected sex, IPV, and multiple sex partners, are also risk factors for unintended pregnancy. Therefore, depending on the population of focus, future studies to evaluate economic interventions are needed that measure both HIV/STI risk and unintended pregnancy, as well as related health behaviors for these outcomes. Furthermore, given the extent of the impact of IPV on sexual and reproductive health outcomes, greater consideration of IPV may be important for the conceptualization, development, and analyses of future economic empowerment programs among women and girls.

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Discussion Questions

1. Compare and contrast the different types of economic empowerment programs. Are certain types of programs (e.g., cash transfer vs. voucher) better suited for specific populations?
2. Given the increase in technology use globally, how might economic empowerment programs be tailored to incorporate apps and the use of tablets, social media, or other technology platforms to better deliver programs to improve the health and well-being of women and girls?
3. While some economic empowerment programs have focused on reducing HIV/STI risk, others have focused on reproductive health outcomes. However, many of the same risk factors contribute to both sexual and reproductive health outcomes among women and girls. How might future economic empowerment programs address both sexual and reproductive health?
4. Discuss the sustainability and cost-effectiveness of each of these types of economic empowerment approaches.

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Chapter 18
Women's HIV Knowledge and Condom Use Across Diverse Relationship Types in the Dominican Republic and Haiti

Jennifer Toller Erausquin

Introduction

The two countries of the island of Hispaniola, the Dominican Republic and Haiti, are home to more than three-quarters of all people living with HIV in the Caribbean (UNAIDS, 2016). In 2015 an estimated 130,000 Haitian and 68,000 Dominican adults and children were living with HIV (UNAIDS, 2016). Although both the Dominican Republic (DR) and Haiti experienced declines in HIV incidence in the past decade, overall adult (ages 15–49 years) prevalence remains relatively high: 1.7% in Haiti and 1.0% in the DR (UNAIDS, 2016). As HIV prevalence has stabilized, there has been a shift in infections towards women (Cayemittes et al., 2001; CESDEM & Macro International, 2008; Gaillard et al., 2006; Halperin, de Moya, Pérez-Then, Pappas, & Garcia Calleja, 2009), highlighting the need to understand factors affecting women's HIV knowledge and related behaviors.

Statistics on HIV in the Dominican Republic show important prevention successes over time, as well as areas where work is still needed. In 2015, HIV prevalence among Dominican adults 15–49 years old was 1.0% (UNAIDS, 2016). Testing data from the 2013 Dominican Republic Demographic and Health Survey indicate differences across age and gender groups, with women showing slightly lower overall HIV prevalence (0.7%) than men (0.9%) (CESDEM, 2014). These recent data are encouraging. In the past 15 years, the DR has been successful in decreasing HIV infections and risk behaviors among high-risk groups including male and female sex workers and heterosexual men with multiple partners (Halperin et al., 2009; Kerrigan, Moreno, Rosario, & Sweat, 2001; Kerrigan et al., 2003; Kerrigan et al.,

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2006). From 2005 to 2015, HIV/AIDS went from being the third leading cause of death to the seventh (Institute for Health Metrics and Evaluation, 2017). However, there is still work to be done in addressing HIV, particularly among women. Prevalence among pregnant women may be as high as 1.5% (República Dominicana Consejo Presidencial del SIDA, 2009), and women of lower socioeconomic status (SES) may be at increased risk for HIV infection compared to women of higher SES (Ashburn, Kerrigan, & Sweat, 2007). Thus, prevention efforts that focus on women in the Dominican Republic should be maintained and strengthened to reduce HIV transmission and to eliminate disparities in infection rates.

In Haiti, national HIV prevalence was estimated in 2015 to be 1.7% among adults aged 15–49 years (UNAIDS, 2016). The 2012 Haiti Demographic and Health Survey estimated national prevalence among 15–49-year-olds to be 2.2%, with higher prevalence among women (2.7%) than among men (1.7%) (Cayemittes et al., 2013). As in the DR, Haiti has shown important progress in preventing HIV over the past 10–15 years, including an overall decline in infections (at least prior to the 2010 earthquake) and a decline in infections among women receiving antenatal care (Cayemittes et al., 2013; Gaillard et al., 2006; Koenig et al., 2010). However, the country's political and economic conditions and the effects of natural and human-influenced disasters (including the 2010 earthquake and the cholera epidemic that followed) put some of these gains at risk. The gender disparity in the Haitian HIV epidemic indicates that prevention efforts should explicitly address the risks and needs of Haitian women.

Heterosexual sex is the primary mode of HIV transmission in both the DR and Haiti, and patterns of sexual partnering continue to drive the HIV epidemic (UNAIDS, 2016). In both countries, for women, serial monogamy—having one sexual partner for a period of time, and only gaining a new sexual partner when the prior relationship has ended—and few lifetime sexual partners are the behavioral norms. However, for men, normative behavior includes concurrent partnerships—having more than one sexual partner over the same period of time—and a greater number of lifetime partners. For example, studies show that for both the DR and Haiti, nearly 30% of sexually active men report having two or more partners in the past year, as compared with fewer than 3% of sexually active women (Cayemittes et al., 2001; Molina Achécar, Ramirez, Polanco, & Quiterio, 2003). Despite the concentration of sexual risk behaviors among men, women remain at risk for HIV infection for both social and biological reasons. Part of their risk comes from sexual networks; women may be monogamous but their partners are not. Further, HIV transmission is more efficient from males to females than from females to males (Nicolosi et al., 1994). Improving HIV prevention efforts in the contexts of both the Dominican Republic and Haiti will require greater understanding of heterosexual relationships and the factors affecting risk behavior within different types of relationships. *Therefore, the purpose of this chapter is to examine the social, demographic, and behavioral characteristics associated with HIV knowledge and condom use among women in the Dominican Republic and Haiti, and to explore these associations across relationship type.*

Background

Women, Relationships, and HIV Risk

Sociodemographic characteristics such as relationship type, age, and socioeconomic status fundamentally affect women's life experiences, opportunities, resources, and choices, including those related to health, sexual behavior, and HIV. Because sexual behaviors occur within the context of interpersonal relationships, the nature of the relationship can affect women's vulnerability to HIV infection, both by influencing awareness or intentions and by affecting the ability to follow intentions with behavior (Blanc, 2001). Theory and empirical evidence suggest that different norms of behavior and ideals about appropriate emotional attachments (e.g., attraction, love, respect, loyalty, fidelity) apply to different relationship types (Connell, 1987). In many areas of the world, ideals of fidelity, trust, and intimacy are more strongly associated with formal and common-law marriages than other, more casual relationship types. Relationship-based norms and ideals make women in marriages and stable unions less likely than women in more casual relationships to engage in several critical components of safer sexual behavior: (1) to know about or admit the risk behaviors of their partners (Hirsch, Higgins, Bentley, & Nathanson, 2002; Hirsch et al., 2007); (2) to talk about sexual risk and condom use with their partners (Amaro, 1995; Hirsch et al., 2002; Mumtaz, Slaymaker, & Salway, 2005); and (3) to use condoms (Macaluso, Demand, Artz, & Hook, 2000; Mumtaz et al., 2005; O'Sullivan, Harrison, Morrell, Monroe-Wise, & Kubeka, 2006; O'Sullivan, Hoffman, Harrison, & Dolezal, 2006; Wingood & DiClemente, 1998). Further, within stable relationship types, HIV knowledge and behaviors may vary based on the living arrangements of partners. In the Dominican Republic and Haiti it is common for partners in marriages or stable unions to live apart, and many women in these types of relationships know or suspect that their partner has other sexual partners (Ulin, Cayemittes, & Metellus, 1993). As a result, women in these "living-apart" unions may be more likely than women in unions with the partner living in the home to seek out information about HIV and to be motivated to use condoms with their partners. On the other hand, women with the partner living outside the home may have limited ability to successfully negotiate condom use (e.g., due to limited partner communication skills, wanting to avoid angering or offending the partner, or desiring to comply with perceived partner desires for condomless sex).

Age is linked to women's HIV-related outcomes, because the types of behaviors and relationships that are appropriate in a given social context may be dependent on age (Gagnon, 1990). In developed countries, research indicates that young adults have greater number of sexual partners and more casual relationships, but also greater condom use, as compared with older adults (typically age 25 and older) (Abma, Martinez, Mosher, & Dawson, 2004; Fergus, Zimmerman, & Caldwell, 2007; Mosher, Martinez, Chandra, Abma, & Willson, 2004). In developing countries with high HIV prevalence, several studies have shown that younger women tend to have partners with riskier sexual behaviors (e.g., concurrent partnerships or sex with sex workers) than older women (Boerma, Gregson, Nyamukapa, & Urassa, 2003; Caldwell, 2000; Caldwell, Caldwell, Caldwell, & Pieris, 1998; O'Sullivan, Harrison et al., 2006; O'Sullivan, Hoffman et al., 2006; Varga, 2003). This evidence suggests that younger women may be more aware of their HIV risk, making them more likely to seek out information about HIV and more likely to use condoms.

Women's socioeconomic status (SES) is also of interest because it affects access to information, resources, and services. Prior research in developed countries has shown a positive association between measures of SES such as education and protective behaviors such as condom use, for both women and men (Manderson, Tye, & Rajanayagam, 1997). In some developing countries, however, the opposite may be true. A more recent analysis of data from five sub-Saharan African countries found education—and in some cases, wealth—to be associated with greater likelihood of HIV infection for both women and men (Fortson, 2008). In the DR and Haiti, studies have shown that low SES can act as a significant constraint on behaviors including health care seeking and condom use (Behforouz, Farmer, & Mukherjee, 2004; Koenig, Léandre, & Farmer, 2004; Louis, Ivers, Smith Fawzi, Freedberg, & Castro, 2007; Miller, Tejada, & Murgueytio, 2002; Smith Fawzi et al., 2006). As measures of SES, *household wealth* reflects the overall resources and life circumstances of women, and *educational attainment* reflects literacy, socialization that occurs through formal schooling, and the potential for women to be economically independent from their male partners.

To date, relatively few population-based studies have examined characteristics associated with women's HIV knowledge and condom use in either Haiti or the DR. In the absence of a vaccine or daily preventive medication for HIV, condom use remains a critical tool for preventing HIV. Insufficient attention has been placed on the relationship context of sexual behavior and sexual health in these countries despite an extensive literature on the nature of Haitian and Dominican intimate relationships (exceptions include Fitzgerald et al., 2000; Kershaw et al., 2006; and Ulin et al., 1993). This analysis uses nationally representative survey data from the Dominican Republic and Haiti to examine two research questions: (1) What are the social, demographic, and behavioral characteristics of women in different relationship types in the DR and Haiti? (2) How are social, demographic, and behavioral characteristics associated with HIV knowledge and condom use across relationship types in the DR and Haiti?

Methods

Study Design

Data Sources

This study analyzed data from two nationally representative household surveys: the Haiti 2012 and Dominican Republic 2013 Demographic and Health Surveys (DHS). These surveys gather information from households and from women and men of reproductive age (described in detail below) and cover a broad range of population and health indicators including sociodemographic characteristics, fertility and family planning, marital history, sexual behaviors, and knowledge and attitudes about HIV. In both countries, two-stage stratified sampling was used to achieve a sample representative at the national and provincial levels. The resulting samples included 9372 women in 11,464 households in the DR and 14,287 women in 13,181 households in Haiti.

The questionnaires and protocols for the DHS were approved by the institutional review boards of ORC Macro and Dominican and Haitian collaborating agencies prior to data collection.

Study Population

The DR and Haiti DHS surveys gather data from all women aged 15–49 in sample households. In the current study, respondents who had not been sexually active in the 12 months prior to the survey, who were missing information on the study outcomes, or who had inconsistent reports of their current relationship status or last sexual partner were excluded from analysis. In addition, one woman who met these inclusion criteria was randomly selected from each sample household. This resulted in an analytic sample of 6220 women in the DR and 8017 women in Haiti.

Study Variables

Several demographic, socioeconomic, and behavioral characteristics of women were examined in this study, including relationship type, age, educational attainment, household wealth, and family planning behavior. The variable for *relationship type* was based on women's answers to several questionnaire items. Respondents indicated whether they were currently married (*casada* in the DR; *mariée* or *placée* in Haiti); in union or living together (*viviendo en union* in the DR; *viv avek* or *vit ensemble* in Haiti); widowed, divorced, or separated; or never married. Women were also asked whether their partner currently lives in the same home with them. A relationship typology variable with the following categories was created: (1) married/in union, partner living in the home; (2) married/in union, partner staying away; (3) formerly married/in union; and (4) never married.

Women's *age* was measured in years on the date of the interview, and ranged from 15 to 49 years. Women's *education* was measured as the highest grade level completed. For the current study, education was collapsed into a dichotomous variable based on initial sensitivity analyses; the variable was coded as (1) completed grade five or higher, and (0) grade four or lower. Missing values on education (0.02% in the DR and 0.08% in Haiti) were imputed from sociodemographic and behavioral characteristics using multiple linear regression.[1] *Household wealth* was

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[1] The characteristics used in this imputation model included age, place of residence (urban/rural), province, number of children, recency of sexual intercourse, pregnancy, use of modern contraceptives, household wealth, household transportation, relationship type, use of health services, HIV knowledge, and condom use.

measured using an index of household assets and amenities developed by ORC Macro (Rutstein & Johnson, 2004). The national distribution of household wealth index scores was divided into quintiles to create an ordinal variable for household wealth. *Family planning behavior* was assessed using questionnaire items about pregnancy and contraceptive use. Women who were not pregnant and were not using any modern contraception other than condoms were coded as (1) at risk for pregnancy; women who were pregnant or who were using modern contraception other than condoms (e.g., using oral contraceptive pills, intrauterine devices, injections, Norplant, diaphragms, or female or male sterilization) were coded as (0) not at risk for pregnancy. This coding scheme allowed the distinction between condom use that was likely exclusively for disease prevention and condom use that was not exclusively for disease prevention (i.e., possibly pregnancy prevention as well).

The analyses in this chapter examined two dichotomous outcomes: knowledge about HIV transmission and prevention, and use of condoms at last sexual intercourse. The measure for *HIV knowledge* used in this study was based on available DHS questionnaire items (common to both countries) about HIV transmission and prevention. These items encompassed whether HIV can be prevented by condom use and by being faithful to one partner; whether a healthy person can be infected with HIV; whether HIV can be passed from a mother to her baby; and whether HIV can be transmitted by insects or by sharing food. Respondents with correct answers to all items were coded as having comprehensive, correct knowledge about HIV. Respondents who had not heard about HIV/AIDS, respondents who did not know HIV/AIDS could be prevented, and respondents who did not answer all six knowledge items correctly were coded as having incomplete HIV knowledge. The resulting dichotomous HIV knowledge variable was coded (1) comprehensive correct knowledge about HIV and (0) incomplete knowledge about HIV. *Condom use at last sexual intercourse* was based on the question, “The last time you had sexual intercourse, did you use a condom?” Valid responses were yes and no. Responses were used to create a dichotomous variable, coded (1) condom used at last sex and (0) no condom used at last sex.

Statistical Analysis

Descriptive analyses were conducted to assess the social, demographic, and behavioral characteristics of sexually active Dominican and Haitian women. Bivariate analyses (Chi-squared analysis and ANOVA, as appropriate) were conducted to assess the distributions of study variables across relationship type. Logistic regression analyses stratified by relationship type were conducted to examine the associations of age and socioeconomic status with HIV knowledge and condom use in the two countries. Separate logistic regression analyses were conducted for each outcome and in each country. All analyses were completed using Stata 13.1/SE (StataCorp, College Station, TX) and used survey estimation procedures to weigh the data and account for the multistage stratified designs of the two samples.

Results

Demographic, Socioeconomic, and Behavioral Characteristics

Tables 18.1 and 18.2 present demographic, socioeconomic, and behavioral characteristics for the Dominican and Haitian samples (sexually active women aged 15–49), including unweighted sample sizes and weighted means and percentages. As shown in Table 18.1, the Dominican sample was on average 31 years old with about 10 years of completed education. The average age at first sex was 17 years. Most Dominican women reported being married or in a union with the partner living in the home (4247; 62.6% of the sample); lower proportions of women reported being formerly married or in union (i.e., widowed, divorced, or separated; 1106; 19.8%), never married/in union (478; 11.1%), and married/in union with the partner living away (389; 6.5%). Three-quarters of women in the Dominican sample were either pregnant or currently using modern contraception other than condoms. With regard to the two study outcomes, 47% of Dominican women had comprehensive knowledge about HIV prevention and transmission, and 16% reported using a condom the last time they had sexual intercourse.

As shown in Table 18.2, the Haitian sample was slightly younger, had less formal education, and showed greater variation in relationship type than the Dominican sample. Haitian women were on average 30 years old with about 6 years of completed education. The average age at first sex was 17 years. Approximately half of women in the Haitian sample (4717; 52.3% of the sample) reported being married or in a union with the partner living in the home; an additional 23.7% (1751) were married/in union with the partner living away, and the remainder were never married/in union (1146; 18.6%) or formerly married/in union (403; 5.4%). Just over one-fourth of Haitian women were either pregnant or currently using modern contraception other than condoms. Finally, 36% of Haitian women had comprehensive, and correct HIV knowledge, and 21% reported using a condom at last sexual intercourse.

Descriptive statistics stratified by relationship type are presented in the four left-hand columns of Tables 18.1 and 18.2. ANOVA and Chi-square analyses showed that all study variables significantly varied across relationship type. In both countries, never-married women tended to be younger than women in other relationship types by about 9 years. Never-married women were also more highly educated, with an average of about 12 years of completed education in the DR, and 9 years in Haiti. Never-married women were also more likely to be in the higher household income quintiles, which may reflect living in their parents' home rather than on their own. Married women whose partners live in the home were more likely to live in poorer households. Family planning behavior varied across relationship type and by country; overall, much higher proportions of women were using modern contraception in the DR, but both countries showed a pattern of married/in-union women with the partner in the home having the highest use on modern contraception, followed by married/in-union women with the partner away, formerly married women, and never-married women. Finally, with regard to the two study outcomes, HIV

Table 18.1 Weighted descriptive statistics of sexually active women aged 15–49 (Dominican Republic 2013 Demographic and Health Survey)

	Married, partner in home		Married, partner away		Formerly married		Never married		Total	
Dominican Republic	***n* = 4247**		***n* = 389**		***n* = 1106**		***n* = 478**		***n* = 6220**	
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
Age (years)[a]	32.6	(8.97)	30.4	(9.0)	30.6	(8.7)	21.9	(5.2)	30.9	(9.2)
Completed education (years)[a]	9.5	(4.5)	10.9	(3.7)	10.0	(3.9)	12.1	(2.8)	10.0	(4.2)
Age at first sex (years)[a]	17.7	(3.9)	18.1	(3.9)	17.1	(3.5)	18.3	(3.6)	17.3	(3.5)
	Percent	N	Percent	N	Percent	N	Percent	N	Percent	N
Has comprehensive knowledge about HIV	44.6	1842	45.2	177	47.3	502	56.6	241	46.5	2762
Used a condom at last sex[b]	4.6	188	9.3	36	36.3	382	48.2	231	16.0	837
Age[b]										
15–24	22.6	976	32.9	113	29.2	308	76.3	364	30.5	1761
25–34	33.7	1500	34.6	144	39.3	435	20.2	94	34.0	2173
35–49	42.7	1771	32.5	132	31.5	363	3.5	20	35.5	2286
Religion[b]										
Catholic	47.7	2049	48.7	203	50.9	540	50.4	254	48.7	3046
Protestant/other Christian	23.0	937	20.4	78	14.0	158	10.6	55	19.7	1228
Other religion/no religion	29.2	1261	30.9	108	35.1	408	38.9	169	31.6	1946
Rural residence[b]	27.0	1338	21.4	96	22.3	244	19.5	106	24.9	1784
Household wealth (national quintiles)[b]										
Poorest quintile	19.8	1112	13.8	72	17.9	224	8.4	60	17.8	1468
Second quintile	22.6	1003	15.8	69	21.5	262	10.9	67	20.7	1401
Middle quintile	20.2	827	25.3	86	21.6	248	17.2	93	20.4	1254
Fourth quintile	19.1	704	23.8	78	22.7	228	29.4	118	21.3	1128
Highest quintile	18.3	601	21.3	84	16.2	144	34.1	140	19.8	1857
Family planning behavior[b]										
At risk for pregnancy	24.7	992	39.9	163	49.3	515	71.0	338	35.7	2008
Not at risk[c]	75.3	3255	60.1	226	50.7	591	29.0	140	64.3	4212
Using modern contraception	*68.0*		*52.5*		*46.2*		*24.9*		*57.9*	
Currently pregnant	*7.3*		*7.6*		*4.5*		*4.1*		*6.4*	

Note: Means and percentages are weighted, Ns are unweighted

[a] ANOVA for distribution of means across relationship type significant at $P < 0.01$

[b] Chi-square test for distribution of proportions across relationship type significant at $P < 0.01$

[c] Not at risk for pregnancy includes women who are currently pregnant as well as women who are currently using a modern form of contraception other than condoms

Table 18.2 Weighted descriptive statistics of sexually active women aged 15–49 (Haiti 2012 Demographic and Health Survey)

	Married, partner in home		Married, partner away		Formerly married		Never married		Total	
Haiti	***n* = 4717**		***n* = 1751**		***n* = 403**		***n* = 1146**		***n* = 8017**	
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
Age (years)[a]	33.2	(8.5)	30.0	(8.4)	31.0	(8.4)	21.6	(4.4)	30.2	(9.0)
Completed education (years)[a]	4.9	(4.5)	6.4	(4.5)	5.6	(4.2)	9.0	(3.6)	6.1	(4.6)
Age at first sex (years)[a]	17.6	(3.6)	17.2	(3.4)	16.4	(2.8)	17.3	(3.3)	17.4	(3.5)
	Percent	N	Percent	N	Percent	N	Percent	N	Percent	N
Has comprehensive knowledge about HIV[b]	32.6	3254	35.8	592	34.6	137	43.5	483	35.5	2675
Used a condom at last sex[b]	8.4	360	19.1	295	27.1	117	55.9	638	20.8	1410
Age[b]										
15–24	16.8	784	32.2	526	26.9	92	76.9	894	32.1	2296
25–34	40.2	1896	38.0	694	37.6	159	22.2	240	36.2	2989
35–49	43.1	2037	29.8	531	35.5	152	0.9	12	31.7	2732
Religion[b]										
Catholic	40.6	1997	46.6	881	46.4	190	38.1	498	41.9	3566
Protestant/other Christian	52.0	2420	45.4	753	44.1	180	55.3	583	50.6	3936
Other religion/no religion	7.4	300	8.0	117	9.5	33	6.6	65	7.5	515
Rural residence[b]	59.0	2964	50.8	968	46.0	179	43.7	538	53.5	4649
Household wealth (national quintiles) [b]										
Poorest quintile	20.2	1220	12.6	311	8.9	41	8.9	156	15.7	1728
Second quintile	18.1	921	16.9	352	14.7	71	11.4	166	16.4	1510
Middle quintile	20.9	1078	20.7	429	27.9	128	17.4	227	20.6	1862
Fourth quintile	21.5	851	24.2	353	23.0	91	24.7	264	22.8	1559
Highest quintile	19.3	647	25.6	306	25.5	72	37.5	333	24.5	1358
Family planning behavior[b]										
At risk for pregnancy	61.4	2830	68.3	1170	79.0	311	93.5	1058	70.0	5369
Not at risk[c]	38.6	1887	31.7	581	21.0	92	6.5	88	30.0	2648
Using modern contraception	*29.0*		*21.5*		*17.5*		*3.6*		*21.9*	
Currently pregnant	*9.6*		*10.2*		*3.5*		*2.9*		*8.2*	

Note: Means and percentages are weighted, Ns are unweighted

[a] ANOVA for distribution of means across relationship type significant at $P < 0.01$

[b] Chi-square test for distribution of proportions across relationship type significant at $P < 0.01$

[c] Not at risk for pregnancy includes women who are currently pregnant as well as women who are currently using a modern form of contraception other than condoms

knowledge in both countries was highest among never-married women (56.6% of Dominican and 43.5% of Haitian never-married women had complete HIV knowledge) and lowest among married/in-union women with the partner in the home (44.6% among Dominican and 32.6% among Haitian women in this relationship type). In the DR, condom use at last sex ranged from 4.6% among married/in-union women with the partner in home, 9.3% for married/in-union women with the partner away, 36.3% for the formerly married, and 48.2% for the never married. Condom use at last sex was higher overall in Haiti than in the DR, but followed a similar pattern by relationship type, with the lowest condom use (8.4%) among married women with the partner in the home, followed by married women with the partner away (19.1%) and formerly married women (27.1%), and then by never-married women (55.9%).

Multivariate Results: HIV Knowledge

The results of logistic regression analyses for HIV knowledge stratified by relationship type and are presented in Table 18.3. *Age* was significantly, positively associated with women's HIV knowledge in both countries, for women in all relationship types except those with the partner away. *Education* was positively associated with HIV knowledge for many women in both countries: in the DR, having at least a fifth-grade education was associated with higher odds of complete HIV knowledge for married women with the partner in the home (AOR 1.75 [1.37–12.24], $P < 0.001$) and for married women with the partner away (AOR 6.95[2.08–23.2], $P < 0.01$). In Haiti, education was significantly associated with HIV knowledge for both groups of currently married or in-union women (married/partner in the home: AOR 2.13 [1.46–2.15], $P < 0.001$; married/partner away: AOR 2.53 [1.88–3.41], $P < 0.001$) as well as formerly married women (AOR 2.08 [1.16–3.74], $P < 0.05$) and never-married women (AOR 2.33 [1.30–4.16], $P < 0.01$). *Household wealth* was not consistently associated with HIV knowledge across relationship types. In the DR, significant positive associations were observed for married/in-union women with the partner in the home. In Haiti, significant positive associations were observed for women in most of the relationship types, particularly at the highest household wealth categories. Finally, *risk of pregnancy* was not associated with women's HIV knowledge in either country, with the exception of Haitian married women whose partners live in the home (AOR 1.39 [1.16–1.66], $P < 0.001$).

Multivariate Results: Condom Use at Last Sex

Table 18.4 presents the results of logistic regression analysis for condom use at last sexual intercourse, stratified by relationship type. *Age* was not significantly associated with condom use. With regard to women's *education*, in the DR education was

Table 18.3 Logistic regression results (adjusted odds ratios) for HIV knowledge among women aged 15–49, Dominican Republic and Haiti

	Married, partner in home			Married, partner away			Formerly married			Never married		
Dominican Republic	***n* = 4247**			***n* = 389**			***n* = 1106**			***n* = 478**		
	AOR		95% CI	AOR		95% CI	AOR		95% CI	AOR		95% CI
Age	1.12	**	[1.04–1.21]	1.22		[0.95–1.59]	1.22	*	[1.04–1.42]	1.71	**	[0.77–1.44]
Age squared	1.00		[1.00–1.00]	1.00		[0.99–1.00]	0.99	*	[0.99–1.00]	0.99	**	[0.99–1.01]
Education												
Less than fifth grade	Ref.			Ref.			Ref.			Ref.		
Fifth grade or higher	1.75	†	[1.37–2.24]	6.95	**	[2.08–23.2]	1.38		[0.75–2.52]	0.52		[0.68–7.85]
Household wealth category												
Lowest quintile	Ref.			Ref.			Ref.			Ref.		
Second quintile	1.52	†	[1.20–1.92]	2.56		[0.98–6.65]	1.14		[0.73–1.80]	0.55		[0.17–1.78]
Middle quintile	1.77	**	[1.22–2.59]	1.37		[0.62–3.03]	1.12		[0.70–1.80]	0.72		[0.22–2.40]
Fourth quintile	1.67	**	[1.23–2.28]	2.49		[0.87–7.08]	1.11		[0.65–1.90]	1.92		[0.60–6.16]
Highest quintile	1.84	**	[1.30–2.60]	3.13	*	[1.30–7.57]	1.65		[0.99–2.76]	1.76		[0.54–5.72]
Family planning behavior												
At risk of pregnancy	Ref.			Ref.			Ref.			Ref.		
Not at risk[a]	1.04		[0.79–1.37]	0.95		[0.52–1.75]	0.84		[0.59–1.20]	1.60		[0.91–2.8]
Haiti	***n* = 4717**			***n* = 1751**			***n* = 403**			***n* = 1146**		
	AOR		95% CI	AOR		95% CI	AOR		95% CI	AOR		95% CI
Age	1.09	*	[1.00–1.19]	1.02		[0.87–1.19]	1.46	*	[1.04–2.05]	1.42	*	[1.08–1.88]
Age squared	1.00		[1.00–1.00]	1.00		[1.00–1.00]	0.99	*	[0.99–1.00]	0.99	*	[0.99–1.00]
Education												
Less than fifth grade	Ref.			Ref.			Ref.			Ref.		
Fifth grade or higher	2.13	†	[1.46–2.15]	2.53	†	[1.88–3.41]	2.08	*	[1.16–3.74]	2.33	**	[1.30–4.16]

(continued)

Table 18.3 (continued)

	Married, partner in home			Married, partner away			Formerly married			Never married		
Household wealth category												
Lowest quintile	Ref.			Ref.			Ref.			Ref.		
Second quintile	0.41		[0.97–1.75]	1.17		[0.75–1.81]	0.28	*	[0.08–0.95]	1.64		[0.87–3.11]
Middle quintile	0.93	**	[1.16–2.00]	1.12		[0.74–1.68]	0.77		[0.25–2.35]	1.92		[0.99–3.73]
Fourth quintile	0.93	†	[1.29–2.27]	1.71	*	[1.09–2.67]	1.14		[0.40–3.22]	2.98	†	[1.62–5.48]
Highest quintile	3.41	†	[1.83–3.46]	2.22	**	[1.40–3.50]	1.52		[0.48–4.81]	2.86	**	[1.58–5.19]
Family planning behavior												
At risk of pregnancy	Ref.			Ref.			Ref.			Ref.		
Not at risk[a]	0.29		[0.78–1.16]	1.10		[0.81–1.50]	1.66		[0.80–3.44]	0.76		[0.40–1.43]

*$P < 0.05$; **$P < 0.01$; †$P < 0.001$

Regressions used survey estimation procedures, which apply weights and account for the complex sampling designs of the two surveys

[a] Not at risk for pregnancy includes women who are currently pregnant as well as women who are currently using a modern form of contraception other than condoms

Table 18.4 Logistic regression results (adjusted odds ratios) for condom use at last sex among women aged 15–49, Dominican Republic and Haiti

	Married, partner in home			Married, partner away			Formerly married			Never married		
Dominican Republic	***n* = 4247**			***n* = 389**			***n* = 1106**			***n* = 478**		
	AOR		**95% CI**	**AOR**		**95% CI**	**AOR**		**95% CI**	**AOR**		**95% CI**
Age	1.05		[0.90–1.24]	1.10		[0.77–1.57]	1.13		[1.00–1.36]	1.26		[0.92–1.72]
Age squared	1.00		[1.00–1.00]	1.00		[0.99–1.00]	1.00		[0.99–0.99]	1.00		[0.99–1.00]
Education												
Less than fifth grade	Ref.			Ref.			Ref.			Ref.		
Fifth grade or higher	1.70		[0.98–2.94]	12.64	*	[1.3–123.6]	1.92		[0.91–4.03]	0.59		[0.09–3.95]
Household wealth category												
Lowest quintile	Ref.			Ref.			Ref.			Ref.		
Second quintile	1.00		[0.56–1.80]	0.65		[0.16–2.65]	0.74		[0.50–1.09]	0.52		[0.14–1.91]
Middle quintile	0.96		[0.51–1.79]	1.21		[0.32–4.63]	0.54	**	[0.34–0.85]	0.90		[0.30–2.67]
Fourth quintile	1.26		[0.68–2.36]	0.27		[0.05–1.33]	0.48	**	[0.29–0.80]	1.12		[0.36–3.49]
Highest quintile	1.37		[0.66–2.84]	0.82		[0.23–2.94]	0.64		[0.36–1.16]	1.18		[0.40–3.43]
Family planning behavior												
At risk of pregnancy	Ref.			Ref.			Ref.			Ref.		
Not at risk [a]	0.22	†	[0.15–0.34]	0.36	*	[0.15–0.90]	0.45	†	[0.30–0.66]	0.38	**	[0.22–0.66]
HIV knowledge												
Incomplete	Ref.			Ref.			Ref.			Ref.		
Complete	1.40		[0.95–2.05]	1.00		[0.45–2.20]	0.93		[0.66–1.30]	0.84		[0.49–1.43]
Haiti	***n* = 4717**			***n* = 1751**			***n* = 403**			***n* = 1146**		
	AOR		**95% CI**	**AOR**		**95% CI**	**AOR**		**95% CI**	**AOR**		**95% CI**
Age	1.08		[0.93–1.25]	0.90		[0.77–1.05]	0.87		[0.62–1.21]	0.89		[0.68–1.16]
Age squared	1.00		[1.00–1.00]	1.00		[1.00–1.00]	1.00		[1.00–1.01]	1.00		[1.00–1.01]

(continued)

Table 18.4 (continued)

	Married, partner in home			Married, partner away			Formerly married			Never married		
Education												
Less than fifth grade	Ref.			Ref.			Ref.			Ref.		
Fifth grade or higher	1.56	*	[1.02–2.36]	2.01	**	[1.24–3.25]	3.38	**	[1.67–6.83]	2.57	†	[1.53–4.31]
Household wealth category												
Lowest quintile	Ref.			Ref.			Ref.			Ref.		
Second quintile	1.90	*	[1.02–3.56]	2.42	*	[1.10–5.36]	2.06		[0.53–8.03]	1.24		[0.72–2.15]
Middle quintile	3.36	†	[1.86–6.07]	3.77	**	[1.52–9.36]	3.06		[0.88–10.68]	1.32		[0.78–2.25]
Fourth quintile	3.56	†	[1.92–6.59]	6.99	†	[2.95–16.56]	5.04	**	[1.57–16.27]	1.58		[0.91–2.77]
Highest quintile	4.75	†	[2.51–8.99]	6.19	†	[2.54–15.05]	3.00		[0.85–10.49]	1.83	*	[1.08–3.11]
Family planning behavior												
At risk of pregnancy	Ref.			Ref.			Ref.			Ref.		
Not at risk [a]	0.21	†	[0.14–0.32]	0.28	†	[0.18–0.46]	0.80		[0.39–1.63]	0.30	†	[0.16–0.55]
HIV knowledge												
Incomplete	Ref.			Ref.			Ref.			Ref.		
Complete	1.69	**	[1.26–2.27]	1.05		[0.74–1.50]	2.24	**	[1.22–4.11]	1.10		[0.81–1.49]

*$P < 0.05$; **$P < 0.01$; †$P < 0.001$

Regressions used survey estimation procedures, which apply weights and account for the complex sampling designs of the two surveys

[a] Not at risk for pregnancy includes women who are currently pregnant as well as women who are currently using a modern form of contraception other than condoms

unrelated to condom use except among married/in-union women whose partners are away; for this group the association appeared strongly positive (AOR 12.64 [1.3–123.6], $P < 0.05$), but the large size of the confidence interval suggests that the estimate of this association may be misleading. In Haiti, education was a strong predictor of condom use across all relationship types, with AORs ranging from 1.56 to 3.38 in two groups of women: married women with the partner away (AOR 2.74 [1.60–4.68], $P < 0.001$) and never-married women (AOR 4.17 [1.68–10.36], $P < 0.01$). *Household wealth* was not consistently associated with condom use. In the DR, only one group of women (the formerly married) showed an association between household wealth and condom use, and it was a negative association, such that women in the middle and fourth quintiles were less likely than women in the lowest quintile to report condom use at last sex (AORs 0.48–0.54, $P < 0.01$). In Haiti, each relationship type showed at least one significant, positive association between household wealth and condom use, and particularly clear patterns of associations—across all wealth quintiles—for the two groups of married/in-union women.

For nearly all women in both countries, *risk of pregnancy* was significantly related to condom use; specifically, women who were not at risk for pregnancy were less likely to use condoms. In other words, women who were either using modern contraception or who were pregnant at the time of the survey were less likely to use condoms than other women. In Haiti, AORs ranged from 0.21 to 0.30 (association was not significant for formerly married Haitian women). In the DR, AORs ranged from 0.22 to 0.45. Finally, HIV knowledge was, on the whole, not an important predictor of condom use. The exceptions were Haitian married/in-union women with the partner in the home and formerly married women, for whom having complete knowledge about HIV transmission and prevention was associated with higher odds of condom use (AOR 1.69 [1.26–2.27], $P < 0.01$; and AOR 2.24 [1.22–4.11] $P < 0.01$).

Discussion

This study described the social, demographic, and behavioral characteristics of women in different relationship types in the Dominican Republic and Haiti, and examined the associations of these characteristics with two outcomes—HIV knowledge and condom use at last intercourse—across relationship type. The results show that in the DR as in Haiti, never-married women tended to be younger and more highly educated than other groups of sexually active women. Married/in-union women with the partner living in the home were more likely than other women to live in poor households. In addition, married/in-union women—both those with the partner living in the home and those with the partner living away—were more likely than other women to use modern contraception and to be pregnant. This finding about contraception and pregnancy is not surprising; in many settings, stable unions are the preferred arrangement for childbearing, and contraception is used for spacing pregnancies in addition to avoiding a first pregnancy. However, in the context of HIV prevention, prior studies show that condom use often declines when other forms of contraception are used. Therefore, healthcare providers and HIV prevention planners will need to consider how HIV prevention efforts are framed, particularly the promotion of "dual protection" against HIV and pregnancy (Berer, 2006).

Multivariate analysis provided valuable insights into understanding women's HIV knowledge and condom use behavior across relationship types. As most studies to date have only examined differences between "married" and "single" women, these findings increase our understanding of condom use behavior and call for further examination of factors such as relationship-based social norms that may facilitate or hinder condom promotion.

For *HIV knowledge*, age and education were associated with HIV knowledge for women in most relationship types. These findings are consistent with numerous studies that demonstrate that education increases women's ability to seek out information and make decisions that benefit their health, including choices about sexual behavior (Coates, Richter, & Caceres, 2008; Greig & Koopman, 2003; Gwatkin et al., 2007; Kravdal, 2002). In this study, education was dichotomized at just fifth-grade education[2], which underscores the potential positive impact of even a low threshold of educational attainment for women. For *condom use at last sexual intercourse*, results showed that age is not associated with condom use for women across relationship types in either the DR or Haiti. This is an encouraging finding for HIV prevention because it suggests that women of all ages, not just young people, can be motivated to use condoms. With regard to women's education, in Haiti, there were significant, positive associations between education and condom use for each relationship type. Prior research suggests that the positive association between education and condom use may be the result of both direct effects and indirect effects (Greig & Koopman, 2003; Rao Gupta, Parkhurst, Ogden, Aggleton, & Mahal, 2008). Education may give these women more negotiating power, may provide them awareness of their partner's behavior and/or their own risk, or may connect them to social networks in which condom use is acceptable. With regard to the other measure of SES—household wealth—the significant associations found in this study were largely among the two groups of married/in-union women in Haiti. More research is needed to understand if this is the result of the affordability of condoms, social norms supporting condom use among the higher SES groups, greater awareness of men having more than one sexual partner, or some other reason. In both countries, being *not at risk* for pregnancy (i.e., being pregnant or using modern contraception other than condoms) was associated with much lower likelihood of condom use. These women remain at risk for HIV infection, and are a key target

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[2] The regression models were also run using alternative measures of education: (1) education dichotomized at the eighth-grade level (completed primary education), and (2) a continuous measure of highest completed grade level. These models showed results similar to those presented here. The education variable dichotomized at the fifth-grade level was chosen in the final models to account for the low average education in Haiti and demonstrate that even a low level of education may be positively associated with HIV knowledge and condom use.

group for future interventions. It would be feasible to reach these women with information, condoms, and risk counseling and other behavioral support when they access medical care for routine prenatal care, labor and delivery, or contraceptive methods. Such health care visits are an opportunity to reach women with information and services they may not otherwise seek out.

Finally, this study found that HIV knowledge was associated with condom use for only two groups of women in Haiti: married/in-union women with the partner in the home and formerly married women. These results confirm the findings of many prior studies of health behavior that have shown that knowledge does not necessarily lead to behavior. This is particularly true for sexual behaviors such as condom use, which are influenced by individual, interpersonal, and contextual factors (Bollinger, Cooper-Arnold, & Stover, 2004; Catania, Kegeles, & Coates, 1990; Dinkelman, Levinsohn, & Majelantle, 2006; Wingood & DiClemente, 2002). Although knowledge may be a prerequisite to behavior, knowledge alone is not sufficient to motivate the adoption of condom use among many sexually active women.

The findings from this study should be interpreted in light of two key limitations. First, detailed information on the dynamics of women's sexual relationships was not available. Dynamics such as relationship duration, level of trust, and expectation of monogamy may mediate or moderate the associations of relationship type with HIV-related outcomes, and could be critical considerations in HIV prevention efforts targeting women and couples. The current study also relied solely on the women's reports of the type of relationship they had with their sexual partners and did not include information on male partners' behavior. In particular, it would have been useful to examine male reports of partner concurrency and condom use with different partners. Future research is needed with men in different types of relationships to understand their social norms about appropriate behaviors within different relationship contexts, and their HIV knowledge and behavior. The current study advances understanding women's HIV knowledge and behavior within sexual relationship contexts. The findings suggest that continued HIV prevention efforts may want to tailor messages and strategies to women and men in different relationship types.

Discussion Questions

1. In this chapter, the data that were analyzed were from women who participated in a cross-sectional survey. Since sexual transmission of HIV occurs within sexual partnerships, what alternative study design(s) might allow researchers to better understand factors affecting HIV risk? Describe the sampling and data collection you would recommend.
2. How might examining the relationship context of sexual behaviors contribute to improvements in sexual and reproductive health services, including HIV prevention efforts? In particular, what changes should clinics and health care providers consider?

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Chapter 19
Women's Partner Relationships and Reproductive and Sexual Health in Lusaka, Zambia

Lwendo Moonzwe Davis

Purpose

Improving women's sexual and reproductive health has been the focus of decades of public health programs and interventions in sub-Saharan Africa. The majority of women's risk for sexual and reproductive health problems occurs within the context of marital or long-term partner relationships. Drawing on primary data collected from an unplanned settlement outside Lusaka, Zambia, this chapter explores the connections between the nature of a woman's partner relationship and sexual and reproductive health. The factors within the partner relationship that may have a negative impact on women's sexual and reproductive health are explored as well as implications for interventions aimed at improving women's health outcomes and reducing their sexual risk.

Background

The majority of most Zambian women's lives are spent within a marital relationship. According to the 2013–2014 Zambia Demographic and Health Survey (ZDHS), on average Zambian women marry at about 18 years of age, and men at about 24 years of age (Central Statistical Office CSO [Zambia], Ministry of Health MOH [Zambia], and ICF International, 2015). About 10% of Zambian women are married by the age of 15 and 45% by the age of 18, whereas only 5% of men are married by the age of 18. With a relatively young age at marriage, women's median age at first birth is 19. However, women with no formal education have their first

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birth about 6 years earlier than women who have more than secondary education (CSO, MOH, and ICF International, 2015).

Maternal and child health in Zambia has improved over the past two decades, but disparities by place of residence (urban vs. rural) and economic circumstances persist. Maternal health practices are improving; the 2013–2014 ZDHS found that almost all women receive antenatal care (ANC) from a skilled provider and more than half met the recommended four or more ANC visits (CSO, MOH, and ICF International, 2015). Childhood mortality has also improved, infant mortality decreased from 107 deaths per 1000 live births in 1992 to 45 deaths per 1000 between 2013 and 2014, and similarity under five mortality decreased from 197 deaths per 1000 live births in 1996 to 75 deaths per 1000 between 2013 and 2014 (CSO, MOH, and ICF International, 2015). However, children in rural areas and those born to mothers with no education have higher rates of mortality.

Similarly, HIV prevalence in Zambia has declined but remains high relative to Western countries, and infection rates for women outpace those of men. According to the 2013/2014 ZDHS about 13.3% of Zambians aged 15–49 are HIV positive, with prevalence higher among women (15.1%) than men (11.3%) (CSO, MOH, and ICF International, 2015). Prevalence is the highest among women aged 35–39 at about 24%. Patterns of partnerships and condom use within those partnerships likely play a key role in the gendered HIV epidemic. Although a higher proportion of men (16%) than women (2%) report having two or more sexual partners, at the population level women are at greater risk of HIV infection (CSO, MOH, and ICF International, 2015).

The status and position of women have remained low in Zambia. For example, in the capital city of Lusaka, women and children constitute 70% of the low-income population (Chola & Robberstad, 2009). Across the country, cultural norms socialize girls to become wives, mothers, and caregivers and to be submissive, whereas they socialize boys to be leaders both in the community and within the household. Such dynamics may be detrimental to women's risk for HIV and other sexually transmitted infections, if they also result in women's limited ability to consistently negotiate sex and condom use (Gupta & Weiss, 1993; Heise & Elias, 1995; Jejeebhoy & Koenig, 2003; Piot, 2001; van Dam, 1995; Worth, 1989; Zierler & Krieger, 1997).

Fear of sexual and physical violence may also diminish women's ability to refuse sex or negotiate condom use (Campbell & Alford, 1989; Go et al., 2003; Jejeebhoy & Koenig, 2003; Maman et al., 2002; Petchesky & Judd, 1998; Santhya & Dasvarma, 2002). Specifically in Zambia, there are limited legal ramifications for acts of violence against women. It was not until 1991 that the Zambian Constitution specified constitutional rights irrespective of sex and marital status. Although women are currently entitled to full fundamental rights and freedoms under the constitution, existing laws, customary practices, and attitudes undermine these rights (United Nations, 1999). For example, gender-based violence (GBV) is common throughout Zambia, yet it was not until 2011 that the country made its first specific legal conviction of GBV, following the signing of the Anti-Gender-Based Violence Act (Government of Zambia, 2011).

Although Zambia is making progress in this arena as they are implementing formal and informal efforts to reduce GBV, ingrained and socially reinforced ideas about gender roles and the acceptability of violence make this issue difficult to address at the population level. Almost half of women and one-third of men agree that a husband is justified in beating his wife for the following reasons: she argues with him, neglects the children, goes out without telling him, refused to have sexual intercourse with him, or burns the food (CSO, MOH, and ICF International, 2015). In 2013–2014, more than 40% of women aged 15 and older had experienced physical violence, with the most common perpetrator of physical violence among ever-married women being their current husband/partner (63%) (CSO, MOH, and ICF International, 2015). Seventeen percent of women reported ever experiencing sexual violence and one in ten women experienced sexual violence in the 12 months preceding the survey (CSO, MOH, and ICF International, 2015). In most of the cases the perpetrator was someone close to the woman, either their current husband or partner, or their current or former boyfriend. Overall, about 40% of women suffered from spousal abuse, either physical or sexual, at some point in their life (CSO, MOH, and ICF International, 2015).

Within this national context of norms and behaviors, a multi-method study was designed to better understand the connections between women's partner relationships and their vulnerability to poor sexual and reproductive health. This study, known as the Women's Empowerment and Sexual Risk in Zambia Study, focused specifically on one area outside the capital city of Lusaka, and aimed to generate information to improve sexual and reproductive health services for women.

The Women's Empowerment and Sexual Risk in Zambia Study

Context

The Women's Empowerment and Sexual Risk in Zambia Study was conducted in an unplanned settlement area located about 2 km outside the Lusaka city center. People in the study area had typically moved there from the western and southern parts of Zambia to look for employment in the capital city. This area had experienced unplanned population growth, and thus consisted of informal dwellings and very little structure in terms of roads, drainage systems, and infrastructure.

Data Collection

This multi-method study employed four primary data collection methods: (1) community observation visits, (2) key informant interviews, (3) in-depth interviews with community members, and (4) a quantitative community survey. Community visits were a key aspect of the initial stages of the project to understand where residences and other landmarks such as schools and churches were located prior to survey distribution. Visits took place two to three times per week between the months of May and November 2011 with time spent in the community ranging from two to six hours per visit. These visits allowed for the observation of the living conditions, challenges/difficulties, and lifestyles of many of the individuals living in the study community. Field notes were taken to document observations. After all data were analyzed, a dissemination event was held in which results were presented to the study community to provide an opportunity for the community to provide feedback and contribute to the interpretation of the results. In this chapter, we focus on reporting findings from the in-depth interviews with women ($n = 41$) and the quantitative community survey ($n = 205$).

Respondents for the in-depth interviews were recruited from the community using a convenience sampling approach. A female community leader was the main point of contact and introduced the research team to several women in the community; other women encountered at common gathering venues in the community, such as markets, were also asked to participate in the interviews. Women at various life stages and with different backgrounds were interviewed. Interviews were conducted face to face by a trained interviewer, in the language that the participant was most comfortable speaking (English, Bemba, Nyanja, Tonga, Luchazi, or Tumbuka). A semi-structured interview guide was used to ask women about their background, marriage (or partner relationship) and sexual activity, partner relationship, empowerment, and social support. The open-ended nature of the questions provided the participants an opportunity to share their experiences, thoughts, and ideas in their own words; participants provided verbal consent prior to the interview and received an incentive of scented lotion and body spray for their involvement in the study.

Survey data collection followed qualitative data collection, allowing the research team to add questions and clarify wording. For the survey, power calculations indicated that a sample of 150 would be more than sufficient (80% power to detect an effect size of $d = .50$, and assuming 5% type 1 error). A recent census divided the study community into zones and into blocks within those zones. Sampling was conducted in three stages. In the first sampling stage, 7 of the community's 15 areas which are called "zones" were selected at random for inclusion. Next, each zone was divided into blocks, and within each block the households/plots were assigned numbers between 1 and 100. From each zone, three blocks were randomly selected; 40 random numbers between 1 and 100 were generated for each block. Trained survey research assistants were instructed to go down the list of numbers (ignoring duplicates) until they had conducted ten surveys in each block with women who met the selection criteria (between the ages of 18 and 59 and married or living with a man as if married). In the event that there were multiple households on one plot, a household was selected at random for participation in the survey. A total of 210 surveys were distributed (seven zones, three blocks per zone, ten sampled households, one survey per household), and 205 surveys were completed and returned. The survey contained questions about the woman's background, her social and economic situation, the nature of the relationship with her husband/partner, social and organizational support, empowerment, sexual health, and sexual risk behaviors. The survey instrument was translated into Bemba and Nyanja, the two main languages spoken in the study community.

Analysis

Qualitative Analysis

Both key informant and in-depth interviews were coded using established codes and emergent codes using Atlas.ti. After coding was complete, we ran queries to analyze the content and themes that emerged from the data. These findings were used to help understand the dynamics of women's sexual and reproductive health and their partner relationships, and in the interpretation and triangulation of findings from the survey data.

Quantitative Analysis

All quantitative surveys were coded and entered into SPSS v. 17. The data were then cleaned and study variables were created, including multi-item scales to assess partner communication, partner support, and experiences around GBV (see Table 19.1). For each scale, the Cronbach's reliability coefficient was calculated to measure the extent to which items in the scale are measuring the same construct.

In addition to the items in these scales, women were asked several questions about reproductive health and both their own and their partners' sexual health and risk. Women were asked if they experienced any of the following: stillbirths, unintended/unwanted pregnancies, medical termination of pregnancy/induced abortions, spontaneous abortions or miscarriages, and if they had any deceased children. The survey asked women how often (regularly, sometimes, never) their partner participated in risky behavior such as having multiple sex partners, going out until late, or coming home drunk. Women were asked about their knowledge of past or current girlfriends and about if they knew their HIV status and the status of their husband/partner. Women were also asked about their marital sexual relationship and condom use within the relationship. The survey also asked women about their HIV status, the status of their husband/partners, and children.

Table 19.1 Communication, partner support, and GBV scales

Type of scale	Definition and construction
Communication	Women were asked if they always, sometimes, or never communicated well with their husband on various topics. A communication was constructed utilizing the 14 questions about husband-to-wife and wife-to-husband communication. The range of the scale was 0–2, with 0 indicating never communicating well and 2 indicating always communicating well (alpha = .926, skewedness = .29, range 0–2, mean = 1.29).
Partner support	Women were asked how often (regularly, sometimes, never) in the past 3 months they received support from their partners on various household tasks. An eight-item scale was constructed with items coded as either sometimes/regularly receiving support or never receiving support (alpha = .886, skewedness = .229, range 0–8, mean = 3).
GBV	Women were asked various questions about experiencing GBV. For all the questions related to GBV, women were asked to respond if the incident either happened always (1), sometimes (2), and never (3) in the past 12 months. The types of GBV included emotional/verbal, physical, sexual, and social violence. A composite scale of the 20 total GBV questions was constructed; the range of responses was from 0 to 17, with a higher number indicating more instances of GBV (alpha = .889, skewedness = 1.058, mean = 4.5). On average women reported experiencing 4.5 instances of abuse in the past 12 months.

Results

Demographics

In-Depth Interview Participants

The 41 women who participated in the in-depth interviews were between 21 and 68 years old, with an average age of 42 years. The level of education for female in-depth interview participants was also low, averaging six years. Of the 41 women who participated in the in-depth interviews, 24 women stated that they were married (with 4 of these reporting that it was their second marriage), 11 were widows, five were divorced, and one was separated. Although some women interviewed in the qualitative component were not in a relationship at the time of the interview, all of the women had at some point been in martial or marital-like relationship and provided information about their previous relationship(s) where relevant.

Survey Participants

A total of 205 women completed the quantitative survey. Women's age ranged from 17 to 53 years with an average age of 31. The women who knew their partner's age (n = 193) reported that their partners ranged in age from 22 to 66 with an average

age of 37. Women's total years of education ranged from 0 to 14 with a mean of 7 years of education, and 16 women reporting no formal education. Women reported that their partners' years of education ranged from 0 to 17, resulting in a mean of nine years and seven male partners reported as having with no formal education. The educational characteristics of women in both the in-depth interview sample and the quantitative survey sample are consistent with the 2015 ZDHS, which found men to have higher levels of education than women, and about twice as many women as men (8% vs. 4%) had no formal education. About 34% of women had some form of employment, compared to 97% of their husbands or partners. Of the women that were employed, 89% were self-employed having businesses such as selling produce or goods, or running hair salons or tailor shops. Whereas only 6% of women had full-time employment, 58% of their husbands/partners were employed full time and 28% were self-employed. More husband/partners (14%) did piece work or contract work compared to 6% of women.

Integrated Findings: Reproductive Health, Sexual Health, and Martial Relationship

We first present a summary of findings (Table 19.2) about reproductive and sexual health, followed by findings about the marital relationship: communication, partner support, and GBV. Qualitative and quantitative findings are presented together, to demonstrate how the different data support, contrast, or expand upon apparent themes and experiences. For quantitative data, descriptive statistics and correlations were calculated to understand some of the relationships between variables; relevant findings are also presented.

Women discussed sexual and reproductive health problems as some of the major challenges they face. Women who reported more reproductive health problems were less likely to be educated, more likely to report experiencing food insecurity, and also more likely to report having experienced abuse in their current relationship. Having a positive partner relationship—e.g., having better partner communication—provided women with a source of support and facilitated discussions that at times mitigated these problems. Greater communication was associated with fewer sexual risk factors and fewer reports of abuse. The survey findings also show that more partner support was associated with less sexual risk. However, regular partner support—especially tasks that culturally defined as being in the woman's domain and those that women discussed as part of their daily routine (i.e., fetching water, cleaning, cooking, and caring for children)—was low.

Partners' behaviors were also discussed as a major factor that impacted women's overall health and well-being. Women who were less educated and reported more instances of food insecurity were also more likely to have their partners participate in risk behavior. Alcohol abuse and extramarital sex were commonly discussed by participants as having a negative impact of the relationship and as a pathway to sexual risk within the relationship. Women discussed their partners' drinking as

Table 19.2 Summary of findings from in-depth interviews and quantitative survey

	In-depth interviews (women) ($n = 41$)	Survey ($n = 205$)
Reproductive health problems	"I had 5 children with him, all but one died. They were all boys and died at the ages of 5 years, 3 years, and 1 year, 8 months, and 10 months. When I went to check with the doctor, I was told that everything was okay with my womb." (44-year-old woman) "I went up to form 2, I got pregnant and that's how I stopped going to school." (47-year-old woman) "Som3e women who are pregnant out of wedlock … they will feel ashamed or if they don't have any means to look after themselves, they wait for the pregnancy and before it becomes too big then they abort. They do this using home remedies … they do not usually go to the clinic." (47-year-old woman)	35.6% (73) women experienced at least one reproductive health problem 4.9% (10) experienced two 2% (4) experienced three Women who experienced more reproductive health problems were also more likely to report having experienced abuse (0.333; $\alpha < .001$)
Partner's behavior and sexual risk	Women described men's drinking negatively and as a pathway to sexually risky behaviors "He goes drinking and starts to insult me and pick fights even when I didn't do anything." (27-year-old woman) "Some time back we used to have problems because of drinking, but now that he has stopped everything is fine." (32-year-old woman) "My husband would have extra-marital affairs and things would be bad when his girlfriends were around." (40-year-old woman) "The relationship got bad because he was looking everywhere for women … he became unfaithful and would chase me out of our home so he could bring other women … sometimes I would sleep in the bathroom because there was nowhere to sleep … when he didn't bring any women home, he would sleep away." (44-year-old woman)	30% of women stated that their husbands had a girlfriend at some point during their relationship and 10% stated that their husband had a girlfriend at the time of the interview 8% of women were HIV positive and 6% of their partners. Seven percent of women did not know their HIV status and 22% of women did not know the status of their husband/partner To the question: can you refuse if your husband/partner demands sex and you do not want it, 144 (70.2%) of women said no and 60 (29.3%) of women said yes To the question: can you ask your husband/partner to use a condom if you wanted him to, 136 (66.3%) women said no and 68 (33.2%) women said yes

(continued)

Table 19.2 (continued)

	In-depth interviews (women) (*n* = 41)	Survey (*n* = 205)
Relational characteristics: communication	"We do not communicate much, he does not like to listen to me or take other people's advice…I don't know what can be done about this." (21-year-old woman) "We are partners. This is what I like about the relationship. Most things we usually consult and do them together. There is nothing bad about the relationship." (43-year-old woman)	Women stated that they communicated better with their husbands than their husbands did with them. More women stated that they always communicate well, with 52% of women indicating that they always communicated well on family matters. For the majority of questions women stated that both they and their husbands sometimes communicated well. The worst form of communication was around topics of disagreement with women stating that 13% of their husbands never communicated well when it came to such topics
Relational characteristics: partner support	If a household has an adolescent niece or daughter, the expectation is that the girl, rather than the woman's husband, performs the majority of the household tasks "The bad thing about the relationship was that I used to fend for myself. I did this by fishing since my husband did not give me support and was not responsible" (*woman age unknown)*	Few husbands regularly helped women on the tasks of cooking (1%), fetching water (1.5%), washing clothes (.5%), and utensils (.5%). Since these tasks are traditionally expected to be women's duties the low frequency of participation is not surprising. Yet more men regularly helped with taking family members to the doctor (16.8%), purchasing groceries (21.2%), and providing childcare (18.5%)
Relational characteristics: GBV	"Women complain that there is too much abuse; some will say that my husband drinks a lot. Such things here (abuse), they don't take them so serious." (30-year-old woman) "There is nothing good about the relationship. He goes drinking and starts to insult me and pick fights even when I didn't do anything … I don't know what I can do to change the situation." (27-year-old woman)	The majority of women (86.8%) experienced at least one form of either emotional, sexual, physical, or social abuse: Emotional (39%) Sexual (16%) Physical (28%) Social (82%) On average women reported experiencing 4.5 instances of abuse in the past 12 months

(continued)

Table 19.2 (continued)

	In-depth interviews (women) ($n = 41$)	Survey ($n = 205$)
Linkages communication and SRH outcomes	"In terms of decisions … there isn't much help. I'm the one that does the purchasing, he doesn't ask where the money is coming from … I can't even ask him why he doesn't help … With the money he earns he either drinks it or gives it to his mom …." (39-year-old woman)	Women thought that they communicated better with their husbands than husbands did with them Limited communication associated with increased sexual risk factors ($r = -.310$, $\alpha < .00$)
Linkages partner support and SRH outcomes	"The children and I go to church, but my husband does not go, he is difficult … I have been for VCT [voluntary testing and counseling], but my husband refuses to go." (23-year-old woman)	More partner support was associated with less sexual risk ($r = -.209$, $\alpha < .001$) Women whose husbands/partners participated in more risk behavior were less likely to receive partner support
Linkages GBV and SRH outcomes	"Many of the women I know, their marriages are not stable their husbands beat them or have another woman that they bring to the house; they are not hiding the fact that they are having an affair." (55-year-old woman)	Having more experiences of GBV was associated with also reporting more reproductive health problems ($r = .323$, $\alpha < .001$) and greater sexual risk ($r = .220$, $\alpha = .002$)

leading to acts of GBV, abuse, and sexually risky behaviors. More instances of GBV were associated with more reproductive health problems and greater sexual risk. Although some women interviewed described leaving abusive relationships, we found that other women did not leave for fears that they would be unable to provide for their needs and/or the needs of their children. Such fears are often coupled with cultural beliefs and practices that make it difficult for a woman to leave her husband.

Conclusion

For women who are married or in long-term partner relationships, the nature of their primary partner relationship plays a critical role in both their sexual and reproductive health, as well as sexual risk. Findings from this study highlight the ways in which aspects of the marital/partner relationship were associated with sexual and reproductive health problems. In general, a positive partner relationship was associated with better reproductive and sexual health. Women in relationships where they experience GBV, poor communication, and limited support from their partners are at greater risk for sexual and reproductive health problems. These findings have important implications for interventions and programs seeking to reduce women's sexual risk and improve their reproductive health outcomes. For women in marital or long-term partner relationships, the nature of the relationship with their primary partner is a significant variable in their sexual and reproductive health outcomes. Therefore, in order to have a significant impact programs and interventions aiming to reduce women's sexual risk and improve their reproductive health outcomes must also target women's primary male partners. Couple-based interventions aimed at improving partner support, communication, and addressing gender inequalities and structural factors that increase women's risk for abuse show promising potential to improve women's sexual and reproductive health outcomes.

Discussion Questions

1. Think about the relationship dynamics of people in your life. What are the positive dynamics or aspects? What are the negative aspects? In what ways do these aspects of their relationship affect other aspects of their life such as their health and well-being?
2. If you were to design a program or intervention to address some of the sexual and reproductive health problems that women face, what kind of intervention or program would it be? Why? What would the key components of the program or intervention be? Why?
3. Women's empowerment programs and interventions have long been implemented as a way to improve women's overall health and well-being. Why do you think these approaches have been implement? What are some challenges that you think would be associated with these programs or interventions? Why?

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Chapter 20
Women's Sexual Pleasure and the Intimate Spaces of Heterosexual Sex in Cape Town, South Africa

Laura Pascoe

> *"I must be very honest; I only became sexually comfortable with myself in my late 20s. I don't want that to happen to my kids. I don't want that to happen to my daughter. Because of society, because of the way we lived—and I lived in a very orthodox society—in the box, where we were segregated from the rest of the world; I don't want that for my kids. I want them to know about things." (Najwa, Indian English- and Afrikaans-speaking female, 38)*

Introduction

This chapter examines how heterosexual women of various racial, ethnic, socioeconomic, and religious backgrounds in South Africa come to understand and engage with their own sexual pleasure as part of their broader experience of negotiating the intimate spaces of sexual activity. Sexual pleasure is often considered a "luxury" in relation to the necessity of negotiating safer sex, yet sexual pleasure is one of the most widely held motivations for engaging in both solo and partnered sexual activity. Additionally, the interruption of sexual pleasure is one of the most frequently cited reasons for not employing HIV- and pregnancy-preventive measures, such as the use of condoms (Fortenberry, 2013; Higgins & Hirsch, 2008; Meston & Buss, 2007; Ott, Millstein, Ofner, & Halpern-Felsher, 2006; Tolman, 2012). Thus, it is critical to examine not only the ways in which sexual pleasure is negotiated in the intimate spaces of heterosex, but also how sexual pleasure and HIV and pregnancy prevention are negotiated *in relation to* one another within these spaces.

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These negotiations of risk and pleasure, in heterosexual relationships, must also be put into the context of gender-power dynamics, or the ways in which social power between men and women is organized through gender roles and expectations (Braam & Hessini, 2004; Wood & Jewkes, 1997). These power dynamics, informed by income inequalities, styles of communication, and societal rules for men's and women's "acceptable" sexual behavior, are some of the greatest influencing social pressures in heterosexual relationships, and often leave women vulnerable to their partner's sexual and contraceptive decision-making preferences (Dunkle et al., 2006; Dworkin, Hatcher, Colvin, & Peacock, 2015; Harrison, O'Sullivan, Hoffman, Dolezal, & Morrell, 2006; Harrison, Xaba, & Kunene, 2001). Where men are expected to have sexual prowess and engage in sexual risk-taking behavior, for example, women are expected to be chaste and bear the burden of pregnancy and HIV prevention (Jewkes & Morrell, 2010; Mantell et al., 2009; Sia et al., 2016; Varga, 2001).

Scholars have highlighted the ways in which women's negotiation of their own sexual pleasure needs to be understood in relation to negotiations of HIV and pregnancy prevention (Higgins & Hirsch, 2007, 2008; Jolly, Cornwall, & Hawkins, 2013). In particular, some have raised the concern that the lack of acquired sexual communication skills around sexual pleasure may disproportionately impact women's subsequent ability to negotiate prevention, as well as their own pleasure (Higgins & Hirsch, 2007; Quinn-Nilas et al., 2015). As Babatunde and Ake (2015) aver, "unequal power relations restrict young women's control of their sexual practices with respect to negotiating their sexual safety and pleasure" (p. 58). Put simply: a woman's ability to successfully negotiate safer sex is, for most, enhanced by her understanding of her own sexual pleasure preferences and her ability to communicate these to her partner(s).

Sexual Pleasure in Context

Unfortunately, positive aspects of sexuality are often left out of sexuality education curricula and public health interventions that, intead, employ fear-based messages focusing on the risks of sex, namely among them HIV and unintended pregnancy (Cameron-Lewis & Allen, 2013; Higgins & Hirsch, 2007; McGeeney & Kehily, 2016). This is particularly the case in South Africa, where the inequalities driving the dual epidemics of HIV and gender-based violence, as well as high rates of unintended pregnancies have provoked a raging moral debate at the intersections of sexuality, race, and class (MacPhail & Campbell, 2001; MacPhail, Pettifor, Pascoe, & Rees, 2007; Mkhwanazi, 2014; Morroni, Smit, McFayden, Mqhayi, & Beksinka, 2003; Posel, 2011).

These moral debates are greatly informed by colonization, medicalization, and, in South Africa, apartheid. Apartheid was a racial segregation system put in place by an all-white government between 1948 and 1994 that also heavily policed sexuality (Elder, 2003; Klausen, 2015; Posel, 2005). These intersecting processes in South Africa led to a silencing around sexual pleasure and, more broadly, a sex-positive approach to sexuality education (Buiten & Naidoo, 2016; Elder, 2003; Posel, 2011). Medicalization, or the process by which human conditions become medical issues to be defined, diagnosed, and treated (Conrad, 1992), has, in conjunction with the colonizing process of "civilizing" and "controlling" the "Other," also meant that discourses around sexuality in South Africa and the region have focused on "disease" and "population control" (Foucault, 1990; Klausen, 2015; McClintock, 1995; Stoler, 1997). African sexualities became something to be contained within the biomedical sphere, with little space to break free from such constraints (Dworkin, Lerum, & Zakaras, 2015; Tamale, 2011, 2014; Vaughan, 1991). Thus, the narrative around what drives the HIV epidemic—individual behavior with roots in the "naturally" hypersexualized African—linked seamlessly with the conceptual framework of sexuality used in colonial relations in countries such as South Africa (Elder & Carmody, 2008; Epprecht, 2008).

From early colonial writings through much of what is written today, these social constructions of race have been mapped on to misrepresentations of female sexuality, including the use of over-exaggerated imagery of large black female genitalia in medical and anthropological texts to "prove" the hypersexuality and bestial "nature" of black female sexuality, which was subsequently situated as inferior to white female sexuality and all male sexualities (McClintock, 1995; Saint-Aubin, 2005). African sexuality then, has become defined by its so-called impulsive essence (Epprecht, 2008, p. 67), and noticed insofar as the epidemics of HIV, rape, and unintended pregnancies wage war through it. Through this lens, black bodies are left to embody only negative, dangerous, and immoral attributes, and female black bodies, in particular, are rarely given the space to be perceived as capable of "normal" manifestations of sexuality, or embodying a "positive" or "healthy" set of desires and moralities (Epprecht, 2013; Osha, 2004; Stoler, 1997; Tamale, 2011). White African sexualities, and especially heterosexualities, are all but invisible, glossed over in the already limited conversation around African sexualities (Arnfred, 2004; Tamale, 2011).

African sexualities have thus been conceptualized as little more than a singular, essentialized entity. This is what Nigerian feminist and literary scholar Chimamanda Ngozi Adichie might call the "single story" of discourses around sex and sexuality (Adichie, 2009). This so-called single story makes it particularly difficult to map notions of love, compassion, health, and nonviolence onto black and non-black bodies as a means of understanding sexuality. Simultaneously, the intimate spaces of negotiating prevention and pleasure in South Africa and the continent more broadly are simplified into a rigid assumption of gender-power dynamics that cast men as all-powerful and women as victims in need of protection, but not worthy enough for true autonomy around their own sexuality and reproduction. The result of this is twofold: it unceremoniously relegates men and women into monolithic categories, and it provides little space for women and men to find positive and productive ways of learning about and negotiating safer and more pleasurable sex, both for themselves and for their sexual partners (Mathe, 2013; Stern & Buikema, 2013; Varga, 2001).

Thankfully, scholars and researchers have more recently sought to debunk these myths and provide more accurate and in-depth knowledge around the full extent of the capacities and experiences of female sexuality (cf. Austin, 2016; Higgins & Hirsch, 2007, 2008; Kolodny & Genuske, 2015; Mazloomdoost & Pauls, 2015; Nagoski, 2015; Saliares, Wilkerson, Sieving, & Brady, 2017). Dworkin et al. (2015) have further brought attention to the dearth of sexuality research relating to women's sexuality and sexual pleasure in the Global South. Adding to this small but growing body of work, the research presented in this chapter contests the monotone around sexuality with great diversity among a highly diverse population.

This works takes a feminist and "sex-positive" approach to sexuality. A "sex-negative" or "fear-based" approach frames sex as negative and problematic and associates it with risk and shame (Fortenberry, 2013). Rather, a "sex-positive" approach—which is not to be misunderstood as "pro-sex"—is far more encompassing and comprehensive; it seeks to remove the attachment of shame and stigma from sexuality, and it emphasizes that all forms and types of sex, as long as healthy and mutually consensual, are a positive and natural aspect of human sexuality (Fortenberry, 2013; Jolly, 2016; Kismödi, Cottingham, Gruskin, & Miller, 2015; Williams, Prior, & Wegner, 2013).

Methods

The primary data for this chapter come from eight in-depth semi-structured interviews with South African[1] women, aged 26–39 in the Cape Town area, who were selected through purposive sampling. The questions asked for this research required a grounded theory qualitative approach (Charmaz, 2006; Charmaz & Olesen, 1997), and the data set was deliberately small as it allowed the focus to be on a relatively "small number of information-rich cases" (Patton, 2014). The interviews were conducted as part of my doctoral research, which included interviews with men as well as women and examined the production and dynamics of gender in the intimate spaces of heterosexual sex, particularly in relation to negotiations of HIV and pregnancy prevention and sexual pleasure. These primary data were supplemented by my experience working in and with the gender justice community in South Africa and the sub-Saharan African region over a seven-year period that overlapped with the timing of this research.

Research participants reflected South Africa's heterogeneous population and consisted of black, white, and colored[2] individuals from Xhosa, Sotho, Afrikaans, English, German, and Indian ethnic backgrounds, all of whom came of age and

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[1] One of my female research participants, Saru, was initially from Zimbabwe, but was included as a research participant because of the similarities of the Zimbabwean cultural and religious contexts and the fact that Saru moved to South Africa before she had had any sexual experiences.

[2] The racial terminology in South Africa is specific to its history and colonial legacies. "Colored" was a term employed by the apartheid government to categorize those who did not fit into the defined "white" or "black" categories, but it continues to be used as a racial and ethnic identity for many. The participants in this research are referred to by the ethnic term they most closely identified with.

became sexually active in the years leading up to or immediately following the fall of apartheid and birth of democratic South Africa in 1994. All research participants had employment and represented a variety of different socioeconomic, religious, and educational backgrounds. Research participants were not asked to disclose their HIV status, although from the details provided in the interviews it appears that no one was aware of an HIV-positive status. Importantly, I chose individuals who self-identified as gender aware, meaning they had an understanding of gender inequality and believed in the value of gender equality. This was key to my approach to this research, as I wanted to speak with and learn from those who were more likely to have positive and gender equitable sexual experiences to pull from, and therefore further challenge the monotone of sexuality research in South Africa.

Procedure

Ethical approval to undertake this research was obtained by both the US host university's ethical board and the in-country ethics board at the University of Cape Town. All interviewees gave consent to their information being anonymously used, and names provided are pseudonyms. I conducted all interviews, in English, although some phrases in both Xhosa and Afrikaans were used and discussed by both the author and participants where relevant. Interviews lasted on average an hour and a half, and were tape-recorded and later transcribed, verbatim. I additionally took notes during the interview and completed field notes immediately following each interview. Data collection occurred during 2014–2015.

Data Management and Analysis

A thematic analysis was conducted using both transcripts and field notes to extract and synthesize key themes. Atlas.ti qualitative analysis software was used to help manage the coding of the interviews. An initial coding structure was developed inductively after I thoroughly read through the transcripts. Through a cyclical process of analysis these codes were then organized into themes by categorizing similar codes together, and additional themes were created as necessary. The data was then reexamined for major trends, relevance, and cross-cutting themes before the final analysis.

Findings

Female sexuality is a complex, multifaceted, and, for many, wondrous entity. However, when women do not understand the basics of their reproductive and/or pleasure anatomy, or have grown up in a society that promotes the notion that one's body is abnormal or shameful, it is difficult to successfully negotiate both the risks and pleasures of sexual intimacy. Through an analysis of how women narrate their experiences of becoming sexual beings, learn or struggle to climax, and negotiate their own sexual pleasure in relation to negotiations of HIV and pregnancy prevention with intimate partners, the findings presented demonstrate that the capacity and inner workings of female sexuality, and in particular women's sexual pleasure, have been misrepresented, misunderstood, and omitted for too long. And indeed, this chapter argues, if HIV, rape, and unintended pregnancies are to be successfully prevented in South Africa and globally, a more nuanced and sex-positive approach to sexuality, one that celebrates female sexuality and recognizes the dynamic ways in which prevention and pleasure are negotiated in relation to one another, is needed.

Experiences of Learning About Sex and Sexuality

Childhood and adolescent years are highly influential in the development of one's sexuality (Germain, 2015; Ponzetti, 2015). Unfortunately, most women interviewed spoke of sex-negative messages about sex and sexuality. Saru, a 31-year-old black Zimbabwean woman describes growing up in the "age of AIDS" in Zimbabwe where she had no formal sexuality education and relied on informal conversations in the school halls and fear-based messages from her mother. Saru recalls the messages her mother gave her: "Men just want sex from you, so keep your legs closed. Sex led to HIV/AIDS, led to men using you, which led to pregnancy, and sex was un Christian." Later in the interview, she explains her feelings of shame for being curious about sex in her adolescent years, and that only recently has she begun to shed these associations with sex:

> I remember once my dad caught me wanting to watch porn … I wanted to sleep in the lounge because there was a TV and I knew there was eTV [a television channel] which was completely soft porn and my dad told me "I know why you wanna watch stuff up there"… and I just remember complete embarrassment, and thinking, "Oh my god I'm so dirty." So I've always had that kind of shut down, all the time … so it's only now that I can kind of, actually, have a bit of liberation, so … now I'm starting to think about the sexual pleasure piece, in my late 20s and 30s; I never did before. (Saru, black English- and Ndebele-speaking Zimbabwean female, 31)

Jana, a 28-year-old white woman, grew up in an Afrikaner and Christian household and attended Christian public schools in Port Elizabeth, a small town in the Eastern Cape province of South Africa. Jana learned the basic "mechanics" of sex, she tells me, including being taught about contraceptive options by an unusually progressive teacher at her high school. Although Jana no longer considers herself particularly religious, she warmly reflects on being part of an abstinence-only, wait-until-marriage program that encouraged students to decide, before they were alone with a romantic partner, what their boundaries were for being intimate. For Jana, such preparation made her feel more in control of how to negotiate sexual experiences, and gave her an opportunity to think through what she was and was not comfortable with. Nevertheless, Jana struggled to learn very much about sex as it was not acknowledged, nor spoken of in the house or at school. She explains:

> We learned the biology of it, I think. And I just remember; it was the awkwardness around all of it … So like kissing boys and getting their attention was one thing; what happened after that was a big, blurry … unknown … And actually for a long time, I couldn't figure out exactly how it works, like the mechanics of basic insemination, at school or anywhere. Because no one would really talk about the act, or anything. (Jana, white Afrikaans-speaking female, 28)

While Jana recalls a general silence around sex interspersed with fear-based messaging, Owethu experienced much more explicit sex-negative messages which resemble that which Saru described above. Owethu, a 35-year-old black Xhosa-speaking woman who identifies as Christian, was also raised in a religious household in the Eastern Cape province. Owethu had a few friends that spoke positively about sex, but her primary information came from her mother and grandmother, who both explicitly employed sex-negative messaging. She says:

> When I asked my mum, she shouted at me, she said, "It's something you cannot do; it's wrong, it's evil"—that's what she told me. And I also went to my grandmother, and my grandmother said, "If you do that, you gonna die."… So I'm telling you, my mum never told me about these things; when I started to have periods, that's when she started telling me, "Okay, if you're gonna sleep with a man, you're gonna get pregnant." She never elaborate or say anything more than that … So that was my fear, but I didn't know anything else about it, but I only knew from friends that sex was good, and you should try it. (Owethu, black Xhosa-speaking female, 35)

Despite Saru, Jana, and Owethu all coming from backgrounds strongly infused with Christianity, their racial and ethnic differences, and indeed the "side" of colonialism on which they fell, informed the ways in which these Christian influences manifested for each of them. That is, Christianity played a key role in South Africa, as elsewhere on the continent as part of the colonizing process that sought to "civilize" black populations such that, as Sylvia Tamale posits:

> Religion, especially Christianity and Islam, stressed the impurity and inherent sin associated with women's bodies (Goodson 1991). Through religion and its proselytising activities, Africans were encouraged to reject their previous beliefs and values and to adopt the "civilised ways" of the whites. With these new developments came the emphasis on covering and hiding body parts. (Tamale, 2011, p. 16)

A few women interviewed experienced more sex-positive messages and openness towards sex within their familial context, such as Addington. Addington, a 30-year-old, English-speaking white woman of Jewish heritage who grew up in Cape Town, explains that her mother "was very like, 'I don't want you to feel like you can't bring someone home; I'd rather know that you're here in the bedroom doing whatever you gotta do than I don't you where you are and who you're with.'" Still, Addington reflects the wider sentiment of those interviewed when she goes on to say:

> We were never taught that sex is an enjoyable thing. So you learnt about what people do, and you learnt the precautions and what can happen, and the diseases; but they were never, like, "This is the clitoris"; and "This is how you should approach the topic with a partner." (Addington, white English-speaking female, 30)

The Road to Climax

"Knowing where the clitoris *is* is important, but knowing where *your* clitoris is … that's power." (Nagoski, 2015, p. 24)

For most of the women interviewed, their journey of self-discovery around their own sexual pleasure was fraught with insecurity, anxiety, feelings of inadequacy, and ongoing uncertainty about the basics of why and how their body responds to certain stimulation and what these responses may or may not say about them. All of the women expressed frustration about how long it took them, once sexually active, to discover their own sexual pleasure, including orgasm.

Lisa, a 26-year-old white woman who grew up attending all-girls Catholic schools in the KwaZulu-Natal province, had her first orgasm a few years after her sexual debut at age 20. She describes herself as being quite late in learning how to orgasm, that she still does not climax easily, and expresses concern that this is not "normal." She references movies she watched growing up, including *Shakespeare in Love*, and the way that the female main character's sexual debut was depicted as filled with bliss and, of course, orgasm. "And it's like," Lisa says, "surely that's not what's happening to most women? That is just … I mean; I didn't have an orgasm the first time I had sex. Did you?" She continues, "And so yeah; that process takes a while to figure out. Even with, like oral sex, I didn't even quite see it coming … which is awful, because you're having a really nice time, and then suddenly—" she references the feeling of surprise when an orgasm is building but not knowing how to handle it, "you're like 'no, I'm fine, I'm fine!!'"

Prior to reaching climax for the first time, Jana, 28, experienced anxiety and fear around the possibility that she would never be able to orgasm. She tells me, "You read these articles where they say 'this many percent women never have one', so then you think 'is that me?'" She reflects on her first experience of climaxing and why she thought it happened when it did, with her partner she is now engaged to and has been with for nearly 6 years. She says:

> Oh yeah; that happened very late … It's funny; I think, only exploring it in a space where I could … relax? … But if I had a daughter, I would want her to own it a little bit more, and not wait for someone else to be like "Can I please you?" And then be like "Yes, yes that would be nice!" Instead being like, "I can please myself, or find some other way to explore pleasure." But it wasn't, like, I actively repressed it; it just was something that I … didn't get to, in a way, in my mind. Yeah so, I had my first orgasm with [my current partner] … it was not during sex, it was him using his hands, to be specific. But yes, it was like "Ohh ok; so this is what happens when you keep going." You realize you would know when it happens! (Jana, white Afrikaans-speaking female, 28)

Natalie, also aged 28, has never experienced an orgasm. Natalie placed a lot of blame and pressure on herself for her self-perceived "frigidity" while at the same time realizing that it was important to have a partner who cared about and showed interest in her sexual pleasure. During the interview, as Natalie shifted around uncomfortably in her chair, she explains that she is quite conservative about sex. She tells me, "I also haven't—and I've lied about this—but I haven't had an orgasm yet.

Yeah; so that is something that [my current partner] and I are … working on. Which is nice; like he's very open and it's really important to him. He's like, 'I can't have fun if you're not having fun.'"

Natalie then shares a bit more about the pressure she feels in needing to achieve orgasm, and the vital role her partner plays in helping her discover her sexual pleasure:

> But I don't know; I don't know why I stop it from happening. It's like, I'm so close sometimes and then I fall back, or whatever. So, I just think [with previous sexual partners]; it wasn't that important to them, and it didn't seem to affect their pleasure. And I was like, "That's fine; then I don't have to face it." But, like, I really appreciate the way [my current partner] is handling it, and … I think it would have been really nice if [my previous two partners] had like, shown interest? … Cuz it is a joint thing, you know; you're supposed to bond, yeah. And if they handled it the way [my current partner] handled it, it probably would have been nicer. (Natalie, white English-speaking female, 29)

For both Lisa and Jana, their first orgasms were the result of clitoral stimulation, either through oral sex or digital stimulation (or "fingering"), and Natalie anticipates having a similar experience. This is not at all uncommon, as the vast majorities of women do not regularly, or even more than rarely, orgasm from vaginal-penile intercourse alone (Wallen & Lloyd, 2011).

Still, for Saru, 31, and Owethu, 35, their preference for clitoral stimulation, particularly as they experience it during oral sex, is marred by social and cultural expectations of what kind of sexual activity heterosexual women should prefer, to the point that they both jokingly suggest that they might be lesbians because they enjoy oral sex. Both Saru and Owethu experienced shame and stigma growing up because they were curious about sex, though both have subsequently become more comfortable with their sexuality. For Saru, her insecurities in enjoying oral sex came from assumptions she had learned from her family, peers, and media about how sex and orgasms worked. She explains:

> I had this assumption that the penis goes in the vagina and you orgasm, so that's what I thought. And I kept waiting! And thinking, "Where are these guys?" These ones are doing their thing and nothing; they seem to be having fun, but I'm not having any fun, it's just [she makes a pounding noise]. You know sometimes I'm just like "Oh my god, please come; I'm really bored now." It just doesn't … the penis … maybe I'm a lesbian, because I just don't … so, sexual pleasure was not even on my radar. (Saru, black English- and Ndebele-speaking Zimbabwean female, 31)

Owethu, a black Xhosa-speaking woman, expresses her preference for oral sex and the tensions she has in enjoying this sexual act considered by mainstream Xhosa culture to be taboo. The Xhosa men and women interviewed explained that mainstream Xhosa culture did not consider "foreplay"—kissing, touching, fondling, and digital or oral stimulation—as an acceptable norm. Xhosa friends of mine corroborated that oral sex, in particular, was considered a cultural taboo—giving and receiving by both men and women. Within mainstream Xhosa culture, it was expected that sexual encounters included initial kissing followed immediately with penile-vaginal intercourse. Of course many Xhosa people, including research participants such as Owethu, have rejected this notion and sought to debunk this taboo both within their intimate relationships and among their peer groups.

Nevertheless, for Owethu, who became sexually active at the age of 18, intimate spaces were comprised of brief kissing followed by penile-vaginal intercourse. Although she enjoyed most of the sex she engaged in during these early years, she would not orgasm. It wasn't until she had sexual partners in her late 20s who initiated and were open to oral sex that she was able to orgasm. Owethu explains: "I used to feel shy when someone put his [tongue] … doing the … sucking … I was enjoying that part; I'm enjoying more than penis. I don't know if I'm a lesbian but I'm enjoying that more than penis; I reach orgasm, when it comes to it. It tickles me. That one; I'm telling you it's intimate but—I enjoy it" (Owethu, black Xhosa-speaking female, 35).

On the other hand Addington, 30, and Najwa, 38, expressed much more confidence in knowing what they wanted, what worked for them, and how to ask for sexual pleasure. Despite describing a delayed discovery of their own sexual pleasure, they were confident in knowing that their sexual pleasure was important. Addington is a self-evident confident woman. She had her sexual debut with her first love when she was 16, and describes herself as a serial monogamist who dates progressive and feminist men. Addington reflects on her discovery of the female orgasm:

> I think the single most, like, significant revelation, was just the female orgasm. I think it took a while to be like, "That's an orgasm." Like, you know that it's nice, and we're told it's amazing, but then you actually have one and you're like, "What was that? That was awesome!!" So that was the biggest revelation. And then just knowing how to get there, and I think that's … maybe it's even come much later for me, being a serial monogamist; maybe I could have really looked harder at how to get there, but I think it's much more of a late 20s, 30s thing. (Addington, white English-speaking female, 30)

She goes on to explain her process of learning her capacity to orgasm:

> That I guess … that was a combination of partner, plus solo masturbation. Because then you realized "*joh!*" it can be much better on my own, which means, ok it's less vaginal intercourse, and it's more clitoral, at which point you're like, "Okay; I've made a big step in my own personal learning." And then when you know that, I also find it can change what positions you work with, because you know what gets you off.

Najwa, a 38-year-old Indian Muslim woman with three children, has had a wide range of sexual and relationship experiences. She explains that, as a Muslim woman, she felt burdened to carry out Muslim values that put women down and limit their sexuality while at the same time let men "go out and do their thing." Now, it is important for Najwa to know what works for her sexually, and also to ensure that her children grow up feeling comfortable to explore their own sexuality. She says:

> So, I must be very honest; I only became sexually comfortable with myself in my late 20s. And, I don't want that to happen to my kids. I don't want that to happen to my daughter. Because of society, because of the way we lived, and I lived in a very orthodox society, in the box, where we were segregated from the rest of the world; I don't want that for my kids. I want them to know about things … They must be open to it; they must be open to other people's ideas and so on. What tickles one might not tickle the other. (Najwa, Indian English- and Afrikaans-speaking female, 38)

Pleasure vs. Prevention: Is One a Luxury While the Other a Necessity?

> "… I was convinced that if this delicate taboo thing—sexual pleasure—could be negotiated by women, then almost anything can be negotiated …"—(Dorothy Akenova, INCRESE, Nigeria, cited in The Pleasure Project 2008 (Jolly et al., 2013))

The following section highlights the ways in which women come to learn about matters of prevention and pleasure in isolation from one another, and, further, the ways in which this has, for some, made negotiating prevention more difficult. Owethu, for example, a black Xhosa woman in her mid-30s, acknowledges that negotiating prevention is less intimidating for her than initiating a conversation around her own sexual pleasure. She tells me, "I will say … it's comfortable for me to ask someone to wear a condom, then anything…I find it easier to tell someone to wear a condom than … than saying I'm not satisfied."

For Saru, her fears around HIV and pregnancy prevention—and her experience that this burden is largely left to her—have had a detrimental impact on her ability to enjoy sexual intercourse. Although Saru feels strongly that men should take more proactive responsibility for safer sex, her experiences have also left her hesitant to trust that men will. She explains a situation in which she and a new partner were engaging in sexual activity:

> I'm thinking I wasn't going to have sex with this guy, so I wasn't really prepared. But then we did. So he pulled out condoms, and then we used them, but then they ran out, I think? But at some point before we'd had sex, alarm bells, he says to me "But you know sex feels best without condoms." So we use the condoms, but I have to check, because I felt like this guy is not going to use them, and then at some point, we ran out, but he still wanted to do it. So we did it like that for a while [with no condom], but then I stopped him. But the only way I could stop him was to insinuate that I might have HIV, because otherwise he was going to keep going. The pregnancy stuff was secondary. It was a really vulnerable, telling, scary moment for me. (Saru, black English- and Ndebele-speaking Zimbabwean female, 31)

Saru has recently decided to both switch to a long-acting reversible method of contraceptive (intrauterine device, IUD) and take more time to focus on and develop an understanding of her own sexual pleasure preferences. She explains that she feels these decisions will help her focus on her own sexual pleasure, and learn to better express her needs and desires:

> For me, part of taking responsibility for this stuff is about me being able to enjoy sex more; if I'm thinking "HIV/pregnancy" the whole time we're having sex, it's not as fun. Whereas if I know I have something, like the IUD, that works a little bit more than just condoms, then I can actually focus more on what's happening with me … And I didn't … I never gave myself that voice. I think the tide has turned on that now, because the last two years have been a little bit of a sexual revolution [for me], thanks to certain people in my life and finally getting some toys to pleasure myself, and that's how I'm starting to figure out what I like, and what buttons to push. Starting to also expect men to go down on me! (Saru, black English- and Ndebele-speaking Zimbabwean female, 31)

Jana and Addington both describe prevention as part of the "mechanics" and "logistics" of sex that they first learned; their own pleasure was something that came after they felt capable of negotiating prevention. Jana explains, “For me, in the way I’ve grown up and those experiences, [prevention and pleasure] were kind of separate. Like, it was the mechanics of it, and the pleasure was kind of a separate thing that happened later.” But, she adds, feeling comfortable with communicating about the pleasure component earlier on would have made negotiating prevention for her much easier.

Addington described learning the mechanics of her reproductive organs and sexual intercourse first, and experiencing this as quite separate from what she learned about pleasure. Addington was quite comfortable negotiating prevention as well as experiencing pleasure with her partners since she first became sexually active, although she too describes not discovering her own capacity for orgasm until her late 20s. Addington’s ability to successfully negotiate prevention appears to be the result of both her own general self-confidence and seeking out gender-equitable partners, many of whom she explicitly describes as feminists. Nevertheless, she is aware that, for many of her partners, their socialization as men has still resulted in a weakened emotional awareness that can make expressing themselves, particularly within intimate spaces, difficult.

Conclusion

This research challenges the traditional public health intervention model which reduces a sexual interaction between two people into a transaction through which risky behaviors occur. In providing a narrative arguing against this model, this research highlights the necessity of incorporating knowledge-building and engagement around positive aspects of sexuality, central among them sexual pleasure. It further illustrates the need for men to be engaged in sexuality education and for both women and men to understand the physical building blocks upon which female sexual pleasure is grounded. This would not only facilitate a better understanding of the gaps and misinformation around female pleasure anatomy and its corresponding desires and arousals, but also arguably highlight the importance of non-penile-vaginal sexual activity in cultivating gender-equitable and mutually pleasurable intimate spaces within a heterosexual context.

Women’s sexual and reproductive autonomies, this chapter argues, are critical for the achievement of gender equality. Leaving sexual pleasure—and the engagement of men—out of public health discourses perpetuates the oppression of women, increases the burden on women, and limits the success of sexual and reproductive public health efforts. For women of color in South Africa, for whom ownership of and control over their own bodies have been historically so extensively denied, this has been particularly detrimental. Developing a positive relationship with one’s own sexuality thus not only increases one's ability to successfully negotiate safer and more mutually pleasurable sex, but is a radical and important act in the pursuit of both gender and racial justice.

Discussion Questions

1. Why does this chapter argue that sexual pleasure, particularly for women, is an important element of sexuality that should be better recognized and incorporated into sexuality education and sexual and reproductive public health interventions?
2. Do you think the issues raised in this chapter are unique to the South African context, or are they recognizable in other contexts? In what ways?
3. In what ways do sexual and reproductive health public health interventions utilize a fear-based/sex-negative approach to sexuality? In what ways do they utilize a sex-positive approach? What do you think is the most effective in achieving long-term and meaningful change?
4. Consider your own experience of coming to learn about sex, including what you learned about both risk and pleasure. What about that experience made you feel good about your sexuality, and what made you feel fearful, ashamed, or unsure? Do you think your experience would have been different if you had been a different gender or sexuality? Why/why not?

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Chapter 21
Cervical Cancer Prevention in East Africa: Moving from Evidence to Implementation

Megan J. Huchko

Introduction

Cervical cancer is the leading cancer killer of women in most developing countries (Ferlay et al., 2015). It is a disease that exposes the marked disparities in women's health that result from income inequalities and place of birth. In the last five decades, it has become a rare disease in wealthy countries with well-organized screening programs (Adegoke, Kulasingam, & Virnig, 2012; Arbyn, Raifu, Weiderpass, Bray, & Anttila, 2009). However, it remains the third most common female malignancy worldwide, with a disproportionate impact in low-resource settings, where it claims the lives of hundreds of thousands of women who could have been saved with screening and relatively simple treatment (Forman et al., 2012). Women in low-resource settings have an up to 16-fold increased risk of developing cervical cancer compared to women in wealthier countries, with a greater risk of dying at a younger age from the disease (Ferlay et al., 2015; Forman et al., 2012). This leads to a significant social and economic impact on the current and future generation of women in these countries.

Despite the persistent disparities in disease impact, cervical cancer represents a worldwide health problem that has the potential to be impacted dramatically through advances in research and relatively simple prevention methods. Cervical cancer is unique among cancer types because it is slow growing, with a long, detectable precancerous stage. The last 20 years have seen an incredible increase in the knowledge about human papillomavirus (HPV), the causative agent in almost all invasive cervical cancers (Burd, 2003; zur Hausen, 1999). This was followed by the development of HPV tests to screen for cervical cancer, and introduction of an effective vaccine

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to prevent cervical cancer. The next challenge for researchers and program planners is to develop implementation strategies to maximize the impact of these effective cervical cancer prevention tools for the populations that need them most.

In this chapter, we present work done to contextualize a low-cost, evidence-based cervical cancer screening strategy for women living in rural western Kenya. Kenya is an East African country with a high incidence of cervical cancer. Western Kenya is a rural region with relatively poor healthcare access and among the highest HIV rates in the region (National AIDS and STI Control Programme, 2008; WHO, 2010). Preliminary work and the success of other preventative health models in the region led to the development of a cervical cancer screening program that employed periodic community health campaigns to reach women in remote areas. We carried out focus groups and in-depth interviews with key stakeholders to identify remaining barriers and facilitators to screening. The results were used to finalize the implementation strategy.

Worldwide Problem and Impact

Despite the fact that cervical cancer is highly preventable through organized screening programs, over 500,000 women are diagnosed with the disease every year (Ferlay et al., 2010b). Cervical cancer results in over 270,000 deaths each year, in many areas of the world impacting more women than pregnancy-related deaths (GBD 2013 DALY and HALE Collaborators, 2015). Cervical cancer shows a strong association with the level of economic development, with incidence being, on average, five-fold higher in resource-limited countries (Forman et al., 2012). About nine out of ten cervical cancer deaths occur in low-resource countries, with a particularly high burden in sub-Saharan Africa, where the mortality rate is 85% (Jemal et al., 2011; Sankaranarayanan, Swaminathan, Jayant, & Brenner, 2011). In sub-Saharan Africa, there are 35 cases of cervical cancer per 100,000 women annually, with 22.5 deaths from the disease (Ferlay et al., 2015). This compares to 6 new cervical cancer cases and 2.5 cervical cancer deaths per 100,000 women in North America (Adegoke et al., 2012). Eastern Africa and Latin America have the highest cervical cancer incidence and mortality rates in the world (Ferlay et al., 2010a). The World Health Organization projects a rise in the cases of cervical cancer over the next 50 years, despite the availability of a vaccine and cervical cancer prevention programs (Forman et al., 2012). The majority of that increase in incidence will be among women in low- and middle-income countries.

Cervical cancer mortality rates jump exponentially among women in their 40s, with women in low-resource settings disproportionately impacted at younger ages. Women between 45 and 54 are five times more likely to die of cervical cancer in low-income settings compared to high-income settings. The prevalence and age distribution lead to an estimated 7.8 million years of life lost in women attributable to cervical cancer (Forman et al., 2012). The loss of women at this age, often when they are the breadwinners and caregivers for their children and elder family members, has repercussions far beyond the grief to the individuals and their families. Cervical cancer deaths can have significant economic costs to the family and the community. Family members may take time off and can incur substantial medical costs caring for women with cancer. Losing women in the prime of their productive years can result in substantially lowered income for the family, pushing them into poverty or forcing them to prioritize their immediate needs of food and shelter over their longer term needs, such as education. In settings where women do not have equal rights or priority in the family, investment into girls' education can be disproportionately impacted (Molla, Mitiku, Worku, & Yamin, 2015).

Etiology of the Health Disparity

The dramatic difference in the incidence of cervical cancer between high- and low-resource countries is mainly due to the lack of access to effective cervical cancer prevention programs. Cervical cancer prevention strategies include vaccination for human papillomavirus (HPV) and organized screening programs. Most low-resource countries lack the healthcare infrastructure required for the cytology-based screening programs that have dramatically reduced the disease burden in wealthier countries. Screening coverage in low-resource countries ranges from 2 to 20%, with very few countries achieving effective screening, in which women are successfully linked to treatment (Louie, de Sanjose, & Mayaud, 2009). To address this disparity, the World Health Organization (WHO) recommends adoption of alternative protocols that employ low-cost or simple-to-use screening technologies (World Health Organization, 2013). One such strategy—high-risk HPV testing—has been shown to reduce the incidence and mortality from cervical cancer when coupled with outpatient treatment for women with HPV-positive results (Sankaranarayanan et al., 2009) (Fig. 21.1).

Structural Factors

The impact of cervical cancer prevention programs depends on two main context-specific factors: (1) women's access to screening and (2) successful linkage to treatment for women who screen positive. Cytology-based screening programs, coupled with effective treatment for precancerous lesions, have dramatically reduced the cervical cancer incidence and mortality in wealthy countries. While effective, these programs are resource intensive, requiring laboratory facilities, trained cytotechnologists and pathologists, laboratory and patient-tracking systems, and multiple visits for screening, diagnosis, and treatment. Most low-resource countries lack the funds, personnel, and healthcare infrastructure necessary to implement these programs that have been so successful at reducing cervical cancer mortality in wealthier countries. When funds are present, there are often competing healthcare and

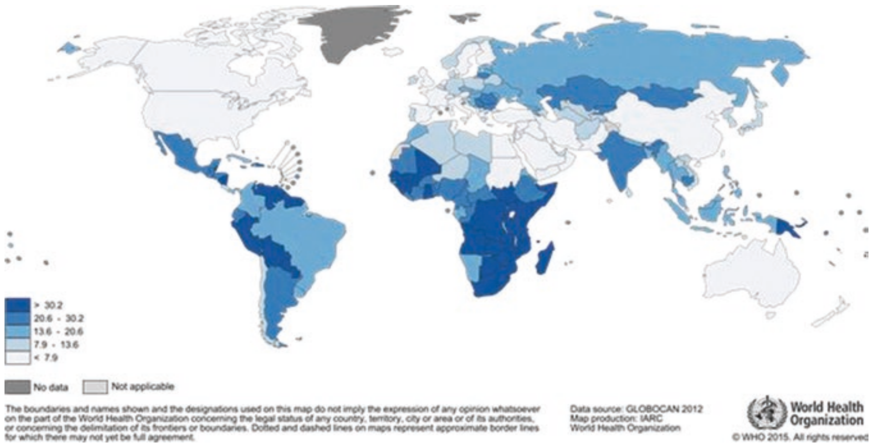


Fig. 21.1 World Cervical Cancer Incidence Map, 2012. Reproduced with permission from M. Ervik, F. Lam, J. Ferlay, L. Mery, I. Soerjomataram, F. Bray (2016). Cancer Today. Lyon, France: International Agency for Research on Cancer. Cancer Today. Available from http://gco.iarc.fr/today

development needs that get priority. Even when funds are available, access to both screening and treatment is most challenging in poor rural areas where the majority of women in many low-resource settings live, due to geographic and infrastructure constraints (Akinyemiju, 2012; Anorlu, 2008).

Screening programs have not only reduced the incidence of cervical cancer, but they have also changed the epidemiology of the cancer that is detected. The vast majority of cervical cancer detected in countries with screening programs is detected at earlier stages, where there are more successful and less invasive treatment options. More cancers of all types, including cervical cancer, are detected at a later stage in low-resource settings, where the poor prognosis is augmented by the lack of treatment facilities. This leads to the higher mortality rates seen in low-resource settings.

Biological Factors

Human Papillomavirus

HPV is the most common sexually transmitted infection in the world, and will infect over two-thirds of sexually active adults throughout their lifetimes. The vast majority of these HPV infections will by asymptomatic and clear spontaneously wit in 6–12 months of infection (Ault, 2006). There are 14 HPV types that are associated with the development of cervical cancer, and have been classified as high-risk. Persistent infection with high-risk HPV is the strongest epidemiologic risk factor for cervical cancer. High-risk HPV has been implicated in over 99% of cervical cancers (Doorbar, 2006; Forman et al., 2012; Walboomers et al., 1999). Risk factors for HPV infection and persistence include early sexual debut, multiple partners, immunosuppression, and smoking (Shields et al., 2004). Studies show geographic and population-dependent heterogeneity in HPV type distribution, which has implications on the effectiveness of both vaccines and HPV-based screening strategies (Bruni et al., 2010; Clifford et al., 2005; de Sanjose et al., 2007). The prevalence of high-risk HPV in sub-Saharan Africa ranges from 20 to 53%, based on studies in Kenya, Tanzania, Mozambique, and Zimbabwe (Bruni et al., 2010; Dartell et al., 2012; De Vuyst et al., 2010; De Vuyst et al., 2003).

Human Immunodeficiency Virus

While HPV is the necessary causative agent in most cervical cancer, there are other biologic factors that increase women's risk of developing cervical precancer and cancer. Women with HIV are at increased biologic risk for cervical precancer and cancer through multiple biologic mechanisms, and that risk increases with advanced immunosuppression (Abraham et al., 2012; Atashili et al., 2012; Castellsague, 2008; Chaturvedi, Madeleine, Biggar, & Engels, 2009; Denny et al., 2012; Schlecht et al., 2005; Strickler et al., 2005). HIV increases the risk for incidence, persistence, and coinfection with multiple HPV types (Dartell et al., 2012; De Vuyst et al., 2003; Denny et al., 2012; Sun et al., 1997). Unlike the other HIV-related malignancies and some non-HIV-related malignancies, studies have not consistently shown that cervical precancer and cancer incidence and outcomes are mitigated by use of antiretroviral therapy (ART) (Adler et al., 2012; Biggar, Chaturvedi, Goedert, & Engels, 2007; Bratcher & Sahasrabuddhe, 2010; De Vuyst et al., 2012). The relationship between HIV and cervical cancer is clearly demonstrated in Uganda, where 42% of women diagnosed with cervical cancer in the Kampala cancer registry between 2003 and 2010 were also HIV infected (Coghill et al., 2013).

HIV has had a broader impact on a woman's risk for cervical cancer beyond the biologic relationship. The countries with the highest burden of cervical cancer are often those with the highest HIV rates, especially countries in sub-Saharan Africa (Chirenje, Marrazzo, & Parikh, 2010). While HIV significantly increases a woman's risk for development of cervical dysplasia and cancer, until recently HIV and AIDS-related mortality outweighed the risk of dying from cervical cancer in these countries. Over the past five years, expansion of the healthcare infrastructure and improved access to highly active antiretroviral therapy have substantially decreased AIDS-related mortality (Bendavid & Bhattacharya, 2009). The impact of this prioritization is twofold. Important resources for other health services, including cervical cancer prevention, have been directed at addressing the immediate health threat presented by HIV. The resulting advances in HIV care and ART availability means that HIV-infected women are living longer and at higher risk for cervical disease in places without the resources to implement cervical cancer prevention programs.

Other Biologic Risk Factors

In addition to HIV, other conditions that decrease the immune function increase women's risk for HPV infection and cervical cancer. These include medications, autoimmune disorders, and organ transplants (Allegretti, Barnes, & Cameron, 2015; Bateman, Yazici, Leff, Peterson, & Paget, 2000; Madeleine, Finch, Lynch, Goodman, & Engels, 2013; Tam, Chan, Chan, Chang, & Li, 2004). Similar to other cancers, tobacco smoking has also been shown to be strongly associated with HPV infection and development of cervical cancer (Vaccarella et al., 2008). The risk is associated with the number of cigarettes and the duration of smoking (Sellors et al., 2000). Past smokers have a lower risk for cancer than current smokers. Other postulated secondary risk factors for HPV persistence and development of cervical dysplasia include use of oral contraceptive pills, a greater number of sexual partners, younger age at first intercourse, and higher body mass index (International Collaboration of Epidemiological Studies of Cervical, 2007). The evidence for most of these additional risk factors comes from epidemiologic studies, which are limited by the presence of confounding factors.

Strategies to Impact Cervical Cancer in Low-Resource Settings

The burden of cervical cancer can be impacted by primary and secondary prevention. Primary prevention is accomplished through vaccination and avoidance of HPV infection through delay in sexual activity and limiting the number of sexual partners. Secondary prevention consists of screening coupled with treatment of women who screen positive. Screening and treatment can be targeted at either precancerous lesions or HPV infections; both have been shown to reduce the risk of invasive cancer.

Vaccination

The most effective way to decrease the impact of cervical cancer on the next generation of women is through the widespread availability of the HPV vaccine. There are three commercially available vaccines that prevent infection with the most common cancer-causing high-risk HPV types. Vaccination is recommended for both boys and girls. The vaccine is given in a series of three doses, and is most effective if given during adolescence, before sexual debut (Petrosky et al., 2015).

In 2008, Gavi, a global organization that works to increase access to effective vaccines for the world's poorest countries, prioritized support for the HPV vaccine. This means that priority countries can access the vaccine at substantially reduced pricing, with additional support provided for vaccine implementation programs (Levin, Wang, Levin, Tsu, & Hutubessy, 2014). The WHO is also supporting research into alternative dosing schedules, looking at the efficacy of one- or two-dose regimens, which may be less challenging to implement in low-resource settings (Dobson et al., 2013).

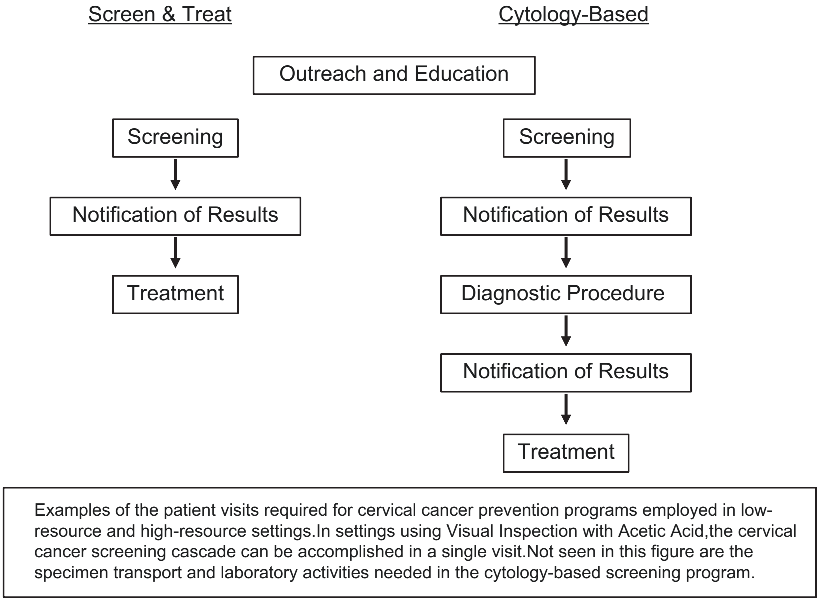
Screening

The high burden of cervical cancer combined with the lack of infrastructure and financial resources for cytology-based screening programs has led to the search for alternative screening strategies for cervical cancer prevention in low-resource settings (Denny, 2012). In order for screening programs to be effective, they must be coupled with effective and accessible treatment. In low-resource settings, it may be difficult for women to come in for the multiple visits necessary to get the diagnostic procedure, receive results, and return for treatment. For this reason, in addition to the limitations in laboratory personnel and the higher costs, cytology-based screening programs have not been suitable for implementation in most low-resource settings.

Screening techniques that can be directly coupled with treatment ("screen and treat") are more feasible in low-resource settings, reducing the visit burden for both patients and providers. In screen-and-treat strategies, a woman who has a positive screening test is referred directly for treatment with cryotherapy, either at a referral site or within the same visit for a "see-and-treat" protocol that does not include diagnostic confirmation with a colposcopy and biopsy (Gaffikin, Blumenthal, Emerson, & Limpaphayom, 2003). Figure 21.2 shows the difference in the number of steps necessary to complete the cervical cancer screening cascade in a cytology-based screening program, compared with a screen-and-treat strategy. While screen-and-treat strategies reduce the number of visits in the cervical cancer screening cascade, eliminating the diagnostic confirmation leads to an increase in referrals or treatment for women who do not actually have cervical precancer (Denny, De Sousa, Kuhn, Pollack & Wright, 2005a).

The most widely implemented low-cost screening technique is visual inspection of the cervix after application of 3–5% acetic acid (VIA) (Bradford & Goodman, 2013). This technique can be taught to and provided by nonphysician clinicians, and provides immediate results so treatment can be done at the same visit. Over the past decade, several large studies have validated VIA as an inexpensive and effective detection method with the potential to decrease cervical cancer incidence and mortality (Arrossi, Ramos, Paolino, & Sankaranarayanan, 2008; Denny, De Sousa et al., 2005a; Nene et al., 2007). In general populations, VIA has been shown to have a similar sensitivity (60–86%) and specificity (64–94%) to HPV testing and cervical cytology (Belinson et al., 2001; De Vuyst et al., 2005; Denny, Kuhn, et al., 2005b; Gaffikin, McGrath, Arbyn, & Blumenthal, 2007).

HPV testing is another method that can be used in a screen-and-treat strategy. HPV testing is more effective than VIA at detecting precancer (Denny, Kuhn, Hu, Tsai, & Wright, 2010; WHO, 2013a) and has been shown to reduce mortality from cervical cancer when coupled with outpatient treatment of precancerous lesions (Cuzick et al., 2012; Sankaranarayanan, Esmy, et al., 2007a). HPV testing is easy



Examples of the patient visits required for cervical cancer prevention programs employed in low-resource and high-resource settings.In settings using Visual Inspection with Acetic Acid,the cervical cancer screening cascade can be accomplished in a single visit.Not seen in this figure are the specimen transport and laboratory activities needed in the cytology-based screening program.

Fig. 21.2 Cervical cancer screening cascade

to perform and provides a simple, accurate result that can be implemented into easy-to-follow protocols (Denny, De Sousa et al., 2005a; Elit et al., 2011; Kuhn, Wang, Tsai, Wright, & Denny, 2010; Richman, Brewer, Liebman, Rinas, & Smith, 2011; Rositch et al., 2012; Stewart et al., 2007). HPV testing has the additional advantage of being offered to women for self-collection, thereby avoiding a pelvic and speculum exam. Self-collected specimens are highly accurate, with comparable results for HPV detection and cervical precancer as clinician-collected specimens (Petignat et al., 2007; Stewart et al., 2007; Zhao et al., 2012). Studies from around the world, including sub-Saharan Africa, have shown that women have consistently found self-sampling to be acceptable and preferable to provider-testing (Igidbashian et al., 2011; Ortiz et al., 2012; Trope, Chumworathayi, & Blumenthal, 2013; Ogilvie et al., 2013; Rositch et al., 2012). Studies in various countries have shown that a self-sampling strategy increases screening uptake by women who do not seek screening at clinics (Darlin et al., 2013; Leniz et al., 2013; Levinson et al., 2013; Sancho-Garnier et al., 2013; Snijders et al., 2013; Virtanen, Nieminen, Luostarinen, & Anttila, 2011). Widespread uptake of HPV testing in low-resource settings has been limited by the cost and availability of testing in these countries. However, in the past 10 years, a low-cost HPV test has been introduced specifically for use in settings with limited electricity and lab capability, vastly improving access to a highly accurate cervical cancer screening tool (Qiao et al., 2008).

Treatment of Precancerous Lesions

Screening must be coupled with one of the relatively simple, safe, and effective outpatient treatments to reduce the risk of cervical cancer. The most common treatment in low-resource settings is cryotherapy, a low-cost, effective method of freezing abnormal cells that can be safely carried out by midlevel providers (Santesso et al., 2012; Sauvaget, Muwonge, & Sankaranarayanan, 2013). The procedure takes approximately 10 min, does not require anesthesia or numbing medication, and is very rarely associated with any adverse events or side effects (McClung & Blumenthal, 2012). Cryotherapy machines are durable and portable, do not require electricity, and can be performed in all levels of healthcare facilities. Another safe and effective outpatient procedure is a loop electrosurgical excision procedure (LEEP). The LEEP shaves the area of abnormal cells off the cervix, allowing for treatment of lesions more concerning for invasive cancer or too large to be treated with cryotherapy. While primarily done by physicians or nurse practitioners, in one study LEEP was shown to be safe, effective, and acceptable when performed by clinical offers and other nonphysician clinicians (Woo, Cohen, Bukusi, & Huchko, 2011). Both treatment methods have very low complication rates, are effective at treating cervical precancer, and have not been shown to increase women's risk of acquiring or transmitting HIV (Chung et al., 2011; Diouf et al., 2011; Huchko et al., 2013). Cryotherapy has also been shown to be protective against future HPV infections, which may be a secondary benefit when cryotherapy is used in "screen-and-treat" strategies where treatment of women with a positive HPV test or VIA without pathologic confirmation may lead to overtreatment (Chirenje, Rusakaniko, Akino, & Mlingo, 2001; McClung & Blumenthal, 2012).

Implementation Strategies

To be effective, screening and treatment must be embedded in a cascade of cervical cancer prevention activities, including outreach, education, screening, communication of results, and linkage to treatment. There is marked attrition when screening and treatment occur in separate visits, reducing the health impact and cost-effectiveness of screening (Anorlu, 2008; Cronje, 2004; Goldhaber-Fiebert et al., 2005). The majority of health care in rural areas takes place in small health facilities with limited space, staffing, and equipment, making it challenging to implement same-day "screen-and-treat" strategies, that have been proposed to overcome barriers to treatment access (Sankaranarayanan, Rajkumar, et al., 2007b). Therefore, even when screening programs can be implemented, women will be required to visit a higher level health facility, often at great distance and cost, to access treatment. Tested strategies to improve attendance at follow-up visits for women with positive screening results are limited (Mutyaba, Mirembe, Sandin, & Weiderpass, 2009), but solutions from other areas of reproductive health include vouchers, text messaging or phone reminders, and mobile treatment units (Free et al., 2013; Herman-Roloff et al., 2011; Obare et al., 2013).

Implementation strategies for this cascade have not been evaluated for most low-resource settings, and most screening programs are done as part of limited donor funding or projects run by nonprofit organizations. One example is Kenya, which has a set of national guidelines for cervical cancer control, but relies on partner organizations for the majority of funding and implementation strategies.

World Health Organization and National Guidelines

In addition to evidence-based screening and treatment techniques, and implementation strategies, reducing cervical cancer rates will require the commitment of national and international policy makers. Addressing disparities in cervical cancer disease burden is a key part of the post-2015 global development agenda (Singhrao, Huchko, & Yamey, 2013; Tsu & Jeronimo, 2013). The WHO has named cervical cancer screening and treatment as a best-buy intervention, and recommends resource-limited countries implement cervical cancer prevention programs that couple HPV screening directly with treatment using cryotherapy for women who test positive, without necessitating confirmation by colposcopy or biopsy (Barnighausen, Bloom, & Humair, 2011; WHO, 2013b). This is based on strong evidence that "screen-and-treat" strategies in which HPV testing is coupled directly with cryotherapy reduce short- and long-term recurrence of cervical intraepithelial neoplasia, the direct cervical cancer precursor (Denny, Kuhn, et al., 2005b; Kuhn et al., 2010), and population-level cervical cancer incidence and mortality (Sankaranarayanan et al., 2009). The reduction in cervical cancer precursors was also seen specifically in HIV-infected women, who make up a greater proportion of the population in low-resource settings (Kuhn et al., 2010).

Case Study: Determining the Barriers and Facilitators to HPV-Based Cervical Cancer Screening in Western Kenya

Background

We sought to develop a context-specific implementation strategy to effectively deliver high-impact cervical cancer prevention using evidence-based screening techniques in western Kenya. Kenya is a country with high cervical cancer and HIV rates. HIV rates range from 2 to 35% in various regions of the country (National AIDS and STI Control Programme, 2008). Western Kenya is a rural region with relatively poor healthcare access and the highest HIV rates in the region (National AIDS and STI Control Programme, 2008; WHO, 2010). International donor funding, in partnership with the Kenyan Ministry of Health, has increased access and quality of health care in much of the region to address the HIV epidemic. This has allowed for healthcare access in many sites where it was previously unavailable. However, there are still struggles to maintain staffing, supplies, and facilities to provide primary care services outside of HIV care. In fact, cervical cancer screening rates are below 3% in rural areas of Kenya (WHO, 2003).

While it is clear that lack of funding and facilities is a substantial structural barrier to effective screening programs in many low-resource areas, we sought to better characterize the specific issues impacting availability and uptake of a nationally recommended cervical cancer screening program in order to develop an effective intervention. Although same-day screen-and-treat strategies for cervical cancer are feasible in some low-resource settings, most rural health facilities in Kenya lack the space, water, equipment security, and staff to support even simple treatment techniques such as cryotherapy (Kenya Ministry of Health, 2011). We completed a pilot study, in which we carried out structured interviews with health providers at Ministry of Health clinics in western Kenya to identify local barriers and facilitators for cervical cancer screening in rural government health facilities. We found that access to screening was limited by lapses in service availability and lack of clinic attendance for preventive care (Rosser, Hamisi, Njoroge, & Huchko, 2015). When services were available, both providers and patients found that the need for a pelvic exam limited the acceptability of screening. Based on our own work and literature from region, we sought to design an implementation strategy that would address the lack of consistent availability and uptake of cervical cancer screening services in health facilities, with a focus on the structural factors and health beliefs and behaviors, including reluctance on the part of providers to perform and women to undergo a pelvic exam.

Community-based health care, in which basic health care is delivered at household or village settings, outside health facilities and often by community health workers, has been explored in many low-resource settings as a way to improve the efficiency and effectiveness of limited healthcare infrastructure. Different models of community-based care have been shown to improve access to care and health outcomes in various reproductive and general health contexts as compared to strategies in which care is delivered through clinical facilities (Lassi, Haider, & Bhutta, 2010; Lewin et al., 2010). One model is the periodic short-term health campaign, a potentially high-impact and cost-effective way of providing healthcare interventions in low-resource settings where uptake of preventive health services is low and clinic staffing and resources are limited (Lugada et al., 2010). These brief but intense health campaigns are ideally attended by a large proportion of the population and provide health education, screening, and diagnostic services. By linking only those who screen positive to care, community health campaigns decrease the burden on healthcare facilities while providing a wider range of healthcare education and preventive services (Chamie et al., 2012). When screening is offered in health facilities, community-level impact is limited by the large number of women who do not attend government clinics or only attend clinics for their children's vaccinations or acute illness (WHO, 2003). Our formative work showed that lack of awareness of screening availability along with time and transport costs required for a clinic visit were major impediments to uptake of screening. We then carried out a successful pilot community health campaign in rural western Kenya, consisting of outreach followed by a brief campaign offering on-site screening and referrals for treatment, which had a screening uptake of >95% and was acceptable to providers (Huchko & Maloba, 2013).

To build on the successful pilot program and address reluctance around pelvic exams, we developed a strategy of screening for cervical cancer using self-collected specimens for HPV testing in periodic, high-volume community health campaigns. The community health campaigns would potentially increase efficiency and allow human and supply resources to be directed toward strategies to increase linkage to treatment, such as intensified follow-up, transportation assistance, or mobile units that bring treatment to remote villages. Thus, as has been seen in antenatal and HIV care (Chamie et al., 2012; Granich et al., 2012; Lassi et al., 2010), by combining community screening with enhanced linkage strategies, we felt that this implementation strategy could maximize the health impact by increasing the number of women screening *and* the proportion successfully accessing treatment. Offering HPV testing via self-sampling at community health campaigns would further address the provider and patient barriers cited above and has the potential to increase community-wide access to screening (Campos et al., 2011).

Methods

In order to further contextualize the intervention, we carried out a series of focus group discussions (FGDs) with women and key stakeholders (community leaders, clinicians, and members of the county Ministry of Health team). The goal of the FGDs was to obtain more specific information about barriers and facilitators of cervical cancer screening, and get feedback on the community health campaign model. The study took place in Migori County in the Nyanza Province of western Kenya. The Nyanza region borders Lake Victoria, with agriculture and fishing as the primary sources of income. Almost two-thirds of people in this region live on less than $1/day. We recruited participants from the population of women aged 25–65 in Migori County to take place in one of the two 90-min FGDs. We also recruited clinicians and key stakeholders for a separate FGD, including community chiefs, leaders of women's groups, reproductive health coordinators, medical superintendents and charge nurses, and community health workers of Migori District Hospital.

FGD guides were developed by the research team in collaboration with community health workers and clinicians who had been working in cervical cancer prevention in the Nyanza Province. Guides covered baseline knowledge and awareness of cervical cancer and screening strategies, personal experience with screening, personal and perceived barriers, and suggestions for improvement at various points of the cervical cancer screening cascade (awareness, uptake of screening, notification of results, and linkage to treatment). We then specifically described some strategies to improve access to care and asked participants to comment.

Results

We conducted two focus groups with female community members (*n* = 24) and one with key stakeholders (*n* = 12). We found frequent misconceptions about cervical cancer, screening, and treatment among community members. Fear and stigma were common themes that arose throughout the focus group discussions. Women feared and avoided screening because they viewed a positive result as a "death sentence." This concept was associated with both a misunderstanding about the process of cervical cancer screening (they felt that a positive result meant they had cancer) and an awareness of the lack of treatment options in their community for invasive cancer. Some women also cited fear of a positive screening result because of their inability to afford treatment services as barriers. Social and psychosocial factors such as fear of pelvic exam and stigma associated with cancer were expressed as significant barriers to screening for community members. Many women expressed preference for a female provider or someone they didn't know to perform the exam; there was a fear of embarrassment and loss of confidentiality reported with clinic-based exams. Stigma was related to misconceptions about the causes of cervical cancer.

> … a person comes to the facility and tests suspicious for cancer and since not all working at the health facility are medics who are bound by the confidentiality oath, it is likely to get to hear about such information in the community that 'so and so was tested for cancer and she is dying soon'
>
> -Provider

> I think it will reduce the level of stigma that people have been having when people thought that once you have cancer then death is the only thing … things that people had in mind that probably a girl started sexual activity at a tender age. So people will understand that cervical cancer is like any other disease that can be arrested when it is still in its early stages. This will make people to have more information about it.
>
> -Community Member

> But when I had been screened I was shocked with the method that was used for screening … (Laughter) and when I narrated to others about it they were equally shocked "does it mean that it has to be done like that". I encouraged them to just partake of the screening but some declined.
>
> -Community member

Both community members and providers reported that conditions in local health facilities limited access to and uptake of screening. Both groups mentioned low staff numbers, provider workload, and a lack of staff specifically trained in cervical cancer screening. These factors left providers feeling overburdened and unwilling or unable to provide screening services. Participants reported a negative provider attitude toward screening and an unwillingness to offer services as major barriers to receiving screening. Furthermore, there were concerns about the providers' ability to counsel women about the sensitive topics of the pelvic exam, HPV, and a potential cancer diagnosis. Women were specifically hesitant to undergo counseling and a screening examination by a male provider, who they would likely see often in their small communities. Lack of trained providers and supplies, cost of screening, and low prioritization of screening by providers were cited as major barriers by both community members and providers.

> The biggest gap is that most of us as staff have not been trained [enough] on Cancer screening and … I don't think I am comfortable enough to conduct that procedure still and I always refer clients to other facilities. Most clients prefer facilities which are like supermarket in that they get all they want within the same facility. Because of the workload due to less staff, sometimes attention to the cancer screening patients is done last because it is not urgent and this again demotivates most women.
>
> -Provider

> The personnel … they are really trying but they are few. The challenge that makes service provision ineffective is that they are overworked.
>
> -Community Member

Peer influence and personal and community networks were potential key facilitators of screening. Peer experience was cited as important in increasing acceptability of cervical cancer screening. Both community members and providers talked about having personal connections to the disease such as a friend, neighbor, or family member who experienced cervical cancer or an abnormal screening test as leading to increased awareness of cancer and screening, personal perception of risk, and willingness to seek out screening.

> I think those who have gone through the process can influence me too; reflecting on their changed lives can encourage me to test too. I am very sure that very many people have it and they don't want to be tested and told that they have it.
>
> -Community Member

> To me the use [of community health workers] is good because I am assured that ones in every month we will have to go to every household and deliver messages related to cancer screening. We have several [community health workers] and each is allocated a village to cover so I know with the number [of community health workers] and the population, I can reach each household.
>
> -Community Member

Education via sources deeply embedded in the community was also frequently cited in both community and provider focus groups. Mobilization efforts by community health workers were cited as an important strategy for organizing and educating women around cervical cancer prevention.

> I have had experience by going through cervical cancer screening myself and I had tension at the start about what the outcome might be, but after getting the results to be negative I was so happy. It has given me the morale of continuing.
>
> -Provider

> CHWs represent people at the village level and they know households and if the unit organizes health talk in the area then youth mobiliser will help in bringing the peers for the health talk.
>
> -Community Member

Availability of other methods of screening as an alternative to the pelvic exam and integration of cervical cancer screening with other services or events such as HIV screening campaigns were recommended.

> One approach that worked out was during a community health week [coincided with] a music festival period and many attended the screening services. It is our strategy that every health function has cervical cancer screening integrated, which has worked well.
> -Provider

> Most of our achievements have been made through conducting the camps, either reproductive health camps or family planning camps because the uptake at the facility level has been very low. We always try to incorporate the screening services in other health events like gender based violence outreaches.
> -Provider

When presented with the model of community health campaigns that would employ HPV testing through self-collected specimens, participants in both provider and population focus group discussions felt that community health campaigns and HPV testing using self-collection would be acceptable and feasible, and would address several of the main barriers to screening.

Discussion

Women and key stakeholders in our population cited workload, lack of consistent supplies, reluctance and fear around pelvic exams, and low prioritization of cervical cancer screening as key barriers to screening. Community education and peer influence were key facilitators. Using this FGD data, we refined and piloted the community health model. In order to rigorously test the strategy of community-based screening against a standard of health facility-based screening, we developed a multiphase cluster-randomized trial that will compare screening strategies and then work to develop and test an enhanced linkage to treatment strategy in partnership with women and key stakeholders in the community.

Conclusion

Cervical cancer is one of the most preventable and treatable cancers. The worldwide burden of cervical cancer highlights global disparities in economics, health outcomes, and women's empowerment. The disproportionate impact of the disease on women in low- and middle-income countries has remained stable over the past few decades, despite the increasing knowledge about the epidemiology and prevention of this disease. This is a crucial time in global women's health. There is an opportunity to strongly impact cervical cancer mortality through population-level implementation of evidence-based technology. There are very promising cervical cancer prevention strategies for low-resource settings, namely a highly effective HPV vaccine and the increasing availability of low-cost molecular testing for HPV. In order to realize this potentially dramatic decrease in cervical cancer risk, policy makers need to prioritize the introduction and support of these strategies. Sustainability will depend upon cost-effective implementation strategies that prioritize healthcare delivery at the community level that is acceptable, low in resource needs, and meet the needs of the community. Researchers, policy makers, and program planners must take up this challenge to make a true impact on a long-standing global health disparity.

Discussion Questions

1. What are some of the individual-, family-, community-, and population-level impacts of the high incidence of cervical cancer in low-resource countries?
2. Are there health beliefs that would impact a woman's decision on whether or not to access screening for cervical cancer?
3. Some people may be hesitant to support a "screen-and-treat" model of cervical cancer prevention. Discuss some of the pros and cons of this model.
4. Any new healthcare intervention, regardless of efficacy, will have some impact on the healthcare infrastructure. Justify implementing a population-based cervical cancer screening program in a country like Kenya. Consider the competing health needs, and how cervical cancer prevention may fit into, augment, or disrupt existing health care.
5. If periodic community-health campaigns are not an effective way of delivering cervical cancer screening, can you suggest alternative community-based models of service delivery?

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Suggested Reading

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Chapter 22
Menopause: A Contextualized Experience Across Social Structures

Engida Yisma and Stephanie Ly

Introduction

As women advance through the life course, they enter into the climacteric period defined as the post-reproductive phase (International Menopause Society, 2016). This period is defined by menopause, a natural phenomenon signaling the decline of ovarian function and onset of the last menstrual period (National Institute on Aging, 2013). Menopause is generally diagnosed in retrospect since the onset is defined as a 12-month cessation of menstrual periods (Barnabei, 2007). The climacteric transition may last a few months or several years typically beginning as a woman reaches her mid-40s to mid-50s with 51.3 years reported as the average age (Brinton, Gore, Schmidt, & Morrison, 2009). Clinical definitions and common symptoms of menopause can be accessed in Tables 22.1 and 22.2.

Although entry into menopause is universal for aging women, the experience is far from uniform. There has been little consensus on menopausal symptoms with wide variations across geographic regions and cultures. Similarly, treatment has been problematic with differing philosophies between natural and medical interventions. The understanding of femininity and purpose has also been questioned during the menopausal years. Once considered a malady, menopause definitions have changed throughout medical and societal history. The myriad of macro- and micro-level factors affecting a woman's menopause experience is explored in this chapter.

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Table 22.1 Clinical terms associated with menopause

Terms	Descriptions	References
Premenopause	Prior to entering the menopausal stages, a woman is considered to be in premenopause after menarche and continuing with normal fertility function	
Perimenopause	It is defined as the transition before and the 12 months after the last menstrual cycle when a woman may experience variable or irregular menstrual cycles and hormonal fluctuations	Brinton et al. (2015) and Harlow et al. (2012)
Natural menopause	It is a natural phenomenon marked by a reduction in estrogen and progesterone levels and eventual cessation of menstruation occurring in women approaching middle age	Dalal and Agarwal (2015), International Menopause Society (2016) and National Institute on Aging (2013)
	During natural menopause, pituitary hormones like follicle-stimulating hormone (FSH) or luteinizing hormone (LH) rise in response to ovarian decline and result in reduced production of estrogen and inhibin hormones	
Surgical menopause	It is a type of induced menopause which is usually performed due to health conditions, heavy menstrual bleeding, and/or symptomatic fibroids (a type of abnormal uterine growths)	Dalal and Agarwal (2015) and Hickey, Ambekar, and Hammond (2010)
	Like natural menopause, it is also marked by decline of hormones produced by the ovaries. However, surgical menopause is associated with a sudden and complete change in estrogen, progesterone, and testosterone levels and this may bring the onset of immediate menopausal symptoms	
Postmenopause	This term includes the period after 12 months without menstrual flow in a woman and this is confirmed when a woman reaches the 12-month mark after her last menstrual cycle	Hoffman et al. (2016)

We begin by introducing the historical context surrounding the treatment and perceptions of menopause evolution over time. There are significant implications globally for menopause in the emerging demographic shifts in older adult populations. Both individual-level psychological factors and sociocultural considerations frame the landscape of the menopausal experience. We then compare different theories and frameworks on menopause. We examine the biomedical approach as the most prevalent method of clinical understanding of the climacteric period. Next, we discuss how the life course perspective intersects history, time, and a woman's life trajectory in the entry into menopause. Finally, we introduce the biopsychosocial model, which examines the influence of hierarchical systems operating on the individual woman in her experience of menopause.

Table 22.2 Clinical definitions of common menopausal symptoms and their treatments

Symptoms	Definitions/descriptions	Key points	Treatment	References
Hot flash	It is a sudden sensation of heat and sweating, which is most notable in the upper body	Hot flashes occur in up to 75% of women and it is common among perimenopausal and postmenopausal women	It can be effectively managed with hormone therapy. For instance, low-dose oral estradiol and venlafaxine were shown as effective treatments in midlife menopausal women	Bani, Hasanpour, Farzad Rik, Hasankhani, and Sharami (2013), Joffe et al. (2014) and Shifren and Gass (2014)
			Lifestyle changes and nonhormonal alternative therapies such as folic acid supplementation have a capacity to reduce the severity, duration, and frequency of hot flashes	
Genitourinary syndrome of menopause	It is defined as a collection of symptoms and signs associated with a decrease in estrogen and other sex steroids involving changes to the labia majora/minora, clitoris, vestibule/introitus, vagina, urethra, and bladder	The syndrome may include but is not limited to genital symptoms of dryness, burning, and irritation; sexual symptoms of lack of lubrication, discomfort or pain, and impaired sexual function; and urinary symptoms of urgency, dysuria, and recurrent urinary tract infections (UTIs)	Vaginal estrogen therapy reduces urinary symptoms such as frequency and urgency as well as recurrent UTIs	Rahn et al. (2015) and Shifren and Gass (2014)
			Lubricants can also serve as a nonhormonal alternative for reducing urogenital atrophy discomfort during sex	

(continued)

Table 22.2 (continued)

Symptoms	Definitions/descriptions	Key points	Treatment	References
Libido changes/problems in sexual function	Sexual problems are common in midlife women and often associated with distress	The decline in estrogen during menopause may lead to a decline in libido, orgasm, or frequency of sex	Counseling and sex therapy are effective interventions for individuals and couples with sexual problems	Avis et al. (2009), Dennerstein, Dudley, and Burger (2001), Lonnèe-Hoffmann, Dennerstein, Lehert, and Szoeke (2014) and Shifren and Gass (2014)
		Menopausal symptoms, which result in sleep disturbance and fatigue, will also affect libido		
Osteoporosis	It is a skeletal condition in which bone strength is compromised, predisposing the woman to an increased risk of fractures	Estrogen plays a major role in postmenopausal osteoporosis since the risk of osteoporosis increases estrogen levels decline during menopause	Hormone therapy is effective in preventing and treating osteoporosis among menopausal women. For instance, estrogen was found to have a direct effect on bone mass and this results in lowered bone turnover and reabsorption, countering osteoporosis	Dalal and Agarwal (2015), Ringa (2000) and Saag and Geusens (2009)
	This condition is considered as a complication rather than a cause of menopause	The modifiable risk factors for osteoporosis include decreased intake of calcium and vitamin D, smoking, and a sedentary lifestyle while nonmodifiable risk factors may include age, Asian or Caucasian race, family history, small body frame, history of a prior fracture, early menopause, and prior oophorectomy	Modifying the risk factors should also be considered	

Menopause History

Throughout time, menopause has been associated with mostly negative connotations. In 1892, Regis de Bordeaux, a French physician, injected an ovarian abstract into a patient to treat her menopausal "insanity" (McCrea, 1983). Similarly in the psychology sector, prominent psychologist Sigmund Freud described menopause as an "anxiety neurosis" and physical illness in the early twentieth century (as cited in Spira & Berger, 1999, p. 2). In 1945, psychologist Helen Deutsch likened menopause to puberty and described menopause as "woman's last traumatic experience as a sexual being" (as cited in Spira & Berger, 1999, p. 2). In one more positive depiction, Colombat de L'Isere in 1845 stated that in menopause, "women now cease to exist for the species, and henceforward live only for themselves" (as cited in Utian, 1997, p. 75).

Well into the twentieth century, menopause remained a condition of deficiency and loss of womanhood (Spira & Berger, 1999). In the 1960s, gynecologist Robert A. Wilson established estrogen replacement therapy to treat lack of hormones,which he believed would enhance youth, maintain femininity, and mitigate aging (Huss, 1966; Voda & Ashton, 2006; Wilson, 1968). Wilson also published a widely distributed book, *Feminine Forever*, claiming menopause to be a decay and a threat to feminine essence (McCrea, 1983; Wilson, 1968). In 1969, physician David Reuben's bestseller, *Everything You Always Wanted to Know About Sex*, described menopause as "estrogen is shut off, a woman becomes as close as she can to being a man … having outlived their ovaries, they have outlived their usefulness as human beings" (as cited in Foxcroft, 2010, p. 4). Rueben also touted estrogen replacement as a way to "turn back the clock (as cited in McCrea, 1983). During this period and the next decade, sales of estrogen therapy were at an all-time high with 51% of women using estrogens over a median duration (McCrea, 1983).

The estrogen therapy popularity began to burst in late 1975, as links were made between estrogen use and uterine cancer in the scientific literature (McCrea, 1983; Utian, 1997). By 1979, the US National Institute on Aging established an estrogen and postmenopausal consensus finding that estrogens increased risk of endometrial cancer but were the only treatment of hot flashes and vaginal atrophy; this concluded in a recommendation of low-dose treatment and informed decision making (McCrea, 1983).

In a counter movement, the backlash from these claims led to women's groups and feminists to challenge the menopause narrative and disease label. Therese Benedek (1973) pointed towards cultural expectations of women in sexual and reproductive roles and thus how menopause brings upon fear and loss. She also connected the decline in hormones and sexualization towards a positive middle age of exploration (Benedek, 1973). The acceptance of menopause as a normal process and realization that myths of inadequacy foster sexism began to emerge (McCrea, 1983). Betty Friedan, an American writer and feminist, emphasized successful aging and rebelling from Western expectations in her 1993 book, *The Fountain of Age* (Foxcroft, 2010).

The feminist leaders not only challenged societal norms but also fought against estrogen hormonal therapy through advocacy and publications in the late 1970s (McCrea, 1983). These efforts later led to the Food and Drug Administration (FDA) to require patient package inserts warning of cancer and risks of estrogen and progesterone. The emergence of major menopause societies like International Menopause Society (IMS) and the North American Menopause Society (NAMS) was also cofounded during similar time periods to establish best clinical and research practices in menopause (Utian, 1997).

The Women's Health Initiative began two decades later in 1993 through the US National Institutes of Health as a result of hormone replacement therapy concerns and ongoing advocacy. This initiative consisted of a major randomized clinical trial evaluating the effects of hormonal therapy on heart disease, stroke, and breast cancer (Voda & Ashton, 2006). Results reported that estrogen and progesterone combined therapy increased risk of stroke, heart disease, and breast cancer but estrogen-only therapy increased stroke risk but had no effect on heart disease or breast cancer risks. These findings led to a tumultuous shift in menopause management with the reemergence of hormonal therapy (Voda & Ashton, 2006). Hormone replacement therapy was subsequently integrated into the NAMS (North American Menopause Society) recommendations. The current landscape of menopause is a mixture of historical influences that are still prevalent in the medical field and management of menopause still including the option of hormonal replacement therapy with health caveats.

Global Demographic Transitions

As we move from historical perspectives, we must consider the important demographic shifts. A growing population distribution of aging adults will be witnessed throughout the world. An estimated two billion people over the age of 60 will be alive in 2050 (WHO, 2015). Since women tend to have higher life expectancies than men in most countries, preparing globally for the incoming cohorts of women experiencing menopause and related transitions is salient. In fact, there are nearly 879 million women today within the typical menopausal age range between 40 and 60 years (Brinton, Yao, Yin, Mack, & Cadenas, 2015; U.S. Census Bureau, 2016). With overall life expectancies increasing globally, the menopause experience and postmenopause years will be a significant and lengthy life stage for women.

Physiologic symptoms during menopause are also subjective based upon geography. After a study of literature on menopausal symptoms across 100 research studies in different countries, patterns of symptoms were found but there were no clear universal symptoms (Obermeyer, 2000). For example, the United States and Canada had the highest prevalence of hot flashes while Japan had the lowest (ibid). In Ghana, the most commonly reported menopause symptoms were fatigue, insomnia, palpitations, and weight gain (Kwawukume, Ghosh, & Wilson, 1993). In Nigeria, women most commonly reported symptoms of joint and muscular discomfort, physical or mental exhaustion, sexual problems, and hot flashes

(OlaOlorun & Lawoyin, 2009). Research exploring sexual function after menopause and difficult or painful sexual intercourse found that women in Asian countries reported lower frequencies compared to US or European populations, where nearly one in three women reported sexual difficulties (Obermeyer, 2000). These studies suggest that symptoms fluctuate in frequency reports depending on the subpopulation and context (Obermeyer, 2000).

When exploring intra-country differences in menopause symptom experiences, variation is also observed across subcultures. The Study of Women's Health Across the Nation (SWAN) is a US-based multiracial and ethnic investigation of menopausal symptoms from Caucasian, African-American, Chinese, Japanese, and Hispanic women (Avis et al., 2001). The study found that Chinese and Japanese groups reported the fewest symptoms while Caucasian women reported more psychosomatic symptoms and African-American women reported more vasomotor symptoms (Avis et al., 2001). The SWAN investigation did not uncover a single menopause syndrome experienced by all women across the country. Another US study supported these findings and found that African-American women were more likely to experience hot flashes compared to Caucasian women (Grisso, Freeman, Maurin, Garcia-Espana, & Berlin, 1999).

As we discuss the history and treatment of menopause beyond straightforward clinical diagnoses, we want to explore the menopause experience as more than biological processes but rather as partial social constructions. Institutionalized sexism and influence of physicians have shaped the menopause dialogue. Social structures have also led to the variation observed in the roles of women after menopause and their varying symptoms during menopause. When we apply these broader external considerations to the individual woman, we can better understand how these structures impact menopause.

Psychosocial Factors

The historical and demographic importance of menopause helps us to understand the temporal knowledge of aging and significant implications for this generation. As the understanding of menopause expands, factors related to a woman's transition also shift from a pure clinical diagnosis. Menopause interlinks biological, social, and cultural components in a woman's life (Spira & Berger, 1999). We specifically explore broad psychological and sociocultural factors and later detail some of these experiences from theoretical frameworks.

Psychological Factors

Women's attitudes towards menopause have a significant role in the experience of symptoms. In one systematic review, women with more negative attitudes towards menopause reported more symptoms (Ayers, Forshaw, & Hunter, 2010). In another review of diverse cultural groups, most of the negative attitudes towards menopause arose from women that had surgical menopause, women that highly prioritize fertility, and women who reach menopause before achieving the number of desired children (Jones, Jurgenson, Katzenellenbogen, & Thompson, 2012).

In a qualitative study conducted in Iran, middle-aged women expressed psychological concerns and preoccupations with the past, future, personal health, family, and finances which were persistent themes (Sharifi, Anoosheh, Foroughan, & Kazemnejad, 2014). Women felt an increased burden due to their roles of parent caretaking and spousal responsibilities. Several psychological tensions felt by the studied women were undesirable physical changes, declining health, menopausal symptoms, decreased mood and mental function, increased tensions, and dissatisfaction with aging (Sharifi et al., 2014).

In a study conducted in Nigeria, mental health was emphasized as a way to advocate for positive attitude tools for women entering into menopause (Osarenren, Ubangha, Nwadinigwe, & Ogunleye, 2009). Participants agreed most frequently with statements about (1) concerns towards how their husband will feel, (2) necessity to see a doctor, (3) menopause as a significant life change, (4) menopause is unpleasant, and (5) feeling freer to do things for themselves after menopause. In an effort to understand the perceptions and concerns of menopausal Nigerian women, targeted medical and psychological interventions can be developed (Osarenren et al., 2009).

The individual expectations and attitudes of women as they enter menopause are related to their overall agency of their transition. An abrupt and early end to their reproductive functions signals a negative outlook while menopause in the middle ages follows expectations in role changes and aging. As symptom management is emphasized in the clinical and pharmaceutical arenas, expansion to psychological health should also be part of menopause care.

Sociocultural Factors

The sociocultural context of women in specific geographical locations affects the meaning and experience of menopause. In the Western world, menopause is treated as if it were a disease necessitating medical intervention rather than a natural phenomenon (Jones et al., 2012). In the Arab world, the rough translation of the word consistent to menopause and midlife means "desperate age," signifying a negative cultural perception towards menopause (Jones et al., 2012). Kaufert (1996) pointed out that much of the research on menopause in Asia, Africa, and South America is based on the same questions and study designs elicited in North American and European populations, which may omit unique cultural considerations (Kaufert, 1996).

The menopausal experiences of women have diverse implications across geographic and cultural borders. In Latin American countries, some aging woman may be abandoned by both her husband and children or expected to take care of grandchildren (Kaufert, 1996). Working women in a rural Indian village felt liberated from the bothers of menstruation and liberated to work on their businesses post-menopause (George, 1996). Urban Korean women felt lifted from oppression and transformed from being a wife and mother into transformed women after menopause (Lee, 1997).

The role of sexuality in menopause also merits unique considerations across populations. Some women embrace the ability to engage in sex without pregnancy while other women experience libido decline (Laan & Lunsen, 2009; Leiblum, Koochaki, Rodenberg, Barton, & Rosen, 2006). External factors like family support and societal expectations during menopause shape the experiences of women across regions.

Social and cultural factors may determine the extent that socioeconomic status, nutrition, and chronic diseases may impact the menopausal experience (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000). For example, women with poor nutrition had lower bone density and economically deprived women had limitations in workforce transition or menopausal therapy (Kaufert, 1996; Meleis et al., 2000). Additional considerations exist with socioeconomic status since women with lower educational and occupational levels had higher associations with earlier age at natural menopause (Schoenaker, Jackson, Rowlands, & Mishra, 2014).

Sociocultural influences are associated with the types of menopausal symptoms commonly reported. The commonly reported menopause symptoms, such as hot flashes and night sweats in North America, may also bolster expectations among women of similar symptoms while disregarding uncommon symptoms as they transition into menopause (Boulet, Oddens, Lehertb, Vemer, & Visser, 1994; Kaufert, 1996). Some research has suggested that the medical field and physicians have dictated the symptom experiences in conjunction with cultural expectations (Townsend & Carbone, 1980). Specific considerations must be made for middle-aged and menopausal women in changing occupational roles, disease risk, familial expectations, and societal norms (Kaufert, 1996).

As we extend our understanding of menopause in both individual and institutional contexts, biological and clinical knowledge must be integrated with understanding of psychological and sociocultural factors. The menopausal experience for individual women is unique and partly shaped by her expectations and outlook. A woman's personal experiences are also operating under large macro-forces, which dictate the societal view of menopause under social conditions and cultural outlooks.

Biomedical Model

The biomedical approach conventionally treats health conditions as purely biological events explained by specific pathways (Hyde, Nee, Howlett, Drennan, & Butler, 2010). Research on women, in particular, has been omitted and is sometimes assumed to be replicas of biological research on men (O'Donnell, Condell, & Begley, 2004). In fact, O'Donnell et al. (2004) found that having a menstrual cycle served as a confounding variable in medical research. Much of the menopausal research conducted from a biomedical perspective has treated menopause as a deficiency condition needing intervention (Hyde et al., 2010). These definitions were not only transmitted from research perspectives but also influenced masses of women and physicians.

In a deeper examination behind the biomedical construction of menopause, Niland and Lyons (2011) examined medical school textbooks from New Zealand and the United States for meanings and social indications (Niland & Lyons, 2011). The authors discovered that the selected textbooks portrayed menopause as a failure or disease, suggesting a continuation of negative connotations (ibid). These textbooks perpetuated menopause as a failure of hormone production, necessitating hormonal therapies in overt and covert language (Niland & Lyons, 2011). In an analysis of self-help brochures for women in midlife, most texts described menopause as a deficiency disease in need of management (Lyons & Griffin, 2003). These depictions made by clinicians for postmenopausal women reinforce the discourse of menopause as a problem.

Biomedical approaches segment the menopausal experience into three stages: premenopause, perimenopause, and postmenopause. Premenopause is the time period after menarche with normal fertility function, which ends with the last menstrual cycle. The perimenopause phase occurs as the last menstrual periods are approaching and may bring symptoms like irregular menstrual cycles and hormonal fluctuations (Brinton et al., 2015; Harlow et al., 2012). Finally, postmenopause is confirmed when a woman reaches the 12-month mark after her last menstrual cycle (Hoffman et al., 2016). These stages have unique implications for each woman and are not as clearly defined as medical textbooks might suggest.

Perhaps one of the most problematic consequences of the biomedical approach is the acceptance of “fixing menopause” and the subsequent medicalization of menopause (Bell, 1987; Dillaway & Burton, 2011). Menopause management, along with the management of other chronic conditions, contributed to the expansion of the pharmaceutical industry, soaring prescription drug prices, and increased drug dispensing in high-income countries (Busfield, 2010). The emergence of hormone replacement therapy is the result of a desire to remain youthful, feminine, and asymptomatic of menopause (McCrea, 1983). While the clinical distinction may be clear to physicians for diagnosis, women may not understand their current menopausal stage.

As feminists and activists normalized menopause as a natural experience not requiring biomedical intervention, new perspectives have emerged. The biomedical model limits the menopausal transition to the physical body and undermines the potentially positive experiences of individual women. An opposing view of menopause would be a continuous, lifelong perspective. In a qualitative study using in-depth interviews, Dillaway and Burton (2011) found that middle-aged women respected the biomedical definitions as a “master narrative” (Dillaway & Burton, 2011, p. 72) but usually turned to less ambiguous experiences of their mothers or female relatives. The description of menopausal symptoms is associated with negativity and inconvenience. Women found that reproductive aging was indefinite and a continuing process, not singularly defined by the final menstrual period (Dillaway & Burton, 2011). Moving beyond menopause as a deficiency, hormone therapy capitalization, and rigid definitions, the lived experiences and lives of menopausal women should be integrated with the current biomedical model.

Life Course Perspective

The life course perspective describes how individuals undergo constant development throughout their life trajectories (Elder & Rockwell, 1979). The life course perspective identifies people within their respective historical time to examine social structures and the influences on individual lives. Recent applications of the life course perspective include studies of racism, nutrition, work stress, and caregiving (Eifert, Adams, Morrison, & Strack, 2016; Gee, Walsemann, & Brondolo, 2012; Herman et al., 2014; Wahrendorf & Chandola, 2016). This theory is used to understand phenomena that impact a person throughout life, not just a singular event with little lasting significance. The life course perspective views the individual as constrained by macro social structures and influences that shift a person's path.

As a person ages, they transition through stages such as childhood, adolescence, adulthood, and older adulthood. The life course perspective consists of five major principles: historical time and place, timing, linked lives, agency, and life span (Elder, 1998). These central constructs apply to the study of menopause over the life course of women. While the biomedical approach to menopause centered on the final menstrual period as the defining event, the life course perspective argues that menopausal transition and quality of life are results of lifelong factors and influences.

In the theory's first principle, historical time and place, the existing societal structures within a specific time period play a major role in a woman's experience (Elder & Rockwell, 1979). When we apply historical time and place to menopause, we consider the historical evolution of menopause management. A woman entering into her menopausal years in the 1970s will have a different experience with physician-recommended hormonal therapy as contrasted to a woman entering her menopausal years in the 1990s, when hormonal therapy was feared (McCrea, 1983). The prevalent attitudes towards menopause at a given time will greatly influence the care or lack thereof a woman may receive. The timing of menopause, the second life course principle, is defined as the life stage of menopause occurrence (Elder & Rockwell, 1979). The typical timing of menopause is in middle age and may coincide with career changes, grandparenthood, or other roles. If, however, menopause onset was unexpectedly early in a woman's mid-30s due to natural or surgical causes, this may disrupt a woman's reproductive plans and suddenly bring upon the premature transition into menopause. Menopause represents a turning point for women but can have very different implications on the life and trajectories of a woman set against her current stage in life.

The third life course principle is linked lives, which explains that individual experiences and historical events are interdependent and linked to the lives of shared relationships (Elder, 1998). The linked lives concept applies to menopause when a woman's experiences are interdependent on the menopausal experiences of her mother, grandmother, friends, and community (Dillaway & Burton, 2011). A woman entering the menopausal years affects and is also affected by her interpersonal relationships. For example, if a woman living in a rural village enters menopause, her husband may be supportive and embrace sex without contraception or he may be unsupportive and even leave their marriage in extreme cases. The fourth principle of agency recognizes that individuals act and decide on their own accord within the constraints and opportunities of their circumstances (Elder, 1998). While a menopausal woman cannot control societal expectations or the reactions of her family, she has some individual agency to make decisions. A woman in the rural areas may enter a new path focusing on her business or retire to the home of her children (George, 1996). Individual women also have agency in medical therapy by deciding to take or not to take hormonal therapy in order to manage menopausal symptoms.

Finally, the life course principle of life span applies to menopause as a process that spans the entire life of the woman. This may be most clearly understood through the concept of cumulative advantage and disadvantage, when early life events shape the disparities or opportunities a person may have access to in their lifetime (Elder & Rockwell, 1979). Kaufert (1996) points out lifelong factors like malnourishment leading to anemia and obesity or lack of reproductive health care leading to cervical cancer as women age (Kaufert, 1996). Women that were disadvantaged from youth may experience deprivation throughout their lives, which may accumulate into multiple morbidities by the time they reach menopause. Cumulative disadvantage can be observed between socioeconomic status groups where women living in low- and middle-income countries tend to enter menopause at an earlier age and have less resources to mitigate menopausal symptoms as compared to women from higher income countries (Gold et al., 2001; Huddleston, Cedars, Sohn, Giudice, & Fujimoto, 2009).

Menopause is considered a significant transition for women, but under the life course perspective, menopause is a lifelong process that is not simply defined by the last menstrual period. Throughout a woman's life, she is preparing for menopause through learned interactions from other female relatives, and health and risk factors, and entering into new life trajectories as she ages. Her experiences are also set in a historical context since culture and medical recommendations of the given time period will impact menopausal treatment. Additionally, societal expectations in peri- and postmenopause dictate physical and psychological role transitions (Kaufert, 1996). Quality of life experienced by menopausal women begins far before their last menstrual cycle but is rather associated with socioeconomic status, access to resources, and other advantages (Meleis et al., 2000). In order for the menopausal experience to be fully understood, the exploration of external environments in a woman's trajectory must be considered.

Biopsychosocial Model

The biopsychosocial model has gained popularity in recent years within the sociology and medical fields with diverse applications in diseases, treatments, and health experiences. The prevailing version of the model was developed by Engel (1977, 1989) to expand the prevailing biomedical model and recognize that social, behavioral, and psychological factors add dimensions to health conditions (Engel, 1977; Engel, 1989). Multiple iterations of the biopsychosocial model have resulted in both reinforcing the biomedical model and developing a more holistic view of health (Pilgrim, 2015). Recent applications of the biopsychosocial model include topics as diverse as arthritis, migraines, and emotional health (Ayers, Franklin, & Ring, 2013; Renjith, Pai, Castalino, George, & Pai, 2016; Sumner & Nicassio, 2016). The similarities shared by applying the biopsychosocial model to health involve taking "the patient and his attributes as a person, a human being" (Engel, 1980, p. 2).

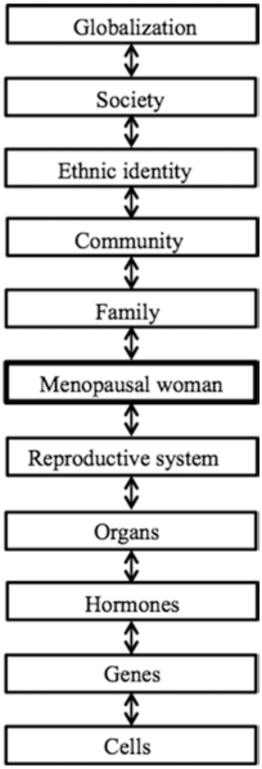
The biopsychosocial model integrates the individual person into a hierarchy of ongoing behavioral, psychological, and social structures (Engel, 1980). This model can be applied to menopause, simultaneously considering both the individual woman experiencing menopause and the broader systems that operate. The biomedical model focuses on the clinical manifestations of menopause while the life course perspective focuses on a woman's experience in the context of time and her life course. The biopsychosocial model introduces a complementary viewpoint, which details the layers of menopause embedded from a micro to macro hierarchy.

A systems approach to menopause, as posited in the biopsychosocial model, creates an ordering of the natural environment. Each level of the natural environment leads to a broader level. For example, the cells and reproductive organs comprise a full body and that individual body also comprises a family, community, and society. When applied to menopause, a woman's hormonal fluctuations and cessation of menstruation encompass the experience of menopause. The same woman comprises a community of women also undergoing menopausal transition and she is part of the larger societal structure. In Fig. 22.1, a biopsychosocial system is represented with an individual woman undergoing menopause at the core level.

At the micro-level of the individual woman, her physical body undergoes biological processes to bring the onset of the last menstrual period from reproductive organs down to the cellular and genetic determinants. These micro factors can determine the age a woman enters menopause, level of hormonal fluctuation, and chronic disease development. While some of these factors are within the agency of the woman's control (e.g., exposures and diet), many of the factors are predetermined (e.g., genetics and cell structure) or influenced by even larger determinants (e.g., socioeconomic status and norms). This micro hierarchy is most emphasized in the biomedical model through its focus on biochemical processes and solution with targeted therapies such as hormonal replacement.

In contrast, the macro-levels above the individual woman can range from her immediate family to broad global systems. The woman's menopausal experiences

Fig. 22.1 Biopsychosocial system surrounding a woman in menopause transition. *Adapted from* Engel (1980). The Clinical Application of the Biopsychosocial Model. *American Journal of Psychiatry 137*(5): 535–544



shape her macro-level structures and vice versa. As previously discussed, cultural and social norms can dictate the woman's changing role and symptom experience in menopause. However, the individual woman may influence her family by sharing her individual experiences with her daughter or relatives, forming a narrative within a community, and possibly influencing the larger social structure. Within the macro levels, health disparities are apparent. If an economic or a racial inequality existed at the societal level, this would negatively impact access to both overall and menopausal health care (Huddleston et al., 2009). Similarly, a woman's beliefs for menopausal treatment, shaped by her community, will affect her decisions in seeking symptom care and types of treatments (Bell, 1990).

A complex interplay of proximal and distal factors surrounding the menopausal woman depicts the social, behavioral, and psychological underpinnings. More than one factor can be active at the same time. For example, a woman's psychological outlook on menopause is determined by both her physiologic body experiences and the perceptions of her family and societal culture. Overall, the biopsychosocial model considers the entire system (Engel, 1989). In contrast to the biomedical model, it connects larger macrostructures. In comparison to the life course perspective, the biopsychosocial model nuances the hierarchy of these systems. The biopsychosocial model has limitations notably missing historical changes and tendency to capture defined systems while missing exploratory phenomena (Pilgrim, 2015).

Summary

For much of history, menopause was classified in negative terms as a neuroses, decline, and illness signaling a decay of purpose and life. Even in the mid-twentieth century, prominent physicians published widely read books and articles on menopause as a loss of femininity and youth. As populations of women internalized the negative discourse, a cure for menopause was sought and temporarily answered in the advent of hormone replacement therapy. The alarming health consequences that emerged from suspected hormones gave rise to a new wave of menopausal conception. Feminists and women's health advocates began examining menopause as a natural process devoid of a medical solution. Women began to understand menopause as a positive life transition and freedom from previous expectations like childbearing.

The rise in the number of women entering into menopause and living for decades postmenopause will define clinical care and social norms in this next generation. The majority of menopause research has centered upon Caucasian women in the Western world, which limits the heterogeneity of experiences like role transitions and symptoms across countries and even within countries. Menopause has also been overwhelmingly described in biological terms, where the final menstrual period and following 12 months marks the end of menopause. Other factors that are less examined include psychological outlooks of individual women and the impact on menopause experience as well as sociocultural factors shaping the subjective norms within a woman's society.

In theoretical applications of social constructions of menopause, we examine the biomedical model, life course perspective, and biopsychosocial model. In the biomedical model, menopause is seen as a series of biological mechanisms within the body that progress linearly and can be clearly diagnosed. This model has been widely adopted in the medical field but limits the contextualized experiences of women and institutionalized structures. The life course perspective views menopause as a lifelong process, constantly changing a woman's individual trajectory and set against historical understandings. Disadvantages that a woman may face in her early life will not only impact her progression throughout life but also the quality of her menopause experience. The biopsychosocial model places a woman within a hierarchical system which includes both biomedical considerations at the microlevel and social structures at the macro-levels.

As the worldwide prevalence of menopause increases, health care professionals must consider a facet of individual and institutional factors when managing menopause. The experience of menopause is unique to each society, community, family, and individual woman. Menopause is associated with both negative and positive perceptions, which change with history and social norms. Further research and information capturing diverse experiences of menopause at the global level is needed to improve our knowledge of the experience. As our collective knowledge of menopause changes, the integration of lived experiences and evolving social structures must also accompany the menopausal dialogue.

Discussion Questions

1. Given the complex history of menopause, what types of structures allow prominent physicians and activists to influence entire societies and individual women?
2. As the number of women entering menopause and living longer in postmenopause increases globally, what factors do you think have been thus far overlooked?
3. When thinking about the life course perspective and menopause as a lifelong process, what types of psychological and sociocultural factors influence a woman throughout her youth and into her menopause years?
4. How does the life course perspective and biopsychosocial model differ from the biomedical model? What similarities still exist?
5. Would you prefer applying the life course perspective or the biopsychosocial model to menopause? What is your reasoning?

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Suggested Reading

Dillaway, H. E., & Burton, J. (2011). "Not done yet?!" Women discuss the "end" of menopause. *Women's Studies, 40*(2), 149–176.

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About the Editors

Shonali Choudhury, Ph.D., M.M.H., was born on December 17, 1979, in San Juan, Puerto Rico, and died in Miami, FL, on November 14, 2014. She graduated from Saint John's School in the Condado of San Juan and completed her B.A. at Bard College in upstate New York. As a child she wanted to be a medical doctor, but during her university years she decided to study social problems that affect health. Her senior thesis looked at mental health care of uprooted Puerto Ricans in upstate New York. After graduation she worked with the HIV Health Services Planning Council in Newark, NJ, and went on to earn a Ph.D. in Public Health at UCLA in 2009, where she earned the Elizabeth Blackwell Award for outstanding work on women's health. Her research on female sex workers in Tijuana for her dissertation required personal courage that reflected her passionate commitment to women's rights and helping disadvantaged populations gain access to health care.After graduation Shonali worked with the Hispanic Health Council and the Institute for Community Research in Hartford, CT, and then accepted a position as Assistant Professor in the School of Nursing and Health Studies at the University of Miami. The multicultural atmosphere and the receptive attitude toward qualitative research made her feel immediately at home. She loved her students and her research. Shonali fought a long battle with the brain tumor that took her life, undermining her capacity to do the work she loved, affecting her eyesight, speech, and coordination. She is remembered for her love of animals, holidays, and gourmet cooking, as well as her bright smile and steadfast loyalty to her friends. In Shonali's honor, the Department of Community Health Sciences at the UCLA Fielding School of Public Health created a scholarship fund in her name that honors her legacy for public health and social justice. A special Shonali Choudhury Fund was established within the Puerto Rico Community Foundation to promote women's rights, health, and education. The Fund has given grants to a women's shelter for victims of violence, and a feminist community organization to promote sex education for adolescents geared to the prevention of sexual aggression.

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About the Authors

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Abigail M. Hatcher, M.Phil., is a Senior Researcher at the University of Witwatersrand School of Public Health. Ms. Hatcher has expertise in designing and testing behavioral and structural interventions for intimate partner violence (IPV). Ms. Hatcher is a Co-Principal Investigator for the WHO-funded Safe & Sound trial, a Co-Investigator for an NIH-funded home-based couples intervention in Kenya, and a Co-Principal Investigator for a UKAID-funded trial testing community action as a method for reducing men's use of IPV in Johannesburg.

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Manju Katoch holds a B.A.M.S. (Bachelor's in Ayurvedic Medicine and Surgery). Currently working as Manager—Monitoring and Evaluation at the Centre for Catalyzing Change (Formerly CEDPA India), Dr. Katoch has extensive experience working with donor organizations, government as well as nongovernment institutions/organizations across India, Southern and Western Africa on program designing, implementation, and monitoring and evaluation. Dr. Katoch has delved in cross-cutting thematic areas—RMNCH+A, Life Skills Education, Governance, Enterprise Development, and Natural Resources Management—to work toward gender and empowerment.

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Pranitha Maharaj, Ph.D., Professor, School of Built Environment and Development Studies, University of KwaZulu-Natal, Durban. Since obtaining her doctorate from the London School of Hygiene and Tropical Medicine Pranitha has accumulated many years of teaching experience while building a strong record of research. Her research portfolio is diverse in character, involving both quantitative and qualitative methodologies. The contribution of her research has been recognized by awards both nationally and internationally. She has published close to fifty articles in predominantly peer-reviewed, SAPSE and ISI/IBSS accredited journals. In 2013, she edited a book on *Aging in Africa* published by Springer, New York.

Jennifer McCleary-Sills is the Director of the Global Program on Violence, Rights and Inclusion at the International Center for Research on Women (ICRW), where she leads research on the gendered dimensions of violence, deprivations of rights, and social exclusion. She has authored dozens of peer-reviewed articles and institutional publications on barriers to gender equality, including gender-based violence and other challenges to women's empowerment. In her previous role at the World Bank Group, she coauthored the flagship publication "Voice & Agency: Empowering Women and Girls for Shared Prosperity" and was the Bank's lead on the multisectoral Violence Against Women and Girls Resource Guide.

Talia Meer is a researcher at the Gender Health and Justice Research Unit and a doctoral candidate in Sociology at the University of Cape Town. Her research interests center on identity, intersectionality, and violence. Her work involves public health and criminal justice responses to survivors of gender-based violence, including survivors with intellectual and psychosocial disabilities; gender, sexuality, and gender-based violence education for adults and teenagers; and gendered experiences of urban public space.

Deborah Mindry is a research anthropologist with the UCLA Center for Culture and Health. She received her B.A. from the University of KwaZulu-Natal, South Africa, and her M.A. and Ph.D. in Anthropology from the University of California, Irvine. Her research interests include gender politics, NGOS and development, and HIV/AIDS. She has conducted qualitative ethnographic research in South Africa since the early 1990s. Her current research examines fertility intentions and safer conception services for HIV infected men and women. She is engaged in similar projects in Los Angeles, USA, Malawi, and Uganda. She has previously conducted work on adolescent sexual reproductive health in Rwanda.

Ricardo Vera Monroy is currently the project coordinator for a study named ESTIMA (Economic and Social Empowerment to Increase Upwards Mobility among Women) at the University of California, San Diego (UCSD). ESTIMA involves the evaluation, via a randomized control trial (RCT), of a microfinance program coupled with business entrepreneurship training on HIV/STI risk and violence among women working in sex work in Tijuana, Mexico. His future interests include establishing profitable businesses which solve social issues to improve health and address poverty.

Alex Müller is an Associate Professor at the Gender Health and Justice Research Unit at the University of Cape Town in South Africa. She trained as a physician and medical sociologist and is interested in employing social science theory to understand health challenges and health and criminal justice system responses, particularly around gender (identity) and sexual orientation. Her research focuses on health disparities and health care for sexual and gender minority people, sexual and reproductive health and rights, and developing competency frameworks for professional education in South and Southern Africa.

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Glossary of Terms

Adolescence	The period between childhood and adulthood, which according to the World Health Organization is between the ages of 10 and 19.
Agency (of young women)	A young woman's ability to make life choices, either through subverting or embracing norms. Women's agency may be limited in contexts where independent decision-making is not supported.
ART	Antiretroviral treatment.
Child marriage	Marriage before the age of 18.
Commercial sex worker (CSW)	An individual who exchanges sex for money or other valuable goods.
Containment	Emotionally supporting and de-escalating distress, a technique commonly used by mental health providers to ensure emotional safety of participants.
Criminalization (of women)	The impact of policies and laws that determine certain behaviors or activities are illegal, a process by which women who engage in these activities are constructed as criminals.
Disability	A physical, mental, or emotional condition that constrains or alters a person's movements, senses, or activities.
Early childbearing	Having a first birth before the age of 18.
Empathetic listening	A therapeutic technique appropriate for responding to intimate partner violence that involves listening and accepting the woman's perceptions and feelings, with the goal of raising self-efficacy and self-awareness for participants without judgment.

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Empowerment model (for Intimate Partner Violence)	An approach to addressing intimate partner violence that posits that a violent partner aims to control the behavior of females and that by increasing a woman's sense of control over her life, she can better develop strategies to reduce violence in her relationship.
Entitlements	Benefits under a welfare scheme—this could range from conditional cash transfer to cashless services to financial concessions for services and supplies.
Establishment-based female sex work	Sex in exchange for money or valuable goods that occurs out of a place of business that may or may not be exclusively dedicated to sexual services. This differs from street-based, home-based, and outcall-only sex work.
Everyday violence	Living with racism, classism, sexism, or other forms of structural violence that are embedded within institutions such as education and health, which limits access and opportunities.
Fertility intentions	What women or men wish to do regarding their reproductive rights; include how many children they want to have and when they want to have them.
Forced sex/sexual assault	Forced vaginal or anal penetration through the use of actual or threatened physical force. Physical force refers to unwanted, rough sex; sex obtained through threats of a beating or threats with a weapon; physical coercion through holding down; or actual beatings prior, during, or after unwanted sex. Physical force also refers to the voluntary or involuntary administration of alcohol or drugs, resulting in lack of consent to sexual intercourse. (See: Bagwell-Gray, M.E., Messing, J. T., & Baldwin-White, A. (2015). Intimate partner sexual violence: A review of terms, definitions, and prevalence. Trauma, Violence, & Abuse, 16(3), 316–335. Stockman, J. K., Lucea, M. B., & Campbell, J. C. (2013). Forced sexual initiation, sexual intimate partner violence and HIV risk in women: a global review of the literature. AIDS and Behavior, 17(3), 832–847).

Gender identity	A person's own feelings about how they see their body, their behavior, and their appearance, in relation to society and other people. This includes their psychological identification as a man, woman, something in between or neither, which may or may not match the person's sex assigned at birth. This can include refusing to label oneself with a gender. (Reprinted from: Meer, T. (2014) All the Tricky Words: A Glossary of terms on Sex, Gender and Violence. Gender Health and Justice Research Unit (UCT). Retrieved from http://www.ghjru.uct.ac.za/ghjru/schools/exercises-posters).
Gender Inequality Index (GII)	Measures gender inequality based on indicators of health, empowerment, and economic status.
Gender justice	The necessary comprehensive and just treatment of men and women in all spheres of life.
Gender minorities	People who do not identify as mainstream interpretations of male or female, whose gender expression and/or gender identity does not match traditional societal norms, for example people who are intersex and transgender. (Reprinted from: Meer, T. (2014) All the Tricky Words: A Glossary of terms on Sex, Gender and Violence. Gender Health and Justice Research Unit (UCT). Retrieved from http://www.ghjru.uct.ac.za/ghjru/schools/exercises-posters).
Global north/Global south	The North–South divide is broadly considered a socioeconomic and political divide, with origins in imperialist and colonialist expansion and exploitation. Generally, definitions of the global north include the United States, Canada, Western Europe, and richer countries of Asia, as well as Australia and New Zealand. The global south is made up of Africa, Latin America, and poorer Asian countries and also includes the Middle East. Global south countries have less strong economies and less developed public services and infrastructure.
Heteronormativity	The assumption that heterosexuality (being attracted to the opposite sex and gender) is normal and applies to everyone, which creates a bias in favor of heterosexual relationships. For example, the fact that there are very few same-sex couples on television, in movies, and in advertising is an example of heteronormativity in the media. (Reprinted from: Meer, T. (2014) All the Tricky Words: A Glossary of terms on Sex, Gender and Violence. Gender Health and Justice Research Unit (UCT). Retrieved from http://www.ghjru.uct.ac.za/ghjru/schools/exercises-posters).

Homophobia	An irrational dislike and fear of sexual minorities (including lesbian, gay, bisexual people). It can be institutionalized in anti-gay laws, policies, and the formal opinions of church and state. Homophobia results in people being excluded from social spaces, as well as in verbal abuse, physical violence, and even murder. South Africa's Constitution gives sexual minorities the same rights as everyone else and the full protection of the law. However, violence toward sexual minorities is a serious and widespread problem that the law will not be able to solve until social homophobia (people's attitudes) is challenged. (Reprinted from: Meer, T. (2014) All the Tricky Words: A Glossary of terms on Sex, Gender and Violence. Gender Health and Justice Research Unit (UCT). Retrieved from http://www.ghjru.uct.ac.za/ghjru/schools/exercises-posters).
Hot flash	A sudden sensation of heat and sweating, which is most notable in the upper body. This symptom is commonly associated with menopause transition in women (Bani, Hasanpour, Farzad Rik, Hasankhani, & Sharami, 2013; Joffe et al., 2014; Shifren & Gass, 2014).
Human Development Index (HDI)	Measures mean years of schooling, expected years of schooling, life expectancy at birth, and gross national income per capita.
Interpersonal violence	The intentional use of physical force or power threatened or actual against another person.
Intersectionality	A framework that views women as negotiating their reproductive lives in a complex system of various interlocking forms of race, class, and gender oppression.
Intimate partner violence	Behavior from a current or former intimate partner that causes physical, sexual, or psychological harm, "including acts of physical aggression, sexual coercion, psychological abuse and controlling behaviors" (WHO, 2010).
Joint family	A household which consists of a married couple, their children, and the husband or wife's family members (most commonly a parent).

Last menstrual cycle	The final menstrual cycle a woman experiences, marking the end of perimenopause and transition into postmenopause (Hoffman et al., 2016).
Libido and sexual function changes	Sexual issues that may include a decline in libido, orgasm, or frequency of sex that arise during the menopausal transition and are often associated with estrogen decline (Avis et al., 2009; Dennerstein, Dudley, & Burger, 2001; Lonnèe-Hoffmann, Dennerstein, Lehert, & Szoeke, 2014; Shifren & Gass, 2014).
Maternal death	The death of a woman during pregnancy or the six weeks following pregnancy terminatio n, which can be attributed to a pregnancy-related or pregnancy-aggravated cause.
Maternal Mortality Ratio	Number of women dying during child birth per hundred thousand live births.
Migrant	Someone who has moved from one region or country to another, temporarily or in the hopes of settling there, including in order to work or for a better quality of life.
Natal family	The family one is born into.
Natural menopause	A natural female phenomenon marked by a reduction in estrogen and progesterone levels and eventual cessation of menstruation, usually occurring in middle age (Dalal & Agarwal, 2015; International Menopause Society, 2016; National Institute on Aging, 2013).
Nuclear family	A household which consists of a married couple and their children.
Obstetric fistula	A hole between the vagina and bladder and/or the rectum and bladder. It is caused by prolonged or obstructed labor, which results in women experiencing incontinence of urine or feces or both.
Osteoporosis	A skeletal condition in which bone strength is compromised, predisposing the woman to an increased risk of fractures. This condition is considered a complication rather than a cause of menopause (Dalal & Agarwal, 2015; Ringa, 2000; Saag & Geusens, 2009).

Passive acceptance	A mechanism of adjustment to life situations that one regards are unchangeable or for which there are no perceived adjustments.
Patrilineal	Describes inheritance, land, and other wealth that are passed down through sons.
Patrilocal	Describes the practice of women moving to their husbands' villages and homes upon marriage.
PLHIV	People living with HIV.
PMTCT	Prevention of mother to child transmission (of HIV).
Perimenopause	The transition period prior to the last menstrual cycle, when a woman may experience variable or irregular menstrual cycles and hormonal fluctuations, and the 12 months afterwards (Brinton et al., 2015; Harlow et al., 2012).
Popular culture	The entirety of ideas, perspectives, attitudes, images, and other phenomena that are within the mainstream of a given culture.
Postmenopause	The period after 12 months without menstrual flow and is confirmed when a woman reaches the 12 months mark after her last menstrual cycle (Hoffman et al., 2016).
Premenopause	The stage in a woman's life after menarche but before entering menopausal stages. Normal fertility function occurs during this time.
Rape	When someone penetrates another person's vagina or anus with their penis, another part of the body (such as their finger), any object (such as a stick), or part of an animal; when someone penetrates someone's mouth with their penis or an animal's penis; or forces another person to do any of these things; without the consent of the person being penetrated, especially by the threat or use of violence against them. Rape is not a result of sexual desire, but a deliberate act of gender-based violence and an expression of power, control, and domination over another person. It occurs at every socioeconomic level of society and in a variety of settings. Rape is never the fault of the victim no matter what they were wearing, where they were when it happened, or whether they were drinking or taking drugs. Rape can happen in relationships (date rape or marital rape) and the victims often know their rapists. Victims often face many obstacles in reporting rape, and in obtaining needed protection and assistance. (Reprinted from: Meer, T. (2014) All the Tricky Words: A Glossary of terms on Sex, Gender and Violence. Gender Health and Justice Research Unit (UCT). Retrieved from http://www.ghjru.uct.ac.za/ghjru/schools/exercises-posters).

Refugee	Someone who has left their country because it was not safe for them there, including, due to war, persecution, or a natural disaster.
Reproductive justice	Linking reproductive health and rights with social justice in order to address historic and contemporary processes of inequality and the influence of this on women's reproductive health.
Resilience	Positive adaptation, or the ability to maintain or regain mental health, despite experiencing adversity. (Herrman, H., Stewart, D. E., Diaz-Granados, N., Berger, E. L., Jackson, B., & Yuen, T. (2011). What is resilience? The Canadian Journal of Psychiatry, 56(5), 258–265.)
Safety planning	A strategy for addressing intimate partner violence where a health worker offers safety advice tailored to a woman's situation and based on culturally appropriate actions for increasing personal safety of herself and her children.
SC	Safer conception.
Sex-positive	An approach to sexuality that is encompassing and comprehensive in relation to issues of identity, diversity, body acceptance, self-esteem, communication, and consent, and it seeks to remove the attachment of shame and stigma from sexuality while equipping people with the necessary information to engage in informed and safer sexual practices.
Sexual and gender-based violence	All acts perpetrated against women, girls, men, and boys on the basis of their gender or sexual orientation which cause or could cause them physical, sexual, psychological, emotional, or economic harm, and includes threats to do so. Commonly, the acts or threats include rape, sexual harassment, domestic violence, child sexual abuse, marital rape, homophobic and transphobic violence.
Sexual assault	Any sexual contact, such as groping or fondling, that occurs without consent, that is not rape, especially if it occurs through physical force or violence, or the threat of force or violence. It is not a result of sexual desire, but a deliberate act of gender-based violence and an expression of power, control, and domination

	over another person. It occurs at every socio-economic level of society and in a variety of settings. It is never the fault of the victim, no matter what they were wearing, where they were when it happened, or whether they were drinking or taking drugs. Sexual offences can happen in relationships, and victims often know perpetrator/s. (Reprinted from: Meer, T. (2014) All the Tricky Words: A Glossary of terms on Sex, Gender and Violence. Gender Health and Justice Research Unit (UCT). Retrieved from http://www.ghjru.uct.ac.za/ghjru/schools/exercises-posters).
Sexual coercion	The use of nonphysical, controlling, degrading, and/or manipulative tactics to obtain (or attempt to obtain) unwanted oral, vaginal, or anal intercourse, including other penetrative acts such as sexual assault with objects. (Bagwell-Gray, M.E., Messing, J. T., & Baldwin-White, A. (2015). Intimate partner sexual violence: A review of terms, definitions, and prevalence. Trauma, Violence, & Abuse, 16(3), 316–335.)
Sexual intimate partner violence	Attempted or completed sexual acts that occur without the victim's freely given consent and perpetrated by a current or former boyfriend, spouse, or dating partner. These acts include rape or penetration, being made to penetrate someone else, nonphysically pressured unwanted penetration, unwanted sexual contact, or non-contact unwanted sexual experiences. (Reprinted from: Centers for Disease Control and Prevention. (2016). www.cdc.gov/violenceprevention/intimatepartnerviolence/definitions.html).
Sexual minorities	This term refers to lesbian, gay, bisexual, and queer people—people whose sexual orientations or sexual activities are not mainstream (heterosexual). This term may also refer to people who do not identify with the norms of being male or female, such as intersex and transgender people, although they are usually grouped under gender minorities. (Reprinted from: Meer, T. (2014) All the Tricky Words: A Glossary of terms on Sex, Gender and Violence. Gender Health and Justice Research Unit (UCT). Retrieved from http://www.ghjru.uct.ac.za/ghjru/schools/exercises-posters).

Sexual orientation	A person's physical, romantic, emotional, and/or spiritual attraction to another person, which they may label as lesbian, gay, heterosexual, bisexual, or asexual. A person's sexual orientation can change, and the labels that people use do not define their sexual lives or limit their sexual expression. Instead, you can think of it as "rounding off" to the nearest label, or choosing the label that fits best, even if it is not precise, or you choose a new label later. Just because a person considers themselves homosexual, queer, gay, or lesbian, it does not mean that they may never feel attracted to the opposite sex or have sexual or romantic relationships with people of the opposite sex. Similarly, many people who label themselves as heterosexual experience same-sex attraction and engage in same-sex sexual and romantic relationships. (Reprinted from: Meer, T. (2014) All the Tricky Words: A Glossary of terms on Sex, Gender and Violence. Gender Health and Justice Research Unit (UCT). Retrieved from http://www.ghjru.uct.ac.za/ghjru/schools/exercises-posters).
Sustainable development goals	Intergovernmental set of 17 goals for health, peace, and justice. Adapted in 2015 by United Nations and member states. (SDG (2016). Sustainable Development Goals. Retrieved from https://sustainabledevelopment.un.org/sdgs).
Social construction	Laws and policies addressing social issues, which are either modified or sustained depending on the political climate.
Social media	Computer-mediated technologies that allow creating and sharing of information, ideas, interests, and other forms of expression via virtual communities and networks.
Stigma	A mark of disgrace associated with a particular circumstance, quality, or person.
Surgical menopause	A surgery-induced menopause, typically performed to correct health conditions, heavy menstrual bleeding, and/or abnormal uterine fibroids. Like natural menopause, a marked decline of hormones occurs; however, the hormonal change is sudden and complete and may onset immediate menopausal symptoms (Dalal & Agarwal, 2015; Hickey, Ambekar, & Hammond, 2010).

Teen pregnancy	Pregnancy to females and males under age 20 years.
Trauma-informed care	An approach to health services that views individuals as resilient survivors; trauma-informed care places emphasis on collaborative therapeutic relationships with health providers—a condition that can assist the process of healing because providers are aware of how their own responses affect the person seeking help.

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