Social Aspects of HIV

Asha Persson
Shana D. Hughes *Editors*

Cross-Cultural Perspectives on Couples with Mixed HIV Status

Beyond Positive/Negative

Springer

Social Aspects of HIV

Volume 2

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Cross-Cultural Perspectives on Couples with Mixed HIV Status: Beyond Positive/Negative

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To the loved ones we lost along the way
To the loved ones who still brighten our lives

Foreword

Cross-Cultural Perspectives on Couples with Mixed HIV Status: Beyond Positive/Negative is an extremely welcome and a very timely addition to the global literature. The book is especially welcome because it explores the interpersonal and social worlds of people in HIV serodiscordant primary relationships. While much has been written about serodiscordance from a public health standpoint, the chapters here take up the "everyday life issues" that people in serodiscordant relationships experience and manage. These issues include the risk of HIV transmission which, as this book makes clear, meshes in complex ways with gender, power, sexuality and reproduction and the ever-present stigma and discrimination that surrounds HIV. It is also the first book to explore intimate serodiscordant relationships between primary partners in a number of different cultural and geographic settings.

Its publication is timely, coming at a point in the history of the epidemic when biomedicine is developing technologies that are changing the face of HIV, both with regard to treatment as well as prevention. In illuminating these changes, the contributors make it clear that serodiscordance is not a uniform phenomenon: it is affected not only by changes in biotechnology but also by social and cultural factors. As the personal accounts and research studies in the book exemplify, serodiscordant relationships are becoming both easier and more complex to manage as the options open to both HIV-positive and HIV-negative partners multiply exponentially. With biomedical HIV prevention technologies increasingly central in the global response to the epidemic, partners in such relationships may now make decisions about reducing HIV transmission with reference not only to condom use but also to the viral load of the HIV-positive partner, if he/she is on treatment, and to whether the HIV-negative partner is taking pre-exposure prophylaxis. Such decisions are also likely to increasingly be at the forefront of serodiscordant partners' minds when they wish to have children.

The book includes research from some countries that, to date, have figured little in the HIV literature. There are chapters devoted to social research undertaken in Papua New Guinea, Vietnam, Peru, Uganda and Ethiopia and from Greece, China, Brazil and India as well as from Europe, North America and Australia. However, as the editors of this book note, there are few chapters that focus on sub-Saharan

Africa, which has the highest HIV prevalence in the world and the largest number of people living in serodiscordant relationships. It is hoped that this book will spur social researchers to fill this gap with respect to sub-Saharan Africa and engage afresh with couples with mixed HIV status in this region.

The book boldly advocates for new ways of thinking about and researching serodiscordance through engagement with the social and cultural issues of gender, power and sexuality. It highlights how recent advances in biomedical technologies can create ways forward for those living in serodiscordant relationships, but might also pose new challenges, which will be vital for researchers to keep close watch over and carefully appraise as the epidemic evolves across the globe. The book will be of interest to a wide readership: not only to those working on HIV and serodiscordance in the social sciences but also to those working in public health, medicine and health care more generally. All have much to gain from reading it. In its original and critical approach to serodiscordance, this book seems certain to change this field of research and inspire a new generation of researchers.

Sydney, Australia Susan Kippax
May 2016

Preface

This book began as an enthused brainwave between two people on different sides of the Pacific Ocean who had never met. We first got in touch one propitious day in February 2013 when Shana emailed Asha after reading an article of hers about serodiscordant relationships. We soon discovered that we shared similar ways of thinking about serodiscordance and a frustration with the formulaic risk discourse that tends to frame this phenomenon. We had both conducted research with serodiscordant couples, and we had friends in mixed-status relationships whose diverse experiences and circumstances far exceeded their one-dimensional representation in public health research. From there grew many discussions and, eventually, the decision to do a book together, a book we hoped would bring together alternative and novel inquiries that could foster more nuanced, situated perspectives on serodiscordance. Our goal was to expand, at least in some small way, how those who live with mixed HIV status are understood within the global response to HIV and by society more widely. In short, we wanted to change the lens and intervene in the conversation. We really had little idea what a mammoth task we had set ourselves. It's been two years of hard work, difficult decisions, delays and disappointments and unexpected losses in our personal lives along the way but also plenty of exciting insights, Skype sessions at odd hours mixing work with lots of laughter and wild musings about life, new and joyous connections with researchers across the world, rewarding dialogues with the contributors, the sense of excitement and fulfilment of seeing the book take shape and, not least, the flourishing of a lovely friendship across the ether. We still haven't met, and yet we have in so many ways.

This book would not have been possible without the support, guidance and kindness of other people along the way. There are a number of people we want to thank especially. Foremost, we extend our gratitude to the contributors for their hard work, collaborative spirit, perseverance and intellectual curiosity. We thank Peter Aggleton for his unflagging support and sage advice at every stage of the project and Sue Kippax for her generous Foreword to this edited volume. We are indebted to Bernadette Deelen-Mans and Evelien Bakker at Springer for guiding us so expertly through the publication process. We are grateful to Pranee Liamputtong for her encouragement as our book adventure began and to Jessica Botfield for her meticulous referencing work as it drew to an end. We also thank all the numerous people who circulated our Call for Papers through their networks or pointed us towards potential contributors and our colleagues at the Centre for Social Research in Health (UNSW Australia) and the Center for AIDS Prevention Studies (UCSF) and beyond for cheering us on. Lastly, thank you to two very special people who bring so much joy and love to our lives: Marc and Brad.

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Contributors

Yemane Berhane is a professor of epidemiology and public health and director of Addis Continental Institute of Public Health, Addis Ababa, Ethiopia. He has worked as a consultant to international agencies including CDC, USAID, WHO and the World Bank.

Adam Bourne is a lecturer at the London School of Hygiene and Tropical Medicine and currently works within the Sigma Research group. He specialises in research of health behaviours among marginalised populations, particularly as they relate to sexual health. He has conducted a number of mixed-methods studies of sexual risk behaviour among gay and bisexual men, in Europe, the Caribbean and East Africa, and of black African migrant populations in the UK. Adam recently led a large community HIV prevention needs assessment of black African people living in London and has previously managed a qualitative investigation of the experiences of people in HIV-serodiscordant relationships.

Liviana Calzavara is a professor in the Social and Behavioural Health Sciences Division at the Dalla Lana School of Public Health, University of Toronto, and director of the CIHR Social Research Centre in HIV Prevention. Liviana has a PhD in sociology, with expertise in the sociological and epidemiological aspects of HIV/AIDS, research design and prevention research. She has over 20 years' experience leading large-scale high-impact cohort studies in HIV in Canada and abroad. She has also been co-chair of Canada's Ministerial Council on AIDS, a member of the CIHR HIV/AIDS Advisory Committee and past president of the Canadian Association for HIV Research.

Sally Cameron has been involved in HIV advocacy and education since the late 1980s and has worked in both government and community sectors. Sally has also undertaken HIV-related consultancies for AusAID, UNAIDS, the ILO, United Nations Office on Drugs and Crime and the Global Network of People Living with HIV. Sally was a member of the Australian Ministerial Advisory Committee on Blood-Borne Viruses and Sexually Transmissible Infections' Legal Working Group and recently represented Australia at UNAID's Expert Meeting on Criminalisation of HIV Non-disclosure, Exposure and Transmission. Sally has a master's degree in women's studies from the University of NSW. She is currently a policy analyst and educator at the Australian Federation of AIDS Organisations.

Amrita Daftary is a scientist at McGill University with expertise in the social and behavioural sciences and qualitative methodology. Amrita has over a decade's experience researching HIV/AIDS and tuberculosis in sub-Saharan Africa and Canada. She has a postdoctorate from ICAP at Columbia University, a PhD in public health from the University of Toronto and an MPH in health promotion from Columbia University. Amrita is a registered pharmacist in Canada. She holds adjunct appointments at the Centre for the AIDS Programme of Research in South Africa (CAPRISA), University of KwaZulu Natal, and Dalla Lana School of Public Health, University of Toronto.

Sangeeta Sharma Dhaor is teaching social work in Delhi University since 2001. Since 2006, she has been actively working with HIV-infected persons. She was selected as a master trainer by the National AIDS Control Organisation (NACO) and the Global Fund to Fight AIDS, TB and Malaria. She has trained counsellors, auxiliary nursing midwives, men who have sex with men, female sex workers and truckers in HIV prevention. Sangeeta has been evaluating NGO targeted interventions for their performance as technical head in Delhi and Madhya Pradesh. She was awarded a doctorate in social work on "Persons Living with HIV/AIDS: Problems and Solution". Findings from this research have been presented at many international conferences, including IAC at Washington, DC, and Australasian AIDS Conference. Her published work includes "Spirituality and Social Work in Health Care" in Verma, RBS (Ed.), *Social Work*: *The Ethical and Spiritual Paradigm*; "The Unreached Goal: Study of the Challenges Faced by Women Living with HIV/AIDS in Delhi, India", *Journal of Social Work Review*; and "Risk Behavior of PLHA and Social Development in India" in Patel, C. (Ed.), *Social Development in India: Critical Assessment*. She is looking forward to take her work further for the betterment of the HIV-positive persons.

Jyoti Dhawale-Surve is a writer, blogger, positive speaker and HIV activist among many other things. She was born in India and currently lives with her husband in Mumbai. She was diagnosed with HIV in 2005 due to medical negligence. She is a member of the Community Advisory Board for the Well Project (USA), an Indian ambassador for the Stigma Project (USA), a face of the *No Shame About Being HIV Positive* campaign (USA) and featured in the documentary film *Through Positive Eyes*. When she dies, her epitaph should read: "Here lies a woman who has not died in vain but lived to the fullest".

Catherine Dodds is a lecturer at Sigma Research in the Department of Social and Environmental Health Research. She has extensive qualitative research experience into the interaction between stigma, social inequality and HIV prevention need among homosexually active men and among African migrants to the UK. She has a particular interest in the way that notions of responsibility are conveyed through HIV prevention campaigns and policies (including the criminalisation of HIV transmission and the use of ARVs for HIV prevention). Catherine has led on the development of key national HIV policy and planning frameworks, supports NGOs in developing their research capacity and focuses on the dissemination of research findings to diverse audiences.

Jeanne Ellard is a research fellow at the Australian Research Centre for Sex, Health and Society, La Trobe University, Melbourne. Her disciplinary background is in anthropology, and her research interests are in the social and cultural dimensions of HIV, sexual health, hepatitis C and drug use.

Xavier A. Erguera is a trained ethnographer and qualitative researcher in the AIDS Policy Research Center at the Center for AIDS Prevention Studies at UCSF. He is a Ronald E. McNair scholar and graduate of the University of California, Berkeley. He has 8 years of experience working in HIV prevention; a large part of his work has been with youth and young adults in street and clinical settings throughout the East Bay of San Francisco. His research interests include the social and sexual health of people living with HIV, including the impact of new biomedical prevention strategies on HIV stigma.

Shana D. Hughes is a medical anthropologist whose work explores connections between states of health and illness, the body and identity, as they are situated in social and cultural context. Currently, she is involved in US-based research on adherence motivations and meanings of pre-exposure prophylaxis (PrEP) for HIV among MSM and narratives of risk and prevention in the context of HIV infection. Her dissertation employed an ethnographic approach to understanding love and risk among HIV-serodiscordant, heterosexual couples in Porto Alegre, Brazil. Shana is a specialist at the Center for AIDS Prevention Studies at the University of California, San Francisco.

Stacy Jennings is a single mother of 1 son and a “glam-ma” of 1 grandson. Living with HIV for 20 years, she calls the experience “nothing short of a blessing”. A writer and activist, she serves on the South Carolina HIV Planning Council and is a member of Positive Women’s Network USA (PWN-USA). She says: “I have a desire to speak up and speak for all that are unwilling to speak out for themselves. STIGMA tried to knock me down but in the end it has allowed me to be blessed with an angel whom I call ‘K.J.’ RIH, sweetheart”.

Carmel Kelly is a nurse consultant in sexual health and holds a joint appointment between the South Eastern Health and Social Care Trust and the School of Nursing and Midwifery, Queen’s University Belfast. Her research interests include HIV, sexual health and sexual risk-taking behaviour. She also specialises in knowledge translation of research. The findings from her PhD research on men and women’s experience of HIV and pregnancy have been transformed into an internationally recognised educational intervention for health professionals on HIV and pregnancy care (http://www.qub.ac.uk/elearning/hiv-and-pregnancy/).

Angela Kelly-Hanku has been involved in the Australian and international response to HIV since 1994. Having herself been in a serodiscordant relationship with her partner until his death in early 1999, she now lives and works in Papua New Guinea. Her research focuses on the sociocultural and gendered nature of HIV and other sexual health matters. She has pioneered research on living with HIV in PNG and is the lead author on the only publication on serodiscordant relationships in the country to date. Together with Asha Persson, she will commence the first study of serodiscordant couples in Papua New Guinea (2016–2017).

Kimberly A. Koester is trained as a cultural anthropologist and serves as the director of qualitative research in the AIDS Policy Research Center at the Center for AIDS Prevention Studies, University of California, San Francisco. Over the last 10 years, a significant portion of her research has been conducted in the context of HIV care settings examining the delivery of health services to people living with HIV. She is particularly interested in and has extensive experience working with gay and bisexual men. As of 2012, she has focused her studies on the social and sexual consequences of HIV pre-exposure prophylaxis.

Kelika A. Konda is an infectious disease epidemiologist with a masters in social and behavioural interventions. She has lived and worked in Peru for over 10 years, focusing on HIV prevention research with men who have sex with men and transgender women. Her work has focused on HIV and STI epidemiology, sexuality and sexual behaviour, gay couples and sero-disclosure. She has also participated in behavioural and structural HIV prevention trials with men who have sex with men and transgender women in Peru.

Huixin Liu is a research associate in the Department of Clinical Epidemiology at Peking University People's Hospital. During her dissertation research as a doctoral candidate at the National Center for AIDS/STD Control and Prevention at the Chinese Centers for Disease Control and Prevention, she investigated risk factors for sexually transmitted diseases among female sex workers, distribution of HIV genotypes across China, prevalence and predictors of HIV drug resistance in treatment-naïve individuals and mediators of ART efficacy for preventing HIV in serodiscordant couples in central China.

Maria Lohan holds a chair in social science and health in the School of Nursing and Midwifery at Queen's University Belfast and has recently been a visiting professor at the School of Nursing of the University of British Columbia. She is a sociologist (PhD, Trinity College Dublin) specialising in critical men's health research with a particular focus on men and young men's reproductive and sexual health. Her research is informed by feminist theory especially critical studies in men and masculinities, and she has published extensively in leading international journals including *Social Science and Medicine*; the *Journal of Adolescent Health*; *Culture, Health and Sexuality*; and *Sociology of Health and Illness*. She also specialises in knowledge translation and is currently leading an NIHR-funded study evaluating an educational intervention aimed at teenage men in relation to unintended pregnancy (http://www.qub.ac.uk/sites/IfIWereJack/).

Ulla McKnight is currently finishing her PhD in the Sociology Department at Goldsmiths, University of London. Her thesis is a qualitative investigation into the requirements of successful HIV antenatal care from the perspective of both practitioner and patient, and it considers how the interests of patients, (unborn) babies and health professionals are reconciled, if at all, within the clinic. McKnight is a member of Unit of Play at Goldsmiths and co-authored "When Debility Provides a Future" in the *Feminist Review* with Annette-Carina van der Zaag.

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Janet J. Myers is a medical sociologist whose research focuses on evaluation of HIV care and treatment interventions delivered in clinical settings. Janet has served as principal investigator on several large multi-site demonstration projects aiming to optimise linkage, engagement and retention in HIV care for vulnerable populations. Her work also focuses on implementation research in correctional settings including jails, prisons and detention centres. She also teaches programme evaluation in the University of California, San Francisco, implementation science certificate programme.

Lizzete Najarro has a B.A. in communications with a focus on social communication. She has 8 years of experience conducting qualitative research. Her experience has been in the design of research protocols, information gathering and data analysis. She has worked on issues related to HIV, including disclosure to children living with HIV and relationships between gay men as well as on chronic disease and obesity and other topics in public health.

Christy E. Newman is a senior research fellow at the Centre for Social Research in Health, in UNSW Arts and Social Sciences, where she conducts social research on health and health care, particularly qualitative research on the lived experience and clinical management of HIV and sexual health. Her research draws on critical theory, health sociology and qualitative inquiry to examine expert and lived accounts, as well as cultural and media representations, of contemporary priorities in health promotion and care, including in recent years to understand the place of sexual health in young adult life.

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John Owuor PhD (Huddersfield, UK) explored the impact of HIV-positive HIV diagnosis on UK resident immigrant men, originally from East Africa and their families. John has worked on various research projects with Sigma Research, including the study on which this chapter is based, a qualitative study involving HIV-serodiscordant couples of Black African descent. John also worked for Terrence Higgins Trust, the largest sexual health charity in the UK, where his work mainly focused on sexual health promotion involving Black Africans, men who have sex with men (MSM) and young people. He is currently a Marie Curie research fellow in the Assistive Technologies for People with Intellectual Disability and Autism (ASSISTID) programme at Trinity College Dublin.

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Asha Persson is a social anthropologist and a senior research fellow in the Centre for Social Research in Health (formerly National Centre in HIV Social Research) at UNSW Australia. Over the past 15 years, she has conducted a range of qualitative projects on the social and lived aspects of HIV. Her research aims to draw attention to the experiences and needs of previously hidden and under-researched populations in the local HIV epidemic and to contribute to HIV health promotion and policy and to scholarly knowledge of the cultural interplay between illness, medicine, gender, sexuality and society. She led the first social research studies ever conducted in Australia on people living heterosexually with HIV, children growing up with perinatally acquired HIV and gay and heterosexual couples with mixed HIV status. Asha has published widely in high-profile international journals in the fields of health sociology, medical anthropology, cultural studies and HIV.

John Rule holds a conjoint associate lecturer position with the School of Public Health and Community Medicine, Faculty of Medicine, University of New South Wales. As a person living with HIV, he has held high-level community representative positions. John has a PhD in education. He has recently published articles in *Studying Politics Today: Critical Approaches to Political Science* and the *Asia Pacific Journal of Public Health*. In 2014, he edited an important historical document, with contributions from over 50 writers, published by the National Association of People with HIV Australia – "Through Our Eyes: Thirty Years of People Living with HIV Responding to the HIV and AIDS Epidemics in Australia.

Clara Sandoval has completed master studies in gender, sexuality and reproductive health and is an anthropologist with extensive qualitative research experience. For the past 12 years, she has worked on issues related to HIV, gay and transgender population in Peru. Her work has included training to implement behavioural interventions, process evaluation for structural and behavioural interventions and health situation assessment with people living with HIV research. In addition, she has conducted public policy analysis to assess the effect of the Global Fund Projects in Peru. Her research experience includes designing, conducting and analysing qualitative research with emphasis on HIV, gender and public health.

Pluto Savage is a performing artist, a writer, a university student and a hairdresser. Pluto began critically engaging with topics around HIV/AIDS through his performance work in his early twenties, as a response to the HIV crisis and its effects on his friends, his lovers and the community around him. Now forty, Pluto has been living with HIV for 10 years. Pluto is currently living a happy and healthy life with his partner in Melbourne, Australia, where he studies the humanities and hopes to make many more valuable contributions to the important discussions around HIV and AIDS.

Sean Slavin works at the Australian Federation of AIDS Organisations, Australia's national federation for the community-based HIV response. He has also worked in HIV social science research and community-based education and prevention over 15 years. His experience spans community-based organisations, university research centres and government. He has conducted social research into various aspects of living with HIV and currently works on a programme of health promotion for gay men and people with HIV that includes HIV prevention and sexual health.

M. Kumi Smith is an infectious disease epidemiologist focusing on behavioural and biomedical interventions for disease prevention in developing country settings. Her research to date largely focuses on real-world applications of biomedical tools for control of hepatitis C virus, HIV, syphilis and other sexually transmitted infections. Her research has spanned many regions including Malawi, India and Vietnam, but her most in-depth research to date has taken place in rural China where she conducted dissertation research on the effectiveness of HIV treatment as prevention in a population of former blood plasma donors.

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Annette-Carina van der Zaag recently finished her PhD in the Sociology Department at Goldsmiths, University of London, which comprised a feminist theorisation of vaginal microbicides. She is a member of Unit of Play at Goldsmiths and teaches at City University London and the University of Greenwich. She is currently writing a monograph entitled *Materialities of Sex in a Time of HIV: The Promise of Vaginal Microbicides*. Other publications include "When Debility Provides a Future" in the *Feminist Review* co-authored with Ulla McKnight.

Caroline Watson is the social justice and communications coordinator at HIVE, an organisation that works to advance reproductive and sexual wellness for individuals, families and communities affected by HIV in San Francisco and beyond (http://www.hiveonline.org). Caroline is also the founder of #WeAreAllWomen, which is an advocacy movement and research project for the inclusion of transgender women in cisgender women's health-care settings. She is in a serodifferent marriage and has a 3-year-old daughter.

Ira B. Wilson is professor of medicine and the chair of the Department of Health Services, Policy & Practice at Brown University and a professor of medicine at Brown's Alpert Medical School. His areas of research include HIV/AIDS, medication adherence, patient-provider relationship, persuasive communication, chronic diseases, psychometrics and quality of health care.

Robert Wyrod is an assistant professor in the Department of Women and Gender Studies and the International Affairs Program at the University of Colorado Boulder. His first book, *AIDS and Masculinity in the African City: Privilege, Inequality, and Modern Manhood* (California 2016), is an ethnographic examination of how the prolonged AIDS epidemic has affected conceptions of masculinity in urban Uganda. His current research explores how the immense growth in Chinese development aid to sub-Saharan Africa is affecting gender relations and the lives of African women.

Abbreviations

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
AZT	Azidothymidine, also known as zidovudine (ZDV)
CBO	Community-based organisation
CD4	Type of blood cell (CD4 T lymphocyte) that helps fight infection. A “CD4 count” is a laboratory result intended to gauge how well the immune system is working. In people living with HIV, lower CD4 counts are strong predictors of viral progression
CSM	Critical studies of men and masculinities
HIV	Human immunodeficiency syndrome
IDU	Injecting drug use
LMIC	Low- and middle-income countries
MSM	Men who have sex with men
PEP	Post-exposure prophylaxis
PMTCT	Prevention of mother-to-child transmission
PNG	Papua New Guinea
PPTCT	Prevention of parent-to-child transmission
PrEP	Pre-exposure prophylaxis
SRH	Sexual and reproductive health
STI	Sexually transmitted infection
TasP	HIV treatment as prevention
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

Introduction: Making "Difference": New Perspectives on HIV Serodiscordance

Asha Persson and Shana D. Hughes

Why This Book?

> Too often, we pour the energy needed for recognizing and exploring difference into pretending those differences are insurmountable barriers, or that they do not exist at all (Audre Lorde 1999).

The ambition of this book is to illuminate and understand mixed HIV status relationships outside the confines of clinical trials and biomedical definitions, especially in the context of an epidemic characterised by both rapid, revolutionary change and tenacious stigma. Our focus is on romantic and intimate relationships between primary partners with and without HIV; unions that are rarely public or familiar outside the HIV field. Despite a now voluminous body of epidemiological, clinical and public health literature on sexual behaviour and HIV transmission in these so called "serodiscordant" relationships, we know little about how serodiscordance is perceived and managed by mixed-status couples in their everyday lives.

Serodiscordance tends to be defined and understood through a limited set of discourses in the available literature and in the HIV prevention field, which contribute to its stigmatisation and render it invisible as a lived experience and social phenomenon. Those discourses typically frame serodiscordance in terms of "risk" and "difference". The origins of the concept of serodiscordance can be traced back to the HIV antibody test, which first became available in 1985. The clinical verification of HIV infection or *non*-infection through this testing technology became and

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continues to be vital to global public health efforts to respond to the epidemic. But, as David Roman (1997) has argued, it also launched a binary between HIV-negative and HIV-positive by introducing the idea of having a "status". And this serostatus binary became "laden with ideological meanings" and socially "divisive potential" (Roman 1997: 163). The word sero-*discordance* itself suggests dissonance and trouble.

Community-based activists have long fought against social differentiation and discrimination on the basis of HIV status (ACT UP 1983; Wright 2013; Gilmore and Somerville 1994; Aggleton et al. 1997; Power 2011). But given its critical role in HIV prevention, the serostatus binary has proved resilient. It remains paramount in public health research on serodiscordant couples, where it is energetically summoned, providing the focal point and rationale for investigations of sexual "risk" and HIV transmission. The notion of difference is similarly invoked in the social research literature, which tends to focus on numerous challenges and frictions thought to arise in serodiscordant relationships. This concern with "difficulties" largely pivots on the assumption that serodiscordance is inevitably experienced through different serostatus identities that exist in tension with each other (Persson 2011, 2013).

The idea of difference has also percolated into HIV health promotion and prevention materials, where mixed-status relationships are described with additional terms, including sero-different, sero-divergent, magnetic, poz/neg, and sero-opposite (Rule and Slavin, "Seeking Seroharmony: Changing Conceptualisations of Serodifference and Serostatus", this volume). Despite the proliferation of names, most still suggest a binary opposition, which has, as in Lorde's quote above, long been considered sexually deleterious and shrouded in silence and taboo.

The doyenne of anthropology, Ruth Benedict (1946), once said that "The purpose of anthropology is to make the world safe for human differences." Following in her disciplinary footsteps many decades later, the philosophical and political impetus for this book has been the importance of engaging with serodiscordant stories, as a way to destigmatise and make "visible" mixed-status relationships. In this process, however, our emphasis on "difference" has a twist. In contrast to the perspectives discussed above, we do not conceptualise serostatus difference as the defining characteristic of serodiscordant couples. Rather, we challenge the notion that we can know *a priori* what kind of difference mixed HIV status makes, if any, in any particular context. In fact, adopting a more open, inquiring perspective on "difference" as regards such relationships reveals their multiplicity, specificity, and cultural embeddedness.

To our knowledge, this is the first book of its kind. It brings together cross-cultural empirical research on couples living with mixed HIV status, conceptual musings on serodiscordance, as well as personal stories by men and women who themselves have the experience of being in a serodiscordant relationship. Together they provide new and thought-provoking insights into the social, medical, sexual, reproductive and everyday issues relevant to gay and heterosexual mixed-status couples in all their situated diversity.

Situating HIV Serodiscordance

Despite their social invisibility, intimate mixed-status relationships are far from rare. There are no global statistics on their prevalence, but the World Health Organization (WHO 2012a) estimates that as many as half of all HIV-positive people in long-term relationships have an HIV-negative partner. Research from around the world similarly suggests that serodiscordant relationships are common (Chemaitelly and Abu-Raddad 2013; Eyawo et al. 2010; Dunkle et al. 2008; UNAIDS 2009; Saggurti and Malviya 2009; Guzman et al. 2006; Grierson et al. 2013; WHO 2012b). The last 20 years or so have brought about dramatic changes in the lives and futures of many people living with HIV. For those with access to effective HIV treatment, increased longevity and decreased infectiousness have opened new possibilities for life after diagnosis, including greater opportunities to form long-term intimate and even reproductive relationships with partners who are HIV-negative (Matthews et al. 2012; Gosselin and Sauer 2011).

Paradoxically, perhaps, these welcome improvements in the lives of people with HIV sharpened the focus on serodiscordant relationships as a primary driver of the global HIV epidemic (UNAIDS/WHO 2009; NIMH 2010). This notion, however, is increasingly challenged by the rapidly moving field of HIV medical science. The recent past has witnessed important developments both in our understanding of the virus and new biomedical technologies for controlling its transmission, most notably in the form of treatment-as-prevention (TasP) and prophylaxes (PrEP and microbicides) (Muessig and Cohen 2014). Serodiscordant couples have played a key part in the research leading to these discoveries. Several trials show that heterosexual and gay couples can safely have sex without condoms if the HIV-positive partner’s viral load is fully suppressed with antiretroviral treatment (Cohen et al. 2011; Rodger et al. 2014; Grulich et al. 2015). In addition, heterosexual couples of mixed status were crucial to the Partners PrEP study, conducted in Kenya and Uganda (Mujugira et al. 2011; Haberer et al. 2013; Baeten et al. 2012).

There is now little disagreement among HIV advocates, clinicians, and medical and social scientists that TasP and PrEP are clinically effective. Nonetheless, debate continues about how biomedical prevention technologies will “work” outside the controlled milieux of clinical trials, especially regarding their population-level effectiveness, their “real-world” implementation, and the political and ethical implications for people with HIV and for their clinicians (e.g. Kippax 2015; Cameron and Goodwin 2014; Sugarman 2014; Haire and Kaldor 2013; McCormack et al. 2014; Wilson 2012). Social scientists in particular have argued that biomedical HIV prevention will be ineffective if it disregards the myriad of social factors that shape sexual practices, risk perceptions and treatment uptake (Dowsett 2013; Nguyen et al. 2011; Adam 2011; Kippax and Stephenson 2016; Kippax et al. 2011). Much work remains to be done on these fronts. At the same time, considering the longstanding discursive construction of HIV as an exceedingly infectious virus, the shift that TasP and PrEP have effected in the HIV landscape is remarkable.

The recent clinical trials have produced a wealth of data on sexual behaviour, transmission risk, and the preventive effects of HIV treatment among serodiscordant couples. Yet, echoing the caution of social scientists mentioned above, it remains unclear how the new biomedical prevention technologies might be incorporated into mixed-status relationships and what this might mean in terms of couples' social and sexual lives. And while scientific attention to serodiscordance validates the existence of mixed-status couples, their invariable conceptualisation through an epidemiological lens of transmission risk does little to deepen our understanding of what "serodiscordance", "serostatus" or "risk" actually mean to couples in different cultural and epidemiological contexts. In addition, it does nothing to reduce the stigmatising divide between HIV-negative and HIV-positive people in society (Persson 2013, 2015).

As advances in HIV medicine are increasingly repositioning HIV as a manageable chronic condition, this book asks how intimate serodiscordant relationships are understood by those who live them; and how this not only shapes HIV risk, but how it impacts upon and articulates with the rest of their lives. In short, it is the explicit goal of this book to explore serodiscordance as a negotiated practice and process, inseparable from the wider social context in which it is situated. Spanning a diversity of geographical regions, the contributors to this book undertake the critical work needed to understand how cultural dynamics of illness, gender, sexuality and power, as well as access to biomedical technologies, both enable and constrain the ways serodiscordance is lived, managed and made sense of in local settings. This "socially situated" approach (Rhodes 1997) to serodiscordance has much to offer scholarship on the social and sexual relationality of illness and has significant implications for HIV health promotion at local and global levels.

Overview of Chapters

This book is divided into three parts, loosely organised around particular issues or aspects of serodiscordance, which often overlap and intersect, both in the chapters and in people's lives. Part I, ***Biomedicine, Change & Diversity: Conceptualising Serodiscordance,*** provides reflections on the changing and multiple nature of serodiscordance, raising questions about the conventional ways that serodiscordance has been and continues to be conceptualised. From different perspectives, each chapter challenges the tendency in public health and prevention discourses to frame serodiscordance as a uniform, coherent phenomenon, as if it is understood and lived in the same way everywhere. The authors upend this notion in novel and compelling ways by showing how mixed HIV status takes on different forms and meanings across cultural contexts and over time, not least in the contemporary and rapidly shifting HIV treatment and prevention landscape.

Several chapters explicitly trace the potentially paradigm-shifting capacity of biomedical HIV prevention technologies in the lives of those who live with mixed HIV status. With humour and poignancy, Pluto Savage traces his personal, embodied experience of re-imagining himself as a non-infectious person with HIV and a safe serodiscordant partner. Kimberly Koester, Xavier A. Erguera and Janet J. Myers explore how PrEP had the capacity to shift attitudes towards HIV and instate a sense of normalcy among young mixed-status couples in California, posing the thought-provoking question whether biomedical prevention is making the concept of serodiscordance irrelevant. In Australia, John Rule and Sean Slavin explore the cultural contingency of "serodiscordance" by analysing how health promotion materials have tended to employ visual imagery that reinforces the idea of serodiscordance as a binary opposition, while recent changes in representational style hint at the possibility of greater "sero-harmony".

The next three chapters consider how HIV and biomedicine converge with cultural and discursive environments to shape serodiscordance. Shana Hughes draws on her ethnographic work in Brazil to unpack the ways biomedical normalisation of HIV, cultural ideals of gender and couplehood, and pervasive HIV-related stigma staked competing claims on members of mixed-status relationships. She shows how couples attempted to discursively mediate such claims through notions of "normality", thus revealing what she describes as the "contingent, biocultural nature of serodiscordance". Angela Kelly-Hanku takes us on an odyssey across historical, epidemiological and cultural contexts to make the case that serodiscordance can mean very different things depending on where it is situated. She invokes her experience as an HIV researcher in contemporary Papua New Guinea to reflect on how HIV treatment affects the lives of local couples and families in ways far removed from her own experience of being in a serodiscordant relationship in Australia in the 1990s. From a different transcultural perspective, Annette-Carina van der Zaag and Ulla McKnight also argue for a conceptual understanding of serodiscordance as multiple and relational by tracing its manifestations as a diasporic, violent and temporal phenomenon in the context of African migrant women attending an HIV antenatal clinic in the UK. Their chapter provides a bridge to the next part, which considers how multiple factors beyond biomedicine configure the ways in which serodiscordance is understood and lived.

Part II, ***Stigma, Culture & Gender: Contextualising Serodiscordance*** , foregrounds serodiscordance as a profoundly *social* phenomenon that far exceeds the clinical categories of "HIV-positive" and "HIV-negative". Moreover, as the chapters herein elucidate, experiences of serodiscordance exceed the sphere of intimate partnerships, as well as the public health notion of "risk" as only pertaining to HIV transmission. Locating serodiscordance in specific cultural contexts, the authors explore how experiences of mixed-status relationships intersect in significant and sometimes deleterious ways with gender and family relations, reproductive projects, social stigma, and cultural understandings about serodiscordance. This part begins with personal stories that highlight how HIV-related stigma in very different parts of the world has affected the lives of Stacy Jennings and Jyoti Dhawale-Surve, two women who are both determined to stand up against this stigma and actively reject its impact on their relationships and well-being.

Drawing on theories of intimacy, Adam Bourne, John Owuor and Catherine Dodds examine tensions between the intensely felt importance of being involved in migrant social structures and the extensive HIV-related stigma within relational, family and community contexts among black Africans in the UK. In so doing, they reveal how serodiscordance was enmeshed with complex social factors that shaped health and well-being, beyond sexual transmission risk. Kumi Smith and colleagues similarly seek to expand on the traditional notion of serodiscordance as operating only at the level of couples, by showing that mixed HIV status affected broader social relationships, including in-laws, and children's marriage prospects in profoundly family-oriented rural China. Also placing serodiscordance in a broader social context, Yordanos M. Tiruneh, Ira Wilson and Yemane Berhane examine how HIV-related stigma, religion, cultural dynamics around gender and reproductive imperatives all shaped experiences and conceptualisations of serodiscordance among couples in Ethiopia. The confluence of such factors gave rise to a complex struggle to resume a "normal" sexual life while also managing transmission risk and the physical and psychological demands of serodiscordant sexuality.

Through a kindred social lens, three chapters specifically zoom in on the interplay between serodiscordance and gender. Drawing on research into serodiscordance in Uganda, Robert Wyrod makes the case for a dialectic relationship between gender and health. He shows how "doing health" and "doing gender" are interwoven in vulnerability to HIV as well as in shaping relationship dynamics in intimate mixed-status relationships. Along similar lines, Carmel Kelly and Maria Lohan provide a critical analysis of the ways traditional ethno-gender scripts and power relations among culturally diverse couples in Northern Ireland were challenged by HIV and re-negotiated in the context of reproductive and sexual decision-making. Sangeeta Dhaor gives us a rare glimpse of serodiscordance in India. She considers how conservative cultural values of sexual modesty, socially prescribed gender roles, and the sacrament of (arranged) marriage can be a source of resilience, but also of guilt and vulnerability among mixed-status couples, raising pertinent questions regarding premarital HIV testing, disclosure and rights violation.

Without losing sight of cultural specificity, Part III, ***Love, Risk & Relationships: Negotiating Serodiscordance*** , further sharpens the focus on the intricate and situated ways couples negotiate their serodiscordance, both at early stages of a relationship and in the longer term. The authors compellingly show how gay and heterosexual couples draw on diverse and sometimes contradictory cultural discourses of medicine, romance, and "normality" to make sense of and manage their mixed HIV status and any perceived risks, not uncommonly in ways that depart from prevailing HIV prevention messages. Retaining the format of starting with the words of those who have lived serodiscordance, this part opens with a personal story by Caroline Watson, an HIV-negative partner who explains how treatment-as-prevention renders her relationship no more "different" than any other. This experience has motivated her and her partner to be public about their mixed status to help normalise it.

In pioneering qualitative research on serodiscordance in Peru, Kelika A. Konda, Clara Sandoval and Lizzete Najarro uncover the challenges gay men confront in disclosing HIV status to a new partner, and also explore how widespread homophobia and HIV stigma shaped gay serodiscordant relationships in this context. Even so, the authors observe that effective treatment was making gay men more comfortable with HIV in their relationships, which may gradually lead to increased social and family support for gay couples in Peru. From another part of the world lacking research on serodiscordance, Chrysovalantis Papathanasiou describes the strong symbolic bond between male homosexuality and HIV in Greece and how it impacted existing and potential mixed-status relationships among gay men, giving rise to narratives of fear and difficulties, but also love, solidarity and subject positions that transcended serostatus.

In another rare contribution to the serodiscordance literature, this time from Vietnam, Khuat Thi Hai Oanh, Sally Cameron and Lan Nguyen detail how romantic attachment and marital ties often outweighed HIV-related concerns when deciding to continue a mixed-status relationship, and how ongoing relationships were shaped and challenged by multiple cultural pressures, such as the importance of children, stigma and limited HIV knowledge. In Canada, Amrita Daftary, Joshua Mendelsohn and Liviana Calzavara invoke the concepts of "HIV talk", "sero-silence" and "sero-imbalance" to unpack the strategies mobilised by couples to disentangle themselves from the seminal presence of HIV within their relationship, resist the social invisibility of HIV-negative partners, and gain a sense of normalcy. Lastly, noting the juxtaposition of the increasing biomedicalisation of HIV and a general decline in public trust, Christy Newman, Asha Persson and Jeanne Ellard examine the specific ways in which "trust" figured among mixed-status couples in Australia. They argue that relationships were greatly supported by an investment in intersecting forms of trust – in medications, in HIV care providers, and in one's partner.

A Cross-Cultural Bricolage

While we make no claims of exhaustiveness, the book does manage to include experiences in many parts of the world, including countries that have so far published little social research on serodiscordance, such as Greece, Vietnam and Peru, and to some extent Brazil, India and China. On the other hand, we received few contributions from sub-Saharan Africa, despite this region being home to the vast majority of the world's serodiscordant couples. Some promising chapters from the region fell away along the way due to inopportune circumstances, while we opted not to include others because they left unquestioned the core assumptions that this book project set out to examine. Given the scale of the epidemic in sub-Saharan African countries, it is unsurprising that epidemiological and public health research on serodiscordance dominates and is prioritised by funders unconvinced of the value of exploring issues that might appear only tangentially related to epidemiology and prevention. There are of course notable examples from the region of interesting qualitative research on couples with mixed HIV status, such as, among others, Rebecca Bunnell and colleagues (2005), Rachel King and colleagues (2012) Laetitia Rispel and colleagues (2011), and Robert Wyrod (2013) whose intriguing article is reprinted in this book.

Compared to the sizeable public health literature, socially-oriented, conceptual and critical work on mixed-status relationships is a much smaller field that is emerging unevenly across the globe. In that sense, this book offers an accurate reflection of the current field. But it also means that there are inevitable gaps not only in the book's geographical scope, but also its coverage of affected populations. We received not one chapter focused on mixed-status couples who inject drugs, despite the high prevalence of HIV among injecting communities in Eastern Europe, Central Asia and the USA (UNODC 2014; UNAIDS 2014). Despite our best efforts to source contributions focused on diverse populations, other affected groups also largely absent in the book include transgender people, sex workers, African Americans, and Indigenous peoples in North America, Australia and elsewhere. We also recognise that our focus on couplehood no doubt inadvertently excluded an array of experiences of serodiscordance. Polygamous unions spring to mind as one example. These gaps suggest the importance of encouraging collaborations across cultures and institutions to foster exchange and documentation of new perspectives on serodiscordance in a broader range of settings and contexts. It is our hope that this book will provide a source of inspiration for researchers across the globe to take up this challenge.

Given the contemporary field of serodiscordance research, this book is perhaps best described as a kind of *bricolage,* crafted from available materials and diverse sources. This pertains not only to its geographical spread and population coverage, but also its conceptual scope. It did not emerge ready-made, Athena-like, from the initial chapter submissions, but is the result of scholarly curiosity and perseverance. Only a few chapters endeavoured, from the outset, to challenge conventional representations of serodiscordance and to argue for more diverse and complex understandings of serostatus. Other chapters were initially framed by the risk paradigm that dominates so much research and discourse on serodiscordance but gradually transformed into something else as the stories within them evolved. And a handful of chapters were based on research that had not even intended to focus on serodiscordance *per se.* But mixed status had come up through the cracks, demanding attention, raising questions and piquing the researchers' interest in the stories they discovered alongside or underneath their primary data. As editors, we were eager to engage these authors in a collaborative process of discussion and revision, and thrilled when they developed their own novel and insightful perspectives that, in turn, challenged and enriched our own thinking.

This book provides a forum for all those stories. Together, they lay the groundwork for future qualitative research on serodiscordance with hopefully broader scope and reach in terms of regions and populations.

A Phenomenon "Under Construction"

The chapters included in this book clearly show how serodiscordance is moulded by cultural contexts and relationship dynamics. In addition, coming—as these chapters do—from different disciplinary perspectives, they also reveal the way methodological approaches and epistemological lenses brought to bear in research frame mixed-status relationships as a particular object of study, in one way or another. What readers of this finished volume cannot witness, however, is the evolution of some of these pieces from initial to final form, with its profound demonstration of the impact of changing one's analytical lens. In some cases, researchers who began to examine mixed-status couples in a different way were led to entirely novel framings—as though something new and unexpected had appeared before their eyes. In this way, research also contributes to the multiple ways serodiscordance is shaped and understood. At the core of this book is the argument that serodiscordance is a profoundly relational phenomenon. This relational aspect is true in the lives of couples and families, as so many of the chapters attest to. But, as the process and labour of this book made clear, it is also true in terms of serodiscordance as an object of knowledge and inquiry.

Our entreaty to researchers, policy-makers, and care providers who engage with mixed-status couples is to refrain from assumptions about the meaning and "inherent" challenges of managing serodiscordance, or about the primacy of HIV "risk". Instead, we urge recognition that such domains may or may not be paramount, and that, in any case, tightly focusing our inquiries on such issues can only reveal part of a bigger and more complex story. From an anthropological perspective, this approach to serodiscordance is merely the application of what Aaron Podolefsky (2011: 81) called out as a hallmark of the discipline: "a habit of mind that begins by questioning fundamental categories of meaning". Such acceptance of the always-provisional nature of our understandings about social life, coupled with openness to multiple meanings may have a practical application in terms of informing health interventions and policy. Increased attunement to the diverse lives and needs of those targeted by such efforts may ultimately contribute to the global goal of ending the HIV pandemic (Havlir and Beyer 2012; UNAIDS 2012).

In addition to such concrete benefits within the field of HIV, the practice of radical reflexivity may also be used to gain insights into health conditions and relationships more widely. Questioning fundamental assumptions allows previously unsuspected dynamics to become visible, such as locally situated conceptions and intersections of disease, sexuality, reproduction, stigma, love and citizenship, as well as the varied ways human beings both resist and make use of the increasing biomedicalisation of the societies in which they live. As such, the insights provided in this book are relevant not only to HIV serodiscordance, but also to other stigmatised and infectious conditions, such as hepatitis C, hepatitis B and sexually transmissible infections, and perhaps more broadly to couples and families who live with chronic illnesses or disabilities.

Returning to the topic at hand, what this book reveals, more than anything, is that serodiscordance is a phenomenon "under construction", to borrow Jacalyn Duffin's (2005: 83) phrase about the medical mapping of hepatitis C (see also Fraser and Seear 2011). While serodiscordance has been almost over-determined medically, it is still very much under construction conceptually and culturally. This book brings home the importance of engaging with empirical stories and critical perspectives to foster rich and contextually meaningful insights into mixed-status relationships. But it does so not with the aim to pin down and settle once and for all exactly what serodiscordance "is", or even to render this phenomenon more coherent or cohesive. Rather, our purpose with this book is to demystify mixed HIV status and reveal the myriad and relational ways it is intimately entangled with local contexts; *and always will be.* Situated in the midst of human life, with all its vicissitudes, all its coextensive flux and continuity, serodiscordance will always be "under construction", and we will always be actively "making 'difference'" by the way we attend to it.

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Part I

Biomedicine, Change & Diversity: Conceptualising Serodiscordance

The Science Made Me Do It! A Journey Toward Reimagining Myself as Non-infectious: Serodiscordant Sexuality in the Age of TasP

Pluto Savage

For Martin (1966–1998)

One white pill and one blue pill sit casually by the side of my coffee mug as though they mean very little. It's an entirely non-threatening scene, mundane even. The pills don't cast a heavy shadow nor do they signify a burden upon me. But the two apparently innocuous objects before me that fit effortlessly into my daily routine, must not be taken for granted, for they are the very small things that have kept me in perfect health for almost a decade. In all likelihood they are the reason I am alive. While my partner and I are share breakfast and chat about the day, I pause to silently observe a moment of thanks for how easy this is for me, before washing my pills down with coffee. This scene is a universe away from the handful of pills I know many people had to take to stay alive before me. Never mind the other handful of pills they had to take to combat the side effects from the first handful. I am acutely aware of the good fortune and enormous privilege that allows me to pop those pills in my mouth each day. I live in a country where my medication is readily available at an affordable cost. And now it turns out, the two pills I swallow every morning are also protecting my partner from HIV infection, and affording us the luxury of condomless sex. Those two small pills are truly no small thing and I make certain I never forget that.

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I occupy an interesting position on the Australian HIV/AIDS timeline. In my teens, my friends and I would steal into Oxford Street, Sydney's queer epicenter at the time, to pick up copies of the local gay paper. We would sit in a café filled with queers and paw over images of the thrilling urban life we desired so much. Then

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pausing, chilled, on page after page of obituaries. A few years later I hit the queer scene, just early enough to pass the spectral form of Brenton Heath-Kerr, maintaining an elegant dignity as he walked painfully down Oxford street in his last days. His fragile frame has left a permanent mark on my memory. I knew he was the genius inside that Tom of Finland costume and many other mind-blowing artworks. He was an icon of the AIDS crisis and there he was walking alone down Oxford Street, heading toward the hospice. By now I was a budding performance artist and was hugely inspired by his work. I had a sense that I was watching some kind of royalty decaying before my eyes.

I walked into a battle-worn community and it was not unusual for older friends to tell me, after another funeral, how lucky I was to have missed the worst of it. So I fit somewhere between the elders who were ravaged by the daily loss of friends, lovers and community, and the young'uns who, if you listen to the popular rhetoric, don't know how it was, and therefore, apparently, don't have a care in the world. It's a pervasive view that really worries me; perhaps being on the cusp of those two generations places me well to observe the disconnect.

*

I was nineteen and fresh out of high school when I had my first crush. Martin was a bit older and a handsome, burly, muscle bear long before they had a name; a clash of Butch and Queen, which he never seemed quite comfortable with. But to me he was perfect. His HIV-positive status made absolutely no difference to me, but it brought him much emotional pain. We only slept together a couple of times because he was so deeply afraid of infecting me. This would not be the last time I was the HIV-negative partner in a serodiscordant relationship. But it was only much later, after my own seroconversion, that I came to understand why Martin was so fearful. No amount of safety in sex, no ironclad condom was enough to alleviate his fear. But we loved each other so we settled for becoming the best of friends. It was 1994. We would shop together and giggle about boys and the bulging crotches that would pass us by. One day when we were out window shopping, he went off his rocker at me over nothing, completely out of the blue. He couldn't be consoled or reasoned with and he disappeared after a huge explosion, scaring the hell out of me. Martin turned up two days later dripping tears on my doorstep and explained to me what dementia was. I promised not to take offence if it happened again.

Soon I met a great man who would become my partner of ten years, and Martin talked me through it. Things were moving fast and I'd not had a boyfriend before. I looked to Martin for guidance, and he encouraged me with all his heart. He was glad the guy I had met was HIV-negative. In Martin's reckoning it gave me a chance to live longer than he believed he was going to. He made me promise I would stay safe and he warned me, "If you die from AIDS like I'm going to. I'll find you in hell and kick your arse!" It wasn't like Martin to speak that way. I told him I didn't believe either of us would be in hell regardless of how we died, but I promised to stay safe.

On the 9th of April 1998, Martin passed away surrounded by friends and family.

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Like most good things, my ten-year long relationship arrived at its use-by date. The separation was mostly amicable, but I still needed a geographical change to shake off the cobwebs. It was 2006. I moved to Melbourne where a friend of mine recently had a room open up in his house. His housemate had died from AIDS-related complications. He and his family didn't believe in western medicine and subscribed to the theory that it was the meds that kill, not the disease. I didn't feel like I would find it hard to move into his room because I didn't know the guy, but I hadn't bargained for what was ahead of me. Arriving in his musty room, I found it was as he left it: dirty socks in the basket, stack of porn by the TV, and the book he was reading—*Catcher in the Rye* by J.D. Salinger—sitting open on the bedhead. Apparently his family didn't believe in claiming his belongings either. I dropped the two cases that nestled my whole life within them on the floor, thought to myself, "Pluto, this is just the kind of situation you would find yourself in" and I laughed long and hard.

I wasn't laughing a few days later, under a cold fluorescent light in Carlton, as a shaky young doctor told me I was HIV+. I think I might have been her first, and in the moment I was more worried about her than myself. She could have saved herself the trouble of saying the words, because I already knew from the flicking of pages and stalling she was doing as she plucked up the courage. I checked if she was okay and rushed out of there as fast as she would let me, assuring her I was fine. This was just one of my regular, routine "works burger" checkups as I used to call it. So my housemate had come with me, not for support, because I was so sure I'd been safe, but for the bike-ride on a sunny spring day. We hugged and cried on the steps of the clinic, just like in the movies. I giggled at myself under the tears for the cliché I had become, and let him lead the way home. He stuck to parkland and side streets; I guess he knew I had no head for negotiating the busy city traffic.

I walked back into my new room, changed forever by a few short words. All of Martin's fears bled into me in that moment and the belongings of the recently deceased leaned in around me. I eyed that copy of *Catcher in the Rye* suspiciously. I had moved it to the bookshelf a few days earlier, and from there it seemed to be beckoning me to read it, with some kind of malicious invitation to wallow in the irony of the time and place. I sat down on the bed and I tried to have a big cry, which my housemate had told me was the natural reaction, but nothing. Apparently I wasn't ready to let it out. So with nothing else to do, I prayed for the first time since I was a very young child. Not to some intangible God, but to someone that had once been warm, and that I knew was capable of love. I prayed to Martin for forgiveness. I was so sorry that I had let him down.

In the weeks that followed, which remain some kind of shock-absorbing haze in my memory, I took to having panic attacks in the street every time I saw a young woman that resembled my diagnosing doctor. This was an unsustainable model for living. I could hardly snatch that copy of *Catcher in the Rye* and crawl into a cave, so I would never again have to see a pretty young woman with dark hair. It just wasn't me. So I dosed myself up as high as a kite on my favorite elixir. Humor.

We affectionately renamed our clammy terrace "The Plague House". Then, surrounded by rising damp and ghosts, I set about laughing the whole thing off. AIDS jokes—the more cutting the better—ran so high and vile that my more sensitive friends found themselves choking up, as I formed the crust of armor around me that would keep me alive. But what of this cosmic joke I had found myself in? Bunking in what I had callously renamed "The Dead Guy's Room", and still surrounded by all the artifacts of his life.

I respectfully boxed up his belongings, omitting those choice items I knew a fellow faggot didn't want his family to see—if they ever claimed the boxes—wrapping fragile things as if someone was coming for them one day. Then I settled into my new room and my new life with a new set of challenges. I decided to see this as a message from the spirit of a guy I'd never met. I imagined him telling me to take my pills when the time came.

As the months passed I made all sorts of progress on things like the fear of death, fear of disclosure, fear of rejection. But I remained paralyzed with fear when it came to sex, which—by the way—I definitely wasn't ready to have with anyone at that stage. Suddenly feeling my own flesh as infectious material was a paradigm shift, a dark plot twist in an otherwise manageable story. The notion of passing on HIV completely freaked me out, so I resolved to only seek the affections of other HIV-positive men. But apparently the cosmic joke wasn't finished with me yet. Along came an HIV-negative man who stirred my heart. I really get why serosorting works for some people and I fully support their right to choose. But for me, apparently, love just doesn't roll that way. I couldn't bar my heart's gate to someone based on their HIV status when I was negative, so why start now?

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I'm now in my fifth serodiscordant relationship, and my third as the positive partner. I remain friends to this day with the first HIV-negative guy I was with after I seroconverted, and I owe him a great debt for helping me to reimagine myself as a sexual being. Those first few months together were filled with guilt and fear and also completely liberating. We were using condoms, but this was when I really knew the fear that Martin had for infecting others. For me though, that fear was overpowered by the epiphany of realising that there was still a life ahead of me that could be filled with the touch of others, and maybe even love. He is a great guy, but we weren't destined to work out as a couple. The next guy was a head tripper and a game player, and as it was the only truly abusive relationship I've allowed myself to be in. I'd like to say he barely warrants a mention. But unfortunately my relationship with a man who used my HIV-status to manipulate me was integral to embedding the message that I was infectious material, or at least, that my status was something I should apologise for; something that meant I should accept second-rate treatment. And so it is with reluctance that I add him to my story.

It was his preference to have unprotected sex, and occasionally I would consent to it, only to be beset by fits of guilt and remorse afterward. He believed that he was somehow incapable of seroconverting based on the amount of unprotected sex he had had with positive people in the past. But his belief was no comfort to me at all, for I knew it was unfounded. Nor did his belief stop him from claiming I was putting him at risk when it suited him to emotionally overpower me. Using my status against me was just one of his many tricks. The rest I don't care to go into. The relevant point here is that I allowed myself to remain in a relationship that I knew was abusive because I was HIV-positive. I actually believed him when, on the many times I tried to end the relationship, he would tell me I couldn't do better than him. No one better would want me with the plague. It was only due to the heavy hand of my friends forcing me out of that relationship that I was able to end it safely.

As the smoke was still clearing from the wreckage of that relationship I met Ethan, the incredible HIV-negative man I'm still with today. At first, I was reluctant to let it go too far because that last relationship had left me swearing off negative guys forever. Never again could I let someone use my status against me. It seemed, at the time, that an HIV-positive partner was the only way to prevent that from happening again. But my heart doesn't listen to reason—especially faulty reason—and things were moving fast again. This felt like the start of another big love, like the one that kept me with my first partner for ten good years. Could I really be that guy who is too scared to open up to someone because my last partner was a villain?

Also apparently the cosmic joke was still not done with me. Ethan was not only allergic to latex but had various unpleasant reactions to all sorts of condoms! We fumbled through all the thick and nasty latex-free options, up and down every shelf in every pharmacy, only to find that nothing was ideal. A couple of times in that heat of the moment and at those dizzying heights of early exploding love, we felt invincible enough to dispense with the condoms altogether. By then I was well and truly settled into my treatment regimen, but the news that medication could keep me from passing on the virus was still in the future. The times we slipped up I went into incredible fits of depression. I was horrified to imagine I was that guy who would put someone he was falling in love with at risk for his own pleasure. I made Ethan swear not to tell anyone because I felt so ashamed.

Ethan is a transman who has had a hysterectomy, but has otherwise kept his original plumbing. At that time, and really still to this day, there is no safe sex information that's specific to his anatomy. Was he more or less susceptible to infection? Were the risks we had taken completely off the scale because of the ways his hormones may or may not affect his vagina? Could his hysterectomy have increased his chances of seroconverting? We searched everywhere for information but there was none to be found. He tested negative, I stopped panicking and we vowed to stick to condoms, not only to protect him, but also to protect me from the bouts of emotional self-flagellation.

I need to be clear here that I bear no ill will or blame towards the person that passed the virus onto me, so I don't take some ethical high ground that the positive person has to take full responsibility to protect others. But if I can save someone else from going through some of the hard times I had, or better still, if I can avoid passing the virus on to someone who might have a much worse time with HIV than me, then I can relax.

Not long into our relationship, news of the treatment-as-prevention (TasP) trial conducted with heterosexual couples, showing that an undetectable viral load reduced transmission, hit the press.[1] The word in the Australian queer press was that we better not burn our condoms just yet, because the study was done on couples who have penis in vagina intercourse. The same reduction in transmissions may not be seen in those engaging in anal sex. As Ethan and I only have penis in vagina sex, we saw this as a green light to dispense with condoms and rely on my undetectable viral load to keep Ethan safe. More studies followed and my fears subsided in direct proportion to how much information I could access. But there was still some lingering mistrust of the facts. I was always bracing for the impact of Ethan seroconverting. It was when HIV organisations like ACON[2] began promoting TasP as a viable safe sex strategy that I realized I could finally relax. Surely these organisations would not put themselves at risk of promoting something that was going to turn out to be wrong. The fact that scientists and health professionals were confident enough to broadcast this information finally outweighed my fears.

But not everyone, it seems, was convinced by this shift. In the lead up to writing this chapter I decided to do my own bit of research; an observation of the public opinions around the new biomedical HIV prevention technologies, PrEP and TasP. I observed a stream of pseudoscience, myths and misconceptions crawling down my Facebook news feed. My friend list is comprised of a very broad cross section of humans, including a lot of men who have sex with men, and a lot of HIV+ folk. My observation is hardly scientific, but the value of it can be found by understanding that this is the world I live in; these are the people whose opinions I'm subject to. These people are the judge, jury, and executioner of my life choices.

Observing a notable silence in the affirmative, a shocking lack of support for the new technologies of protection, the discourse seemed to be almost entirely dominated by accusations of selfishness; self destruction; the young and stupid jumping at any chance to throw away condoms because they don't know what it was like to lose so many; fears of a drug-resistant super plague incubating in reckless bodies; biblical notions of payback and consequences; even the old favorite mythical "bug chaser" made a guest appearance. Tempers ran hot, and any time I suggested that times could be changing, that we should open our minds to new modes of protection, or "isn't it great there's now more than one way to be safe", I was met with violent backlash in caps lock; Facebook's peer review process. My research confirmed that my practices were not only unpopular but also considered deadly

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[1] The HPTN 052 trial: http://www.hptn.org/research_studies/hptn052.asp

[2] ACON is the AIDS Council of New South Wales, the most populous state in Australia.

and evil. If I were to believe the Facebook oracle, I'd be imagining myself a murderous pleasure-seeking monster about now.

In an age where the Australian mainstream media is still printing articles aligning the "threat" of same sex marriage with AIDS, I feel like a little less infighting and sweating on the details about how we fuck, would serve us well.

My partner and I have been together five years now. He's never used my status against me, and we haven't used a condom for four years. I take my pills every day, we get our bloods done regularly, and take responsibility for our own part. And I'm finally able to re-imagine myself as non-infectious.

I miss Martin always and I wish he could be here to hear me say I can make love to my partner without fear.

"PrEP Makes My Relationship Even More Normal:" The Discursive Production of Hope in the Context of HIV Pre-exposure Prophylaxis Among Young Adults with Partners Living with HIV Infection

Kimberly A. Koester, Xavier A. Erguera, and Janet J. Myers

Introduction

Nearly 35 years ago, the first cases of what eventually became known as "HIV/AIDS" were identified. An estimated 39 million people worldwide have died from this infectious disease while 5700 become infected each day. Social scientists have long attended to the evolving discourse on HIV and AIDS (e.g., Treichler 1999; Patton 1990; Watney 1997). Early on, they noted how the metaphor of "the plague" profoundly influenced responses to the epidemic (Treichler 1999), and drew attention to the social and psychological difficulties faced by people infected with and affected by HIV. Progress in treatment and prevention has substantially weakened the plague metaphor, even giving rise to a new slogan heralding the "End of AIDS" (Sidibé 2011). Framing the latest biomedical discoveries in these terms invokes a future where HIV is no longer transmitted and is a powerful discursive turn in the history of the epidemic.

Two fairly recent major biomedical advances, including the use of antiretroviral treatment as HIV prevention (TasP) (Cohen et al. 2011) and as a pre-exposure prophylaxis (PrEP) (Grant et al. 2010), allow us to consider a future with no substantial increase in HIV incidence; hence, the notion of the end of AIDS. However, we have not witnessed equivalent breakthroughs at the societal level (e.g., Nguyen et al. 2011; Young et al. 2014). For example, the HIV discourse in the United States, while continually evolving, vacillates from medical professionals counseling a person newly diagnosed with HIV that s/he will live a normal life, to the criminalization of approximately 180 people (from 2008 to 2013) through their arrest and/or prosecution for exposing an uninfected partner to HIV through consensual sex, or by biting or spitting on an uninfected person (Richardson et al. 2015). These

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messages – “you will live a normal life” and “you could be arrested for having sex”– present opposing biological and social realities.

In this chapter, we offer an analysis of a contemporary representation of HIV as we enter the “End of AIDS” era. Specifically, we present views from the social worlds of young people in serodiscordant relationships, in which one partner is HIV-negative and the other HIV-positive, as they reflect on a novel biomedical HIV prevention strategy. The focus of this chapter socially situates the discourses circulating about pre-exposure prophylaxis (PrEP) by exploring how young people coupled with HIV-positive partners are making sense of PrEP. We argue that this biomedical intervention is shaping the individual-level discourse on HIV in ways that portend a potentially brighter future, one where the discourses of fear, stigma and shame are replaced by hope and empowerment.

The clinical science on PrEP’s efficacy is clear, with studies demonstrating that it reduces HIV acquisition risk by 78–95 % when taken as directed (Grant et al. 2010; Baeten et al. 2012; Thigpen et al. 2012). But the *social* and *behavioral* implications of PrEP use, particularly among those in serodiscordant relationships are less well understood. As powerful medications to effectively treat and prevent HIV have ushered in the possibility of seeing HIV as a disease with an end in sight, the meaning of serodiscordant couples is also “on the move.”

Research Setting and Methods

Part of testing the promise of PrEP to help push us towards an “end of AIDS” is to explore whether the notion of this biomedical prevention method holds any appeal to people vulnerable to HIV. Researchers who study peoples’ everyday experiences, such as anthropologists and sociologists, are particularly interested in understanding how scientific research becomes embodied in the lives of those “targeted” with biomedical interventions (e.g., Rosengarten 2009; Rosengarten and Michael 2009; Kippax 2010). In 2012, we conducted a pilot study to gather input on how to best design sexual health services for young people vulnerable to HIV, primarily young gay men of color, but also for female and male sexual partners of youth living with HIV who received treatment in the HIV clinic where we carried out the research. The information we learned during this process informed the design of a PrEP demonstration project open to gay and bisexual men who have sex with men (MSM), transgender persons, and the sexual partners of HIV-infected individuals (aged 18–29). The Committee on Human Research at the University of California, San Francisco approved the research.

We purposefully sampled and conducted in-depth interviews with 15 HIV-negative youth for the pilot study, nine of whom were in serodiscordant relationships. It is these nine interviews that we draw on in this chapter. Prior to the interview, each participant talked with the clinic’s health educator about the concept of PrEP.[1] None of the participants were using PrEP. During the interviews, we explored topics about health, sexual health and aspects of the participants' serodiscordant relationships; how they came together, when and how disclosure of HIV status occurred, strategies related to HIV management, overall relationship dynamics, including sexual dynamics and finally, we discussed PrEP. The interviews were digitally recorded and transcribed verbatim. Participants were assigned a pseudonym to protect their privacy. Working with the transcripts, we wrote analytic memos on each interview noting similarities and differences across the interviews. The analysis for this chapter incorporates multiple data sources: fieldnotes, transcripts and memos.

Findings

Drawing on the nine interviews with participants in serodiscordant relationships, we present three representative cases. Table 1 contains demographic information and the duration of the relationships.

"It [PrEP] makes my relationship even more normal, as if we both didn't have anything"

Janeah had been dating John, a patient of the clinic, for about 6 months. During our interview, Janeah recounted how she learned about John's HIV status. In relating this story, she articulated an identity shift; not only had she become a young woman in love, she also became a young woman in a serodiscordant relationship. Below, her quote epitomizes an experience labeled by Ware and colleagues (2012) as the

Table 1 Participant and Partner Characteristics

Participant	Partner characteristics	Sexual orientation	Duration of relationship
Janeah, 20, African American	Male, African, perinatal infection	Heterosexual	Less than a year
Jaime, 20, Latino	Male, White, behavioral infection	Gay	About a year
Jose, 20, Latino	Female, African American, perinatal infection	Heterosexual	About a year

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[1] At the time of this research, PrEP was not easily available, insurance companies had not officially added it to their formularies, and PrEP users were primarily white gay men participating in PrEP research studies or had the resources to pay for it out of pocket.

"serodiscordant dilemma," a commonly occurring crisis that ensues when a couple is faced with serodiscordance.

> Then he finally told me, and I was like, "Oh my God, like, are you serious?… I'm dating somebody that's known HIV-positive." It just never, ever occurred to me. I was like, wow, so this is going to be my sacrifice. I'm going to have the man of my dreams, but the man of my dreams is going to have a deadly virus, and that's my catch.

At first, Janeah interpreted HIV as a "deadly virus," positioning it as a possible threat to her boyfriend, herself and their relationship. She explained that John had told her about his infection about 2 weeks after they began dating. She said that he had expected his disclosure of HIV would end their budding relationship.

Soon after learning John's HIV status, Janeah discussed her "catch" with people she felt close to, including her grandfather, whom she was living with. Many of her confidantes encouraged her to reject John as a potential boyfriend. In her interview, Janeah expressed feelings of initial ambivalence, echoing dominant assumptions about who constitutes an ideal partner when she stated: "it's not what's absolutely best for me, to be with someone who's HIV-positive." Ultimately, however, Janeah decided to stay in the relationship in spite of the reactions of her friends and family, but not without consequences. Because of her decision, her grandfather kicked her out of her house, which demonstrates what Jacoby (1994) defines as enacted stigma; a behavior or act of discrimination. Janeah held steadfast in her decision to remain in the relationship and moved into John's house, which ended up strengthening their bond.

Janeah fell in love with John first and learned about his HIV status second. She endured the hardship of being rejected by her family. The early days of love allowed her to "accept" rather than reject John, which surprised him. She explained:

> Sometimes I don't think logically, or I don't do what is absolutely best for me. I just follow my heart. That's when I was like, 'you know what, I'm going to accept you for that'. And he was like, 'Wow, are you serious? It's okay, you can leave me'. And I just wanted to cry for him, because I can't imagine how much that sucks. He was just as in love with me as I was with him.

Janeah described her decision to be with John as illogical, implying that she perceived there may be negative social repercussions from this decision. John's response, that leaving him would be acceptable, reinforces Janeah's interpretation and further positions serodiscordance as a highly undesirable relationship characteristic. Together, they constructed the situation as ill-fated and irrational. Both placed a negative value on HIV-positive serostatus, which reflects (and sustains) common cultural narratives of HIV-related stigma. PrEP, however, offered a way out of this dilemma, as explained by Janeah's reaction to hearing about the "new HIV prevention drug":

> I was [watching] CNN, and I saw an advertisement for it. It just said, 'New HIV-prevention drug'. And I was like, 'Oh, my God!' Because we were new in our relationship, and I'm like, 'This is so cool!' I'm like, 'If there's some way that I can protect myself even more, then it just makes my relationship even more normal, as if we both didn't have anything'.

In Janeah's interpretation, the new HIV-prevention drug was not merely a way to protect herself from the virus. PrEP also served as a mechanism that could, in a sense, "cancel out" her boyfriend's HIV status, since, if transmission were no longer an issue, then it was as if he did not even have HIV. PrEP's appeal, as Janeah forecasted, was a future where they were no longer the exotic "other" as a serodiscordant couple, but rather a "normal" couple. She also explained that PrEP would allow her and John to reclaim "our connection again with sex," by which she meant that they could have sex without the interference of HIV. Janeah was on the birth control pill and thus, HIV was symbolically present in their sexual relationship every time they used condoms. In the beginning of their relationship, prior to John telling her about his HIV status, they had had condomless sex. Notably, in addition to being on antiretroviral treatment, John had taken care not to expose Janeah to bodily fluids[2] – he had pulled out before ejaculating. For Janeah, PrEP promised to take them back to the time before HIV disrupted their sexual connection:

> I feel like unprotected sex is more of a connection. If there's a way I could get that back, our connection again with sex, then that would be great …There's a big difference from when you're using a condom and you're not; I know he's not enjoying it as much. I don't want my sex life to go downhill. It's like if he's not enjoying it, then that's going to affect how I feel about it, too. That's when he goes into saying, 'Oh, I wish I didn't have this, and I wish I could be normal'. So it [a condom] does affect my sex – it acts as a barrier between the two of us, because that connection isn't there.

Janeah's embodied sexual experience was set in a particular social and gendered context, a serodiscordant context that she described as missing or lacking in "connection." Her description illustrates the relational feedback between her and John that occurred through sex. His sexual enjoyment was important to her, yet her vulnerability to HIV created a tension for them both. This type of vulnerability experienced during sex was new to Janeah and a situation she felt somewhat powerless to change. She reported that they used condoms about 80 % of the time and that he did not ejaculate when they had sex without a condom. Janeah's subsequent imagination around PrEP conferred optimism, as she perceived an opportunity for greater bonding between her and John, bonding made possible by PrEP's perceived ability to neutralize the couple's serostatus. Others, as we describe below, discussed similar aspirations, suggesting that PrEP can create opportunities for renegotiating the embodied experience of serodiscordant sexuality. Let's shift to Jaime, a young gay man, who shared some of Janeah's emergent hopes.

"I want to see if it helps improve my relationship."

Jaime met his partner, Mark, on an online social/sexual networking application (app) designed to facilitate contact between men who have sex with men. Many such apps allow users to include photos, physical descriptions and demographic information—including serostatus—in the profile that other people view. This makes it possible for the disclosure of a potential partner's serostatus to happen

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[2] Though commonly practiced, this is not an effective HIV prevention (or pregnancy prevention) strategy.

passively; meaning that someone's serostatus becomes a trait like height and weight, which may (or may not) then be taken into consideration as a viewer is sorting through various profiles. This is what occurred between Jaime and Mark. In contrast to Janeah's reaction of surprise to John's disclosure, Jaime took in the information differently. He described his experience in first meeting Mark:

> I wasn't really surprised [that he was HIV-infected] because he had that positive sign on his profile. I ignored it because I wasn't going to be, like, 'Hey, are you HIV positive?' He told me [later]. I was at work that night and asked my co-worker: 'If you're going to date somebody, and they told you they had HIV, would you still go out with them?' She was like, 'Well, I don't know. Do you think it's worth it?' And, I was, like, 'Well, I'm not going to deny somebody just because they have HIV'. Cause I have a friend that has HIV, and he would always tell me how nobody was going to be able to love him again cause he had HIV. And he came into my head. And, I was, like, 'I'm not going to say no to Mark just because he has HIV.'

At first, Mark and Jaime initiated a friendship. Mark verbally disclosed his HIV status before they started formally dating. Jaime clarified why he had ignored the positive status on Mark's profile; he had thought that Mark was either HIV-positive or, because he noticed that Mark wore a cross necklace, was just "really into crosses." He also felt it would be rude to ask if Mark was positive: "you can't just bluntly ask a question like that." Like Janeah, Jaime prior to getting too far into the relationship, discussed the serodiscordant dilemma with a friend, who responded by asking a rhetorical question: "Aren't you going to regret it later?" insinuating that dating a person living with HIV was a dangerous proposition. We noted this pattern in other interviews – friends and family reacting with concern and expressing a lack of support, thereby reinforcing the dominant cultural perception that serodiscordant relationships are problematic. It is not clear if these reactions stemmed from concerns related to the possibility of HIV transmission specifically, or more generally to the idea of dating a person with a stigmatized disease, although the two are closely interrelated.

Both Janeah and Jaime turned to friends and family to discuss the issue of dating and loving someone with HIV. Jaime, in particular asked: "what would you do?" Both initially endorsed the socially unappealing idea of dating a person with HIV. Their timing of grappling with the serodiscordant dilemma differed in that Janeah had already fallen in love with John when she learned about his status, whereas Jaime had not yet begun dating Mark. In both situations, the presence of HIV caused both to pause and reflect on what to do next.

When asked about PrEP and sex, Jaime explained that he had heard about PrEP just prior to dating Mark. Once they began dating, he and Mark decided to talk with their respective health care providers about accessing PrEP. Jaime described what he hoped PrEP would do for him; his response echoed Janeah's. He too wished for greater connection with Mark through engagement in condomless sex. But unlike Janeah, his hopes were not that PrEP would restore a lost sexual connection, but that it would bring about a connection through the possibility of an expanded sexual repertoire. And while Janeah's hopes hinged on PrEP reducing her own fears of infection, Jaime hoped it would lessen the fears of his positive partner. In the excerpt below, Jaime explains how sexual encounters with Mark unfolded, contextualizing why PrEP had a strong appeal for him:

> [For Mark] to cum inside of me would just be my fantasy. That hasn't happened, and I want it to happen … Because when we're having sex, he doesn't want to pass [HIV] on to me. So he just pulls away and he's just so worried that he goes limp. Like right away, after five minutes of starting. He just pulls out and I feel like just the thought of passing HIV to me turns him off … I think it [PrEP] could get us a little bit more connected; sex would be way better than him just being worried about it. I just want to see if it helps improve my relationship.

Thus, in Jaime's telling, PrEP held the potential to alleviate the oppressive fear of HIV transmission that likely contributed to Mark's erectile dysfunction and to their mutually unfulfilled sexual desire. Jaime was tentative in his expression of hope: "I just want to see if it will improve my relationship." Like Janeah, he envisaged PrEP working on the relational level. It was not just a chemical technology with the ability to prevent HIV from binding to his cell receptors, but because his receptors *would* be protected by PrEP he expected his boyfriend's body to respond differently – more successfully – thus leading to improvements in relationship satisfaction. Both Janeah and Jaime predicted that the benefits of PrEP would be mutually experienced and that PrEP would have an equivalent effect on their partners. Next we turn to our final example of Jose, which adds further variation on the meaning of serodiscordance and PrEP.

"It's just something you have. It's like me being a graffiti artist, a thief, and a pothead. It's something we are…."

Jose was partnered with an HIV-positive patient named Laura who was 7 months pregnant with Jose's baby at the time of our interview. His reaction to Laura's disclosure differed significantly from the narratives expressed by other participants. While telling Jose she was positive was challenging for Laura, Jose was refreshingly unperturbed by the revelation. In fact, he interpreted the news as an opportunity to deepen their relationship, to exchange intimate and potentially stigmatizing information about what each of them brought to the partnership, as reflected in Jose's story of Laura's disclosure:

> She didn't tell me in person, she told me in a letter. It was hard for her to tell me, but I understood it, because we both wanted something real, and she didn't want me to be frightened or scared of what she had and me to run [away]. And I didn't … I told her 'It's just something you have. It's like me being a graffiti artist, a thief, and a pothead. It's something we are. It's the same aspects – it's something that you come with. You can't change me and I'm not going to change you'.

Jose's interpretation of Laura's HIV status rendered it unremarkable, as her "spoiled identity" (Goffman 1963) was cast as comparable to the transgressions Jose had himself made. He turned hegemonic connections between social stratification and deservingness on their head by arguing, "Everyone that's a jerk gets everything nice in life" and "Someone who has a disease ends up being born in the wrong neighborhood – those are mostly good-hearted people." HIV served as a marker of prior social marginalization ("born in the wrong neighborhood") and one that Jose leveraged to his advantage in that he traded acceptance of her so-called socially undesirable illness for acceptance of his socially undesirable and illegal activities. His acceptance and normalization of Laura's HIV status was influenced in particular by his personal experiences of stigmatization as a thief and misunderstood urban artist.

Jose continued to build on this normalization of HIV during our discussion about how HIV played into sexual situations. He told us that sex with Laura was no different than sex with previous partners who were HIV-negative and insisted that he did not want it to be different. This came through perhaps most notably in his comments on the space HIV occupied (or did not, rather) in their sexual relationship:

> It's not a problem. It's never on my mind during sex. I never think about it because, to me, I see the point of sex as a point to be one with the other person. I'm not about to drift off and be somewhere else. I'm not like that. If I wasn't drifting off and thinking about some other stuff when I was having sex with someone who wasn't positive, why am I going to do that with someone who is positive? It doesn't make sense to me. I just act the same as I do to her as I did to other girls. It's not at all different. Maybe a little bit more special, but that's about it. She is my baby mama [laughs].

In clear contrast to Janeah and others, Jose claimed HIV did not change his experience of sex as an opportunity "to be one" with Laura. His assertion that he was not the kind of person who would worry about HIV during sex appeared to be a strong and self-congratulatory rejection of stigma. Likewise, when we asked about his feelings about contracting HIV, Jose told a very different story than did other participants, who feared becoming HIV infected. For example, when Laura became pregnant, the clinic staff encouraged him to be tested for HIV. During the testing process, instead of feeling anxious, he accepted the possibility of a positive test result and believed it would bring him and Laura closer; he would then understand the world as she did because they would share the illness experience. He explained:

> The first time I got tested here was because she had gotten pregnant, so they tested me. When I got tested, I didn't really have a fear of getting the disease or not. I wasn't scared of it. I thought I would be scared of it, but my girl's had it since she was a baby. She was born with it. That's 19 years living with it. That's a lot of years for someone, and I'm thinking, if she can do it, she's still looking at life so happily – if I catch it, she gave it to me… My burden and her burden become our burden, rather than one of us having it; it'd be both of us. I wasn't like, 'oh, I can't get it, my life is going to be over'. I was like, 'now I get to see life through how she sees it', basically.

Jose's relative comfort with the possibility of becoming HIV-infected extended to ways he would react in situations that other participants might have seen as risky. He noted that, when Laura had had bloody noses, "I still find a way to help and not just stand there being 'what do I do?'" HIV did not stand between these partners the way it did in other couples.

Such equanimity, while important, did not indicate the absolute normalization of HIV. While Jose's narrative mainly evoked the values of a chivalrous young man standing by his partner, unafraid of HIV, suggestions of ambivalence emerged as well. For example, he revealed a sense of vulnerability and disempowerment when he recounted his experience of observing and listening during Laura’s medical exam with her HIV care provider. The terminology used during this encounter was foreign to him, making him feel overly reliant on Laura to honestly translate what he intuited as a serious discussion. This was the one occasion when he associated the term “scary” with HIV. In that scenario his fear was tied to the virus’s impact on his partner; was her health getting worse?

Interestingly, the only mention of HIV-related fears for himself surfaced in Jose’s reaction to the idea of PrEP—and notably those fears were only articulated when the effectiveness of PrEP was explained to him. He responded:

> It just sounds crazy – a pill you take and you won’t get HIV. [Health educator] told me, ‘Oh yeah, it can lessen the chances of you getting it’. I’m all like, ‘All I got to do is take it once a day?’ It was interesting to me … I feel like I’d be able to live life a little bit better … It’ll take some of the fear away of having a chance of catching it. Make life a little easier.

Compared to Janeah and Jaime’s reactions to PrEP, Jose’s was more even-keeled. The difference he hoped PrEP would make—to take “some of the fear away” and “make life a little easier”—seemed to be one of degree rather than of kind. This makes sense, given the way his overall conception of HIV contrasted with other interviewees’. And yet the fact that PrEP did still make a difference to Jose, albeit slight, points to the power of hegemonic perceptions of HIV and serodiscordance. This, in turn, renders even more remarkable PrEP’s capacity to engender new ways of being in relationship to HIV, and subsequent renegotiations of the meaning of serodiscordance.

Discussion

Medications for treating and preventing HIV are having an impact on the social and sexual worlds of people that are vulnerable to the virus. In this chapter, we have presented how some young HIV-negative people in mixed status relationships are engaging with PrEP’s “transformative imperative” (Persson 2013:1065). We set the stage for positing PrEP’s effects in serodiscordant relationships by first explaining our participants’ relationship to HIV. We examined their narratives to elucidate the meanings of HIV and, in doing so, analyzed how youth made sense of serodiscordance. In their interviews, participants revisited conversations with family, friends, and close confidantes. By reviewing these conversations, we observed tacit values and assumptions at play, specifically we noticed how HIV-negative bodies come to be discursively produced as normative.

The young people in this study assigned hopeful meanings to PrEP against a backdrop of touching stories of romance and love, as well as troubling situations that they found themselves in as a result of being in a serodiscordant relationship. With PrEP, youth imagined that their relationships would change, even flourish, without worries about HIV transmission or anxieties inhibiting a sense of sexual connection. In these moments, youth expressed hopes that taking PrEP would transform their relationships.

The transformative power of PrEP comes from seeing it as more than just an HIV prevention strategy. Rather than merely a protective shield against an invisible virus, interviewees see PrEP as capable of helping couples achieve *normalcy*. In this way, PrEP has the potential to neutralize serodifference. Janeah illustrated this best when she described her impression of PrEP: "it would be as if we both didn't have anything." Thus, PrEP, particularly in combination with TasP, may reduce fear and serostatus-related perceptions of otherness and allow couples to move forward in their lives together, not so much as a "serodiscordant couple," but as a couple managing ordinary life situations.

PrEP may afford opportunities to break from the constraining instances of serodiscordance because the features of PrEP (highly effective, non-disruptive during sexual encounters, female- or receptive-partner controlled strategy) offer a solution to difference, whether serostatus difference, or difference through social stigma. Members of serodiscordant couples may no longer feel the need to "deflect feelings of otherness" (Persson 2008:505) within the relationship and in relation to the larger social world. As our case studies suggest, biomedical prevention technologies such as PrEP might enable new ways to articulate and enact mixed HIV status that lay claim to a less injurious "sero-neutral" or "sero-normal" status.

Here we propose that the concept of a highly effective daily pill to prevent HIV (PrEP) can neutralize serodiscordance and in doing so generatively influence the individuals within mixed-status couples and, by extension, the communities around them. Let's consider what would happen if we moved forward with Janeah's anticipation that her relationship would become more normal because PrEP would make her feel less vulnerable to HIV. Janeah's attitude pushes towards a discursive position that begins to locate bodies with HIV within the same playing field as bodies with asthma or diabetes, thus subtly shifting away from the dominant stigmatizing attitudes about HIV and instead takes steps to normalize it. The social agenda working to de-stigmatize, humanize and dignify people with HIV may be further advanced by PrEP.

The biomedicalization of HIV prevention and treatment allows us to imagine a world in which we (attempt to) "end AIDS." Although we may never achieve this (we have yet to "end" malaria, for example), putting forth new language changes the conversation, generating new practices associated with HIV. It is possible that the campaign to dignify people living with HIV could be advanced by the early advocates of PrEP. As foregrounded by the stories told in this chapter, contemporary PrEP-use candidates are re-thinking their corporeal vulnerability to HIV, which is shaping their social and emotional reaction and relationship to people living with HIV. If people living with HIV become un-infectious because their viral load is undetectable, and if HIV-negative people use PrEP as a way to further decrease any vulnerability posed by serodiscordance, the virus itself is rendered impotent, at least from a biomedical perspective.

Scholars are attending to the ways in which biomedical interventions intended to enhance sexual health, such as Viagra and the recently FDA approved female libido enhancing drug Addyi®, influence and reproduce normative notions of masculinity and femininity, erotic conduct and how the embodied sexual act should be carried out (Potts 2004; Race 2009). It remains an outstanding question to scholars whether PrEP will follow along this trajectory. Thus far, PrEP has been framed as liberating (Koester et al. 2014; Koester and Grant 2015; Jacobs 2015; Godfrey 2015), as well as criticized as culturally damaging (AIDS Healthcare Foundation 2014). Critics are concerned about high levels of non-adherence and that its use will lead to the erosion of condom use (Auerbach and Hoppe 2015). We argue here that there is potential for PrEP to generatively re-shape the social milieu.

Our proposal to recognize the social and relational benefits of PrEP complements the ideas found in Persson's most recent work on "pharmaceutical citizenship" where she foregrounds the "potentialities" rather than the limitations associated with TasP (2015). Persson's work with serodiscordant couples in Australia over 10 years illustrates the evolution of the everyday meanings of the biomedicalization of HIV treatment and prevention, including her important underlying argument that biomedical and pharmaceutical citizenship "has multiple effects, including the power to optimise life and counter stigma" (2015:12). Persson's work is situated within a rich conversation occurring chiefly among social scientists calling attention to the potential perils of pharmaceutical solutions, such as Nguyen and colleagues (2011) who described concerns related to the "remedicalization" of HIV; of seeing HIV as a medical problem to be managed by biomedical professionals (Nguyen et al. 2011:292). They argued that the shift towards biomedical interventions and away from non-medical prevention strategies is a step backwards. Given that Nguyen and colleagues wrote this opinion piece 5 years ago now, what might they make of the hope so many people today are experiencing in relation to the promise of both PrEP and TasP? Can there be room for both vigilance and optimism in relation to the "game-changing" potentials of these biomedical interventions? The answer to these academic arguments and debates may be borne out in the future as the social and sexual influences of TasP and PrEP are monitored over time.

In conclusion, we propose that PrEP has the potential to create a new and more neutral interpretation of HIV-positive serostatus. Our orientation is informed by the youth in our study for whom the social environment has proven oppressive and exclusionary when it comes to serodiscordant couples. We wonder if it is possible for couples in mixed status relationships, where one has an undetectable viral load and the other is using PrEP, to refuse the label "serodiscordance" altogether. What utility would this label have in such a scenario if the original intent of the label was to create action – to prevent the transmission of HIV between the serodiscordant bodies? If the possibility or actuality of HIV transmission is virtually eliminated, then do we need the label at all? This is perhaps the most optimistic way of interpreting the discursive production of hope emerging from the interviews with young people partnered to people living with HIV.

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Seeking Seroharmony: Changing Conceptualisations of Serodifference and Serostatus

John Rule and Sean Slavin

Introduction

In this chapter we use images from community-based HIV prevention as a means of focusing attention on the ways that serodifference has been represented in gay communities in Australia. The images or representations ground our argument. We read these images and representations as cultural artefacts that embody and conceptualise serodifference. In turn, these representations have amplified social understandings of serodifference and shaped the relational possibilities for such partnerships.

Throughout the history of the HIV epidemic in Australia, textual and photographic representations have influenced government policy and social attitudes (Sendziuk 2003:5). Representations of serodifference have often sought to address negative stereotypes of those living with HIV, with the aim of removing the fear of sexual partnering with a person with HIV and encouraging the possibility of mixed HIV-status coupledom. We suggest the images also operate to code already extant and acceptable social and sexual practices with the intention of amplifying those practices.

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The images examined in this chapter promote an understanding that sexual partnering of HIV-positive and HIV-negative men is acceptable and generally “OK”. Some image-making has suggested that partnering with a person of a different serostatus is perhaps also a place and space for the possibility of “true love and romance”. Other images display desirable outcomes from the attraction of “opposites”. Schatzki (2010) describes the ways in which “general understandings” are developed through social processes; general understandings that might be gleaned from the images we examine here are supportive of partnering and sexual negotiation between HIV-positive and HIV-negative men within the gay community. However, in examining these images more closely, we also identify some inconsistencies within the image-making.

One major problem is that in the image-making and amplification process, a binary has been maintained. The language of serodiscordance, generally used as the terminology to describe serodifference, suggests that seropositive and seronegative are incompatible. We also note that this binary, which was established in the literature and community discourse and came to be represented in various Australian images, left out the possibility of other alternatives, such as not knowing one’s HIV status. In each of the images we go on to examine, there is a coded assumption that the persons represented know their HIV status, whereas in reality a significant proportion of people have an uncertain HIV status at any given time (Pedrana et al. 2012; Holt et al. 2015).

Our observations are made not just as researchers and writers, but also as practitioners in the field of HIV health promotion and as people who have lived the realities of negotiating different relationships within a world that talks of serodiscordance. Our observations suggest that, as the language of serostatus has changed over time, so perhaps will it change further in the future – hence we emphasise the potentiality of language such as *serodiversity* and *seroharmony.* If language is not only a way of communicating or representing how we see things, but also, as Schatzki (2010) and other critical theorists argue, capable of shaping realities, then we see a shift to a language of serodiversity and seroharmony as assisting in the generation of new relational possibilities.

In this chapter we investigate the reasons why cultural constructions of a serodiscordant binary remain, and ask: what is the possibility of talking and practicing “serodiversity” and “seroharmony”? The notion of an “undetectable” HIV identity has now emerged; an identity that has potentially existed since the introduction of antiretroviral Therapy (ART) in the mid-1990s, but that has now gained increasing currency in community discussions with the recent Treatment as Prevention (TasP) strategy (Grace et al. 2015; Race 2015). Later we examine a visual representation of this identity. We note that the category of “undetectable” is very different to that of an uncertain HIV status, as the use of “undetectable” now also implies that an individual is on ART. We also note that people whose immune systems naturally suppress HIV to low or even undetectable levels may not be included in this new description of being undetectable and on ART. This supports the argument we are making for *serodiversity*; as it is now possible that people living with HIV are “undetectable” on treatments, but may also be “undetectable” without ART. We conclude by arguing that the binary of HIV-positive and HIV-negative still exists, but it exists within a mix of new HIV-identities in what Grace and colleagues (2015) have described as an “altered sexual landscape”, and what Persson (2015) has noted as a time when serodiscordant sexuality can potentially be reframed “away from risk and stigma”.

How Has Serodiscordance Been Understood in Australia?

The early responses to AIDS in Australia required gay men to alter their sexual behaviours in the context of a frightening and rapidly spreading disease (Altman 1986; Carr 2013; Duffin 2014). The problem recognised very early in the epidemic, in terms of intervening and creating and supporting safer sex behaviours, was one of “making sense of what gay men actually did” in their sex lives, as opposed to how they may have talked about it (Altman 1986:169). In this context, safe or safer sex for all was the message promoted.

Before HIV was identified and a reliable test for its presence available, the identifier of infection was not the presence of HIV but the presence of AIDS in one or more of its many forms. Until AIDS manifested, any man having sex with men was simultaneously both potentially not infected and potentially infected. A binary of “discordance” in this context was not relevant. By 1985, the modes of HIV transmission were understood and a reliable test for the presence of HIV antibodies was developed. The knowledge that it was the presence of the antibodies which indicated the presence of HIV, and therefore the possibility of developing AIDS, shifted the health intervention focus from just care and palliative care, to include a focus on the prevention of transmission from HIV-infected persons to others.

However, once a test became available, there was some resistance to identifying those who were HIV-positive during the early years of the HIV epidemic in Australia. Some gay men took the position that they would not test, firstly because there was no value in knowing their status (as no effective treatments were available), but secondly, because they did not wish to have the gay community separated into those who were HIV-positive and those HIV-negative. For these men, an unknown or an uncertain serostatus was a potentially HIV-positive status; for many this was a deliberate act of solidarity with those who were HIV-positive. At that time, as the Australian HIV specialist Adam Carr (2013) described in a retrospective speech, the aim was to be a “united gay community” that resisted any form of “antibody apartheid”.

In the absence of mandatory HIV testing (which was never supported by the gay community in Australia), the universal prevention message became: safe sex for all. For those who knew their serostatus in the early years of the HIV epidemic, this message dampened conversations about how HIV-positive and HIV-negative men might have a sexual relationship that bridged the problems of different serostatus. We have found no evidence in the literature that serodiscordance existed as term or concept at that time, and personal accounts (Paterson 2014) also point to its absence from the lived experience of the epidemic in the mid-1980s. Clearly gay men were having sexual relationships with men of different serostatus – whether they knew this or not – but during the 1980s, at least in Australia, these relationships had not been named as "serodiscordant".

By the mid-1990s, in writings from the US and soon in research literature in Australia, "seroseparating" and "seroseparation"[1] (Sadownick 1996:221) became part of the lexicon and terminology used in the discussion of maintaining safer sex practices and sexual negotiation between HIV-positive and HIV-negative men. In Australian AIDS education, the expression "negotiated safety" and "strategic positioning" in relation to safer sex practices started to be used (Van de Ven et al. 2002).[2] The argument was developed that "seroadaption", "serosorting" and "seropositioning" – all descriptors of different ways gay men used known serostatus to make decisions about their sexual practices and condom use within relationships – were effective strategies to reduce the risk of seroconversion (Van de Ven et al. 2002; Philip et al. 2010). It is not necessary here to recount the whole of this debate but to emphasise that "sero-identities" had now clearly emerged and that "serodiscordance" was now named and was a subject for research and specific health promotion interventions and strategies within gay communities. As we will argue, although HIV status came to be spoken about as a binary identity, in reality it has never been a simple oppositional relationship between two identities, but rather a "cluster" of identities. Most notably, there is a third group: those whose infection status is not known, as well as other potential and emerging serostatus identities.

Reading the Images

Serodiscordance has generally been represented in HIV prevention messages as a binary opposition. Despite attempts to make that binary appear complementary, an implicit assumption of oppositionality remains. In order to represent this oppositionality, a number of proxy devices are used. HIV status cannot be seen, so visual representations are arrived at, worked into and worked up within the context of gay community focused health promotion activities.

Stuart Hall (1995) has argued that visual signs always include particular codings, but the existence of different knowledge frameworks means that visual signs are usually read (or decoded) differently, according the knowledge framework of the

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[1] Sadownick (1996: 221) uses this terminology to describe the decisions of some gay men to only have sex with other gay men when their HIV status was disclosed and if their HIV status was the same – that is both were either HIV-positive or both were HIV-negative.

[2] The expression "negotiated safety" was used to refer to an agreement between HIV-negative men that would limit condomless anal intercourse to only between partners within a regular relationship. Any sex with other partners outside the primary relationship would have to be protected sex using condoms. "Strategic positioning" was used to refer to the way men determine sexual roles based on serostatus during condomless anal sex as a risk reduction strategy. The HIV-negative partner takes the insertive position and the HIV-positive partner takes the receptive position.

reader. This understanding sets us up to offer our readings of the following images as one of any number of possible readings. That is, if we understand images to be a communicative exchange in Hall's (1997) terms, the readings we apply to these images are not the only possible readings. Meanings are never permanently fixed, messages are never transparent and the reader is never the passive recipient of an intended meaning. In effect, we continue to read into, over and beyond these images. We suggest that, through image-making and cultural messaging within the gay community, the imaging of HIV-positive and HIV-negative gay men has been a repeated practice constructing understandings of serodifference in ways that have maintained a positive/negative binary.

In the following sections we offer some detailed readings of these images to see how oppositionality is visually embedded in HIV prevention messages. We seek to challenge that framing, by talking about multiple HIV identities. We then turn to some concluding remarks where we explore the idea that a significantly different conceptualisation of HIV serostatus – serodiversity and seroharmony – would start by saying that we are all alike and yet possibly HIV-different. Through the lens of serodiversity and seroharmony, HIV serostatus (particularly serodiscordance) is not seen as an opposition or cleavage, but simply a cluster of possible HIV-related identities; managing sexual negotiations and relationships between people within this cluster is a matter of managing a difference much like any other. Importantly, this includes recognition of a desire for sexual relationships across or despite those HIV serostatus differences.

Image 1 from 1994

The artist David McDiarmid first produced an image for use by the AIDS Council of New South Wales (ACON), a community-based HIV prevention and service organisation, in 1988; the screen printed poster image, in black and white, advertised a "Safe Sex Ball". The image included details of the event, naked male torsos and buttocks, as well as condom packets. In 1988, there was no representation of HIV-positive or HIV-negative. David McDiarmid's subsequent artistic work for a series of health promotion posters in 1992 was the first time that images of HIV-positive and HIV-negative, represented by plus and minus signs, started to be made in the context of HIV education. Done in gouache on paper, the series of posters, which were also turned into postcards, looked at HIV and serodiscordance in a "pro-gay" and "pro-sex" way. The surrounding text in some of the ACON images included:

> "Some of us have HIV, some of us don't. All of us fuck with condoms – every time!"
>
> "HIV, discrimination and grief threaten our community. Build our strength, stay together and support each other".

The "Yes" image, shown here below, was produced 2 years later in 1994, and was part of McDiarmid's art dedicated to the cultural politics of HIV and AIDS, a

Image 1 Yes, David McDiarmid, 1994. Large acrylic on canvas. Heide Museum of Modern Art, Melbourne (Reproduced with the permission of the David McDiarmid estate)

process he worked on between 1987 and 1995. McDiarmid's graphic design practice was used to promote tolerance, fight intolerance and to stop prejudice against gay people and people with HIV and AIDS. The "Yes" image has many of the same motifs used in the 1992 ACON poster campaign, including muscled bodies, boxed heads and inscriptions of HIV-positive and HIV-negative symbols. We have chosen to focus on the 1994 image in this chapter as it speaks to some specific issues we want to address.

The "Yes" image would have been read in a particular way by the Australian gay community when it first appeared, because of the different historical and cultural context in which it was produced. But how might it be read from today's perspective? The image seems to be saying that the world in which HIV and AIDS exist is a world in which two men can embrace closely and nakedly. Perhaps they could be considered buddies or friends supporting each other. However, the sexually explicit nature of McDiarmid's earlier images in the 1992 ACON campaign, of men fucking and placing a condom on an erect penis, suggests that the context here is also sexual – an encounter and a coupling between men, one of whom is HIV-positive and the other HIV-negative.

At first glance, the image appears to diminish difference by casting serostatus as merely the difference of a stroke between a minus (−) and a plus (+); a seemingly minor and unproblematic difference. The image suggests that HIV-negative and HIV-positive can and do fit together. The image promotes, perhaps even celebrates the possibility of closeness between men of different serostatus. The "muscle-ness" of the image may be an immediate appeal to the gay men the message is targeting, but is also an interpolation of a normativity around body types. The image generally suggests that serodiscordance is acceptable and even that such couplings may be attractive and desirable. And yet, the image also suggests that gay men are either HIV-negative or HIV-positive and that these states are in tension and need to be actively reconciled.

These men are nameless and anonymous caricatures. The HIV-negative man has no name; the HIV-positive man on the other hand has several names inscribed on his body; it could be any of Paul, Mark, Jeff, John, Chris, Brian, Frank or Bill. Are we meant to read this as: any man can have HIV? The answer is probably yes. Is it also suggesting that the HIV-positive man is everywhere and at the same time promiscuous? This answer is less obvious. It is unlikely that this was the message intended by the artist, especially given his known intentions were to prevent discrimination and stereotyping. However, HIV was linked to stereotypes of sexual promiscuity from the beginning of the epidemic and shifting this association has proven difficult.

The HIV-negative man has no name, but is given a descriptor as the "yes, yes, yes" man. This suggests vitality and activity, whereas the HIV-positive man appears to be more passively positioned, enclosed by the arms of the HIV-negative man. Perhaps this is a position of "yes, I care", or a defiant stance of "yes, I am comfortable with serodiscordant sex", and "I say yes to HIV-positive men". But it could also be read as a position of "yes, I have control of this situation". In short, what is the significance of the "yes" and of it being confined to the HIV-negative man? It is possible to read themes of dominance and subordination in serodiscordant relationships in this image, as if HIV-negative men are positioned with more agency than HIV-positive men. To explore this particular reading of the image further, we observe that the two men are not looking at each other, but outward; is this an invitation to participate with the "yes" HIV-negative man in control of the HIV-positive anybody? Looking at the image in this way, perhaps desire can be read as one-sided. Is the HIV-negative man with the ability to say "yes" the gatekeeper of the sexual negotiation? The "yes" inscribed exclusively on the body of the HIV-negative person could be seen as emphasising this; a kind of dominance also suggested by the fact that he is placed as the potential insertive (behind) partner in a potential act of anal intercourse.

Extending Hall's (1997) argument that decoding images depends on the knowledge framework of the reader of the image, we could say that there are other suggestions built into the McDiarmid image regarding anal sex and different sexual roles. For gay men who had some detailed information about modes of HIV transmission at that time (that is, gay men who had a particular knowledge framework), an HIV-negative man may have considered that insertive anal intercourse was a way to reduce the possibility of HIV transmission where a partner was known to be or was potentially HIV-positive. Using the image we can ask the question: were HIV-negatives established as the suitable "top", while the invitation was for HIV-positives to be the "bottom"? Was this an attempt to "position" HIV-positive men as "bottoms" as part of a coded strategy aimed at preventing HIV transmission?

The image seems to be silent about whether knowing one's sero-status is desirable or of any use. The image is also silent about whether there are any concerns about serodiscordance and yet, in summary, the binary is established and made clear. HIV-positive and HIV-negative are imaged, embodied and coded as "different".

Image 2 from 2005

Below is the front cover of a booklet, which was a collaborative project between ACON and the Victorian AIDS Council Inc/Gay Men's Health Centre Inc. The intended purpose was to provide information for HIV-negative men in serodiscordant relationships. The booklet, entitled *Opposites Attract*, is about living in "a discordant world" and contains tips and suggestions for the HIV-negative partners of men who are HIV-positive.

In reading this image, one way to make sense of its message might include the following; this could be a heteronormative version of gay relationships. On the other hand, because the image was most likely produced by gay men working in HIV education programs, it might equally represent aspirations of happiness that are not particular to heterosexual, homosexual or any other differently gendered partnering arrangements. There is also a "camp" or ironic tone to the image. Inside the booklet, the images continue in the same campy vein to portray serodiscordant relationships between gay men as acceptable, uncomplicated, enjoyable and even fun. Notably, however, it is not made clear who is HIV-positive and who is HIV-negative, which potentially normalises serodiscordance and erases difference (though it could be argued that "difference" is encoded by the ethnic backgrounds of the men in the image). Flow, harmony, electro-chemistry and domestic bliss are implied with the appearance of things "fitting in" with two people oriented towards each other, but facing outwards with happiness and pride.

The images imply that everything is going "to be roses" or full of "daffodils, angels and matching yellow shag-pile carpets", but perhaps this obscures how difficult serodiscordance might be to negotiate. The booklet itself expounds themes of

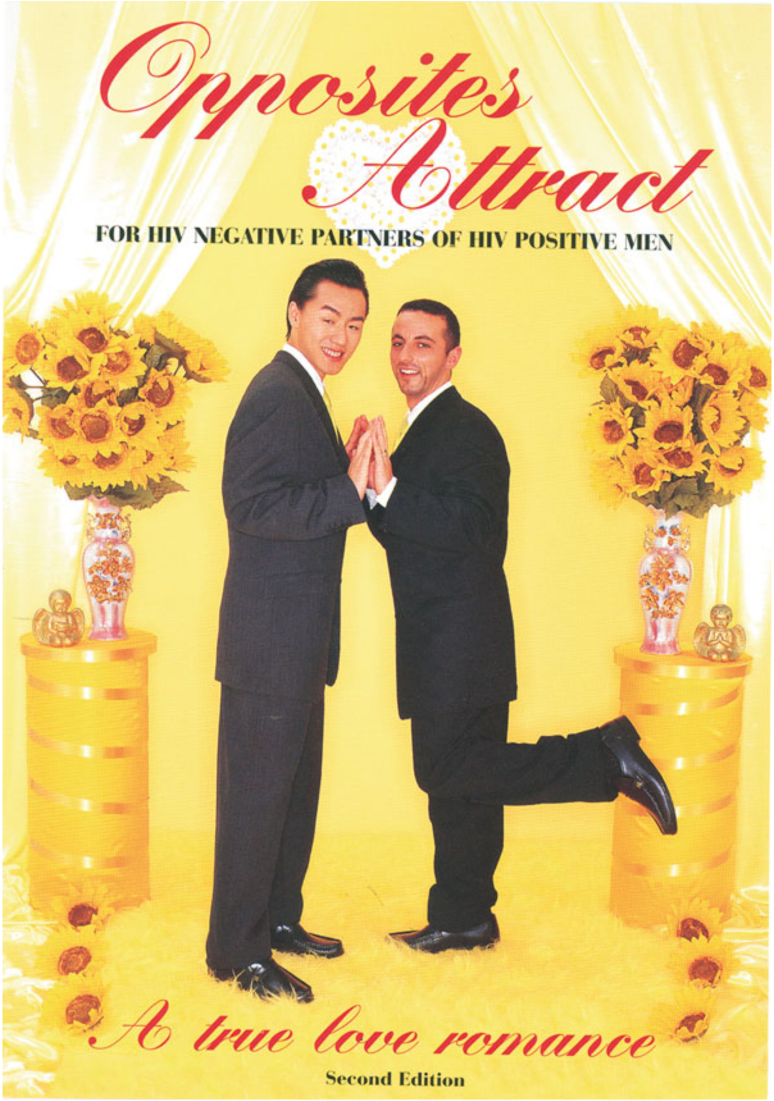

Image 2 Opposites Attract – A true love romance. June 2005. ACON and the Victorian AIDS Council Inc/Gay Men's Health Centre Inc (reproduced with permission from the copyright-holder)

communication and trust within a serodiscordant relationship, but genuine questions about rejection, sexual challenges, or HIV transmission fears are not represented through the cover image or any other image in the booklet. Uncertainty, misunderstandings and the potentially difficult parts of negotiating "opposites attracting" are relegated to the text of the booklet. Much of the text, addressed to the HIV-negative partner, recommends positive ways in which serodiscordant relationships may be managed.

The images in the booklet promote the idea that happiness, or domestic bliss, can easily be achieved by gay men in serodiscordant relationships and that the presence of HIV in such relationships can be managed – the whole tone seems to suggest that there can be a “happy-ever-after” experience. Whilst the “Yes” image is represented as a static moment with explicitly sexual connotations, the images in *Opposites Attract* position negotiations in serodiscordant relationships as something that includes love, loss, home-life, and perhaps home-work-life. Whilst negotiations around sex do feature within the booklet under a heading “Bedtime stories”, the muscly, naked and sexually charged imagery of “Yes” is not seen in *Opposites Attract.* In a sense, in its attempt to normalise serodiscordant relationships, the booklet’s imagery ends up inadvertently “domesticating” gay men and their sexual desires.

Image 3 from 2011

This image was one of a series of images from an online social marketing campaign conducted by the Australian Federation of AIDS Organisations and the National Association of People with HIV/AIDS Australia in 2011. The FearLessLiveMore campaign aimed to reduce HIV stigma by challenging assumptions and beliefs that many HIV-negative men hold about HIV and people with HIV. According to de Wit and colleagues (2013), there was evidence that a serostatus divide existed among gay men in Australia and this campaign addressed itself to that issue.

If images are to be read as an “encoding” (Hall 1995, 1997) of accepted norms and as a representation of “general understandings” (Schatzki 2010), then this image does represent a significant attempt at normalising gay male serodifferent relationships. The normalisation is not being done through the image alone—that of two men walking along hand-in-hand—but also by the surrounding text spelling out that serodifference is “as normal as dealing with arguments over toothpaste or snoring”, or that the negotiation of serodifference is like any other relationship challenge or difference.

Both *Opposites Attract* and *FearLess* emphasise the ordinariness of HIV-positive and HIV-negative men in relationships and this is done with nuance and subtlety. This might also reflect a more general and growing acceptance of same-sex relationships, including those of gay men, in contemporary Australia. The assumed different HIV statuses of the couple in the *FearLess* campaign is encoded and perhaps decoded as unremarkable and manageable. Nevertheless, “difference” remains the key representational device, through the use of the proxy difference of a tall and short person, or differently shaped bodies, or a mixed race couple; a binary is still implied.

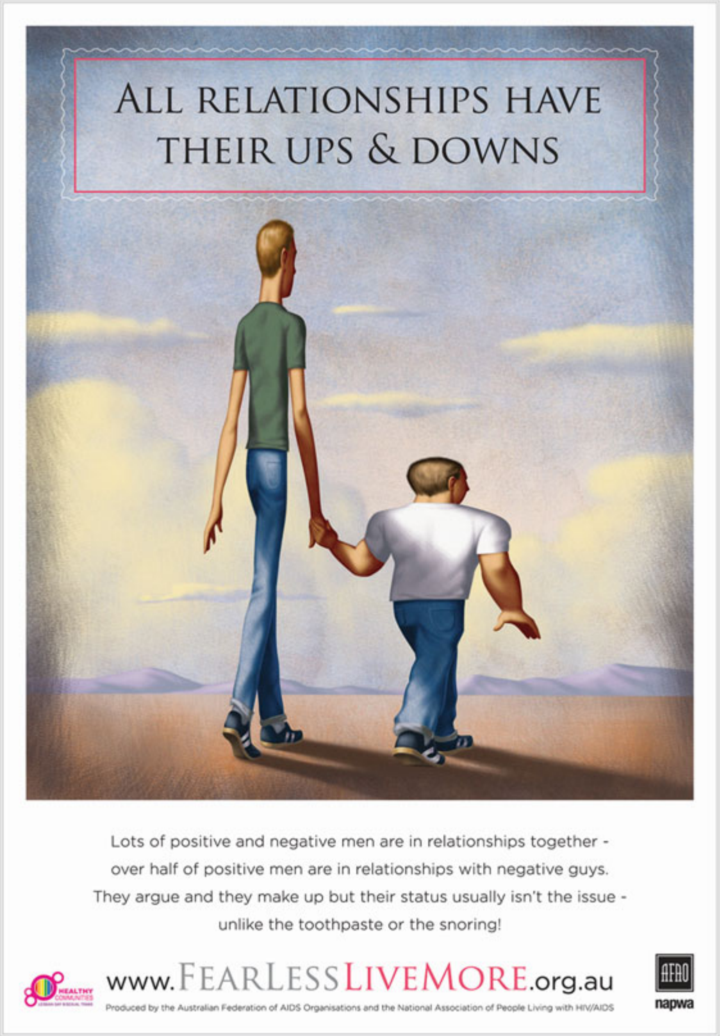

Image 3 FearLessLiveMore. 2011. Australian Federation of AIDS Organisations (reproduced with permission from the copyright-holder)

Image 4 from 2012

In 2008, the community organisation Positive Life NSW, representing people living with HIV in New South Wales, commenced a campaign to "start a conversation" about gay men living in serodifferent relationships. The title of the campaign was "Why let HIV get in the way of a good relationship?" The first phase of the campaign included community meetings and on-line discussions. Drawing on personal stories, the campaign aimed to cover a range of potential problems that might occur in these relationships, including disclosure and possible rejection, intimacy,

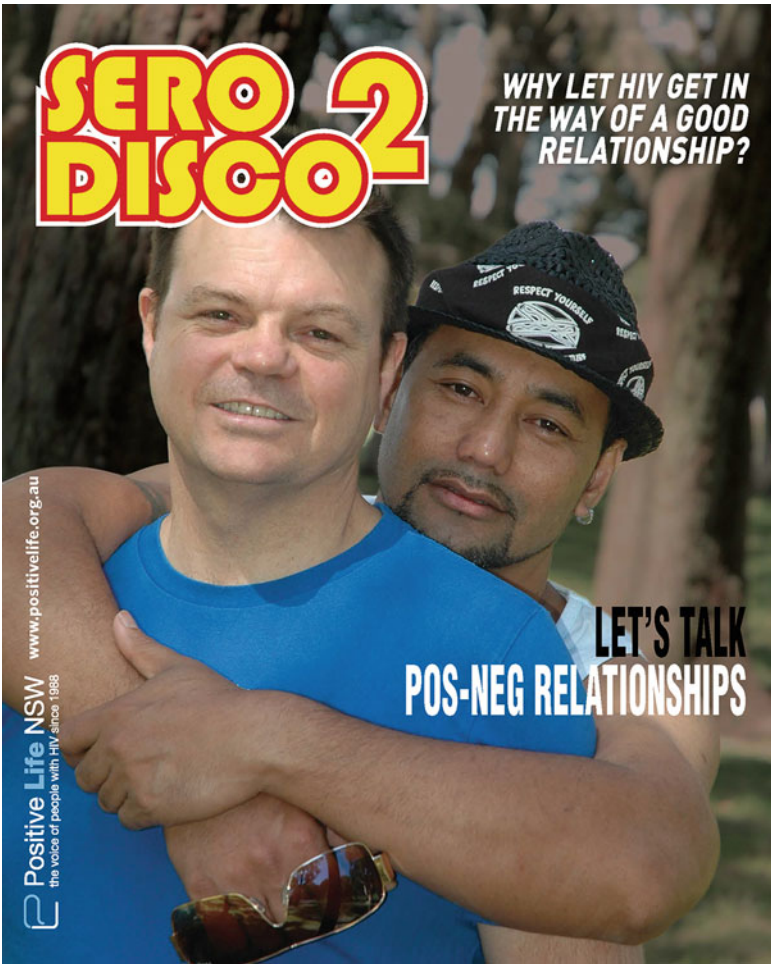

Image 4 SERO DISCO 2 – Let's talk. 2012. Positive Life New South Wales (reproduced with permission from the copyright-holder)

vulnerabilities, relationship agreements and attitudes towards sex. For the first time in community-level discussions, this campaign invoked the word "undetectable", meaning that a person's viral load is fully suppressed through effective antiretroviral therapy (ART). It also explored the idea that being "undetectable" meant that an HIV-positive person was "un-infectious".

The second phase of the campaign included a 59 page magazine-style publication, entitled *SERO DISCO 2*, which was released in 2012 and was an attempt to capture and represent the diversity and complexity of what was by then referred to colloquially as "pos-neg" relationships. It was also an attempt to address cultural barriers in the Australian gay community, which many contributors to the development of the campaign had identified. Indeed, in the above image, which was the cover image for the booklet, we see a further normalisation not only of serodiscordance but also inter-racial relations. The pose in the *SERO DISCO 2* image is strikingly reminiscent of the earlier McDiarmid image of arms wrapped around a lover. But unlike McDiarmid's "Yes" image, there are now faces to the image and there is no attempt to code a distinction between who is HIV-positive and who is HIV-negative. Similar to McDiarmid's image, the gaze is outward, but not necessarily an outwardly sexual invitation. The text surrounding the image ("Let's talk") is an integral feature, without the implication that "talk" is simply about sex.

The images examined so far in this chapter can all be seen as gay community responses to the "social silence" (Persson et al. 2015) that has surrounded serodiscordant relationships. Looking back over these images, we can see an increasing realism, from figurative and cartoonish representations to the appearance of models whose faces were known within the community and who were willing to be identified. The *SERO DISCO 2* cover image, along with the other images in the campaign, is presented in a rather "no-nonsense" manner; "this is what two gay men in a serodifferent relationship may look like". Perhaps it is possible, from seeing this kind of imaging develop, to speak of seroharmony rather than serodiscordance. Unlike the earlier *Opposites Attract* campaign, the harmony is not constructed in the *SERO DISCO* image as camp artifice, but appears genuine and frank, as these two gay men in a "pos-neg" relationship pose comfortably with each other and are prepared to look out to the world (and also apparently comfortable to be looked at by the world).

Image 5 from 2015

The possibility that people who are treated with ART are sexually non-infectious has been part of community discussions for many years, particularly since the release of a statement to this effect from the Swiss Federal AIDS Commission in 2008 (Vernazza et al. 2008). The idea that an undetectable viral load can be a method of HIV prevention for serodiscordant sexual partners has come to be known as "treatment as prevention" (TasP) and is now well supported by clinical trial evidence (Cohen et al. 2011). In a recent article, Race (2015) talks about "discourses of undetectability", noting that gay men with HIV have begun to adopt the term "undetectable" as a self-descriptor in online hook-up environments.

The above image, taken from the cover of the national magazine for people with HIV *Positive Living*, imagines the gay man with an undetectable viral load as an emergent superhero (Menadue 2015). The image is striking for a number of reasons. It is both hypermasculine and individualistic; the figure is alone, baring his chest to the viewer. It is possible to read several messages into this image of masculine power and its superman referenced character: "I can do anything and I'm doing everything I can (to stop the virus), which makes me responsible and therefore a hero", but also "I can do anything sexually, with anybody, because I'm non-infectious and therefore of no risk to anyone".

It is quite conceivable that this emergent undetectable identity would be a relief to many HIV-positive men as it presents an empowered image. As David Menadue

Image 5 Cover image of the Positive Living magazine. 2015. National Association of People with HIV Australia (reproduced with permission from the copyright-holder)

(2015) writes about the so called "undetectables": "If [they] sound like a bunch of superheroes, working silently to change the world for the better, then maybe – when put in the context of a desire to reduce HIV transmissions – that's kind of what they are."

But the image can also be read as a caricature of the sexually empowered and autonomous post-modern gay man. The highly individuated figure is nonetheless not an individual but merely a faceless cipher. Paradoxically, "undetectable" is imagined as an identity that is no identity, and the sexually empowered individual is one that exists outside of sexual relations. Such an image leaves much outside the frame, including the relational elements of all human sexuality, as well as those people with HIV who cannot achieve an undetectable viral load despite good treatment. At the same time, however, the emergence of the undetectable identity does destabilise the HIV-positive and HIV-negative binary. There are now more identities in the mix.

Discussion: Hints of Seroharmony

Our reading of these images is not intended as a critique or evaluation of health promotion campaign materials produced about serodiscordance. They all served an important purpose at their time. Rather, we have used the images to pay particular attention to the way that the binary of HIV-positive and HIV-negative emerged and how that binary has been hard to jettison. We traced how that binary was established and showed how the discourse of serodiscordance is one predicated on difference. However, as we suggest below, there have been other, parallel ideas about how serodiscordance or difference can be understood within the HIV epidemic and within gay men's sexual relationships, ideas that can be seen as precursors to a conceptualisation of "seroharmony".

In his preface to *Practices of Freedom*, Simon Watney (1994) reflected on what gay identity meant to him. He talked about ordinary activities of friendship and intimacy, the exchange of ideas, of lovers and friends coming and going in one's life. Relevant to the idea of seroharmony, he talked about affirming the ethical and political dimensions of gay friendships and relationships, including the importance of avoiding any separation between HIV-positive or HIV-negative gay men. Watney (1994:137) argued that gay men, both those infected with HIV and those not infected, invented safer sex as one of the gay communities' "cultural practices" in response to the HIV epidemic, demonstrating the ability of working together across serostatus differences.

Similar arguments can be found in Australia. In a monograph, which drew on empirical material from the Australian *HIV Futures* surveys, the monograph's editor and social researcher Michael Hurley (2002) introduced the concept "cultures of care" to describe a range of apparent and emergent personal and gay community practices. In one of the monograph's chapters, researchers extended "cultures of care" conceptually into the arena of sexual negotiation and the sexual lives of both HIV-positive and HIV-negative men – with "self-care" and "care-of-others" being the emphasis (Willis et al. 2002). This work was an early and genuine nod toward the possibility of "seroharmony". We argue that the "cultures of care" approach has offered a counter-narrative to the so called "serostatus divide" (de Wit et al. 2013; Persson 2015) or what Carr (2013) referred to as "antibody apartheid", by foregrounding gay men caring for each other *regardless* of their HIV status. This was an approach of inclusivity rather than separation, one that aimed to emphasise harmony rather than difference. Like Watney in the US, Hurley and others in Australia explicitly worked against a binary of HIV-positive and HIV-negative.

Conclusion

From the early AIDS epidemic until now, images of "serodiscordance" have framed sexual relationships between gay men of different HIV statuses. These representations often implied that different serostatuses were a significant problem to be overcome and this problem was binary in nature. By showing both the variety of these representations and their change over time, we wish to highlight their historical and cultural contingency despite their sometimes "common sense" appearance. We have, through examining this imagery, noted how the separation of the identities of those infected with HIV and those not infected has left out other groups, most significantly those whose HIV status is unknown. Their exclusion became cemented as health promotion strategies increasingly relied on imagery and language that was binary.

The biological fact of HIV infection is assumed to determine serodiscordance, but this fact has perhaps always been more unstable than it seems. In earlier years, this instability was underpinned by uncertain knowledge of HIV status, due to the lack of a reliable HIV test, or gay men not being interested in testing, or a political commitment to downplaying status differences and, throughout the epidemic, the possibility of HIV prevention measures failing. More recently, new scientific knowledge has emerged that has continued to change the meanings of HIV status and the potential for transmission. To live with HIV and have an undetectable viral load implies a different and new way of being HIV-positive, and this has profound implications for what it means to live in a serodifferent relationship. We imagine that the meanings of HIV serostatus will continue to evolve in light of scientific developments. For example, both HIV cure research and vaccine development suggest the possibility of people being HIV antibody positive but uninfected with active virus.

Despite the good intentions of earlier representations that sought to emphasise the desirability and normality of sexual relationships between those with different HIV statuses, it is only in recent years that representations of serodifference have shifted from difference as oppositionality to difference as multiplicity, with HIV serostatus difference being relativised as a kind of difference like any other between two people. This shift presages a movement beyond binary HIV identities towards something more diverse and hopefully inclusive; a world of seroharmony in which people may be, among other things, HIV-negative, HIV-positive, HIV-positive and undetectable, HIV unknown, or HIV-negative and on PrEP. It is perhaps only through the undoing and denaturalising of the serostatus binary that the persistent stigma of HIV will finally lose some of its power.

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HIV Serodiscordant Couples and the Discourse of Normality: Reconciling the Biomedical and the Social in Porto Alegre, Brazil

Shana D. Hughes

Introduction

Serodiscordant couples have played key roles in research on the recent wave of game-changing biomedical HIV prevention technologies, namely Treatment as Prevention (TasP) and Pre-Exposure Prophylaxis (PrEP) (Cohen et al. 2011; Baeten et al. 2012; Mujugira et al. 2011). Despite this, we know relatively little about such couples outside of a clinical context concerned with transmission risk. A more holistic view—one that includes but also transcends biomedical notions—is required if we are to understand the experiences and address the needs of those in mixed-status relationships.

This chapter draws on ethnographic research on love, risk, and HIV among heterosexual, mixed-status couples in Porto Alegre, Brazil from 2009 to 2010. I focus on a specific sub-set of data which comes largely from interviews and observations with six heterosexual serodiscordant couples. These are supplemented with interviews, observations, and informal conversations with biomedical providers, staff, and HIV-positive patients at a municipal HIV clinic. The sub-set of interest, which I call the "discourse of normality," is a collection of statements that surfaced in the speech of both seropositive and seronegative participants, and that applied both to life with HIV and to mixed-status relationships. In what follows, I employ discourse analysis to explore the etiology and function of the discourse of normality (DON), as well as ask what it reveals about serodiscordance.

Before embarking on this journey, a prefatory acknowledgment: These data predate the publication of trial results confirming the efficacy of TasP and PrEP. This, however, does not render the findings irrelevant. Rather, especially given the dearth of similar data, they provide an important window into a period when the perceived

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risk associated with serodiscordance was likely greater than it is today. Second, exploring the lived practices of serodiscordance in the pre-TasP era (at this writing, PrEP is not yet widely available in Brazil) may help us better understand how relatively recent advances in biomedical prevention strategies might be impacting Brazilian couples of mixed status.

Methods

Data reported in this chapter are drawn from a 17 month-long ethnographic study conducted in Porto Alegre, Brazil from 2009 to 2010. The main research objective was to understand the place HIV occupied in the everyday lives of heterosexual mixed-status couples and how they constructed and negotiated risk while managing their relationships. All research procedures were approved by the University of South Florida's Institutional Review Board, and the Research Ethics Committee of Porto Alegre's Municipal Health Secretariat.

Ethnographic fieldwork was conducted at a municipal clinic specialized in treating HIV and other sexually transmitted infections. This clinic was the treatment site for the seropositive members of participating couples; the goal of the clinic-based research was to better understand their HIV treatment experiences. Observations and interviews with providers and staff took place from August 2009-April 2010. Observations were conducted both in the waiting area and in individual patient consultations.

Serodiscordant couples were recruited in a two-step process. Clinic patients with HIV were screened for eligibility criteria, including: intimate relationship with an HIV-negative, heterosexual partner; partners' mutual awareness of HIV status; residence in the Porto Alegre metropolitan area; and age between 18 and 65. After screening, eligible and willing patients were asked to discuss the study with their partners prior to follow-up. Subsequently, each couple was provided with more information about the study and the opportunity to decline participation. Couples were purposively sampled to include an equal number of seropositive men and women. Participation was limited to a small number of couples to facilitate deep engagement with each one.

Six couples participated in multiple participant observation sessions outside of the clinic, as well as repeated joint and individual semi-structured interviews over the course of 11 months. Interview guides covered relationship history; current daily life; sexual practice; household finances and employment; HIV diagnosis, disclosure, and treatment experience; family ties; and general perceptions about gender, couplehood, and HIV. Interviews were digitally recorded and transcribed verbatim. Transcripts and relevant fieldnotes were subjected to thematic text analysis (Ryan and Bernard 2003). The exploratory nature of this research called for inductive analysis (Bernard 2006:493), but some themes derived *a priori* from the interview guide and theoretical considerations were also employed. Throughout this chapter, participants are referred to by pseudonyms to protect confidentiality.

Findings

Participating Couples

As outlined in Table 1, participants ranged from 30 to 57 years of age; for women the average age was 40 years, for men it was almost 39. As mentioned, in terms of the gender of the seropositive partner, the study couples were evenly divided. Time since diagnosis ranged from two months to 14 years. Relationship duration ranged from 1.5 to 12 years. Two couples had been together when the seropositive partner received her diagnosis; the other four had begun their relationships from two to 10 years afterwards. Only one couple had a biological child together (born during the research), though children from previous unions resided with three of the couples, and in another couple both partners had adult children. For half of the couples, providing for their family's basic needs each month posed a challenge. Others were more comfortable, though still had limited household budgets.

All the HIV-positive partners were in care and had undetectable or declining viral loads. None were entirely open about their serostatus. In most cases, at least some members of their families had not been told, let alone friends or casual acquaintances. Yet, in general, both partners downplayed the impact or importance of HIV in their relationship. One way they did this was through the DON.

Table 1 Participant profiles

Seropositive partner (gender, age)	Seronegative partner (gender, age)	Length of relationship[a]	Time since HIV diagnosis[a]	Couple formation, relative to HIV diagnosis	Children together
Iara (female, 44)	Jorge (male, 30)	5 years	8 months	4+ years prior	0
Xavier (male, 45)	Juliana (female, 57)	7 years	14 years	7 years post	0
Renato (male, 35)	Milene (female, 30)	3 years	13 years	10 years post	0
Bibiana (female, 33)	Felipe (male, 32)	2+ years	16 months	~1 year prior	0 (1 abortion)
Rita (female, 35)	Adriano (male, 43)	1.5 years	9 years	7.5 years post	1
Wílian (male, 50)	Pamela (female, 45)	12 years	~14 years	~2 years post	3 adopted

[a] At time of consent to participate in study; ~ = "approximately"

What Is the Discourse of Normality?

What I call the DON was a specific way of talking that occurred in the speech of both seropositive and seronegative participants. It often—but not always—asserted the "normality" of certain aspects of life with HIV or mixed-status relationships. Such assertions seemed odd because they violated a notion, common among discourse analysts that, while the normal aspects of life differ from place to place and over time, they are usually not semantically marked. As James Paul Gee (2014:14) notes, "Communication and culture are like icebergs. Only a small 'tip' is ever stated overtly. A vast amount lies under the surface, not said but assumed to be known or inferable." Essentially, what is "normal" goes without saying—and certainly goes without having to call attention to how normal it is. Hence, instances of the DON seemed likely to offer insight into underlying constructions of HIV and serodiscordance, particularly when they occurred in the course of discussing participant-driven topics, rather than in response to a direct question of mine. The examples that follow illustrate patterns and variation in this discourse.

Renato (35, HIV-positive, partnered with Milene) described the emotionally difficult period when he began taking antiretroviral therapy (ART), then contrasted it with his life at the time of the interview. He concluded, "So today I live normally! … As you can see. I mean, people who see me, they see how healthy I look and say, 'No, that's a lie. You're lying [that you have HIV]." His narrative returned to the idea of a "normal life" several times, so I asked him to explain what that meant. He mused, "Normal life. How can I say it? A life as though I didn't have [HIV]. As though I weren't seropositive. And it doesn't really come up. Here at home, I mean."

Indeed, when asked about the impact of HIV on their relationship, most participants claimed it was minimal, contrasting current treatment success with the "death sentence" that HIV used to be. Both Milene (30, HIV-negative, partnered with Renato) and another seronegative participant, Adriano (43, partnered with Rita), further normalized their relationships by claiming their own health was often more problematic than their HIV-positive partner's. Regarding the quality of life people living with HIV could expect, Adriano noted, "There's a living example right here [gesturing to Rita]. You just have to know how to take your medicine and take care of yourself. You'll have a normal life like anyone else."

It should be noted, however, that the DON exhibited flexibility in terms of just how "normal" life with HIV was framed as being. For instance, Felipe (32, HIV-negative, partnered with Bibiana) commented during his individual interview: "[With] discipline … life can be very close to normal … [HIV] is something you can live with nowadays, without serious problems." For him, life in a mixed-status couple was not "normal", but *nearly* so. In other cases, even this near-normality melted away. Juliana (57, HIV-negative, partnered with Xavier) recounted that her daughter's husband had hidden his positive serostatus for years during the couple's marriage. Her daughter remained seronegative, but when she opted for divorce Juliana urged her to make it clear in court that the man "got HIV after you got together … You didn't get married to him [knowing] he had it. You married him when he was normal, healthy." Hence, in this occurrence, the DON actually constructs HIV and normality as mutually exclusive.

Other examples illustrate how competing interpretations of normality could surface and collide. Iara (44, HIV-positive, partnered with Jorge) reported a conversation in which she suggested to her partner that he might be better off leaving her to find a seronegative woman. According to her, this had prompted an emotional exchange. She reported Jorge asking, "Why are you saying that?" She replied, "So you can have a normal life." He objected,"But my life with you *is* normal." She protested, "A woman who wants kids—a family!" This evoked a future the couple had discussed before her diagnosis, but that she no longer felt was possible. Interestingly, Jorge's response neither affirms nor denies the "normality" of childbearing. Instead, Iara says he told her, "But I don't want that; I want to be with you." In addition to addressing the potential dissolution of their relationship, Iara and Jorge were airing ideas about what "normal" conjugality looks like, and how important this would—or would not—be for them.

Drawing from these examples, it is possible to highlight several features of the DON. First, there was a positive value assigned to normality. In no case did a participant question the value of the norm being referenced, let alone extol the virtues of non-conformity. Second, the DON was flexible. Sometimes it was used to reject the construction of HIV and serodiscordance as a source of fundamental difference, as Renato, Adriano, and Jorge did. However, in other instances study participants highlighted (sometimes inadvertently) the way HIV or mixed-status relationships deviated from normality. Thus, for Renato, a "normal life" was a "life *as though* I didn't have HIV," and Iara assumed that Jorge's life with her *could not* be normal because of her serostatus. A third feature of the DON is that the fundamental, though usually implicit, point of reference for "normality" is seronegativity. As Asha Persson (2011:576–577), drawing on Roman (1997) has written, "Left unmarked, HIV negativity has come to assume the status of the norm, of an unproblematized natural state." This is clear in the examples above.

Surveying the literature, statements that might be examples of the DON are reported by other scholars as well. Here I focus on research from Brazil. In a qualitative study conducted in the Center-West region, Miranda and colleagues noted that many of their interviewees described their serodiscordant relationships as "quiet and normal." A female participant's quote serves as an example: "Now it is nice … it is a normal living … We date, go out, we walk together" (Miranda et al. 2013:592). Polejack and Costa (2002:137) report on counseling serodiscordant couples in a hospital in Brasília, observing that "some of them clearly established a non-verbal contract of denial of seropositivity." They cite a male participant to support this claim: "We choose to live as a normal couple, so we don't talk about it." Notably, the authors assume that denial is the only way in which such a couple could live normally. In a final example, Reis and Gir discuss the "naturalization" of HIV observed among serodiscordant couples in a qualitative study undertaken in a clinic in Southeast Brazil. The words of one female participant are said to exemplify the trend: "I don't worry about it too much, I lead my life normally. I don't think [my male partner] is at risk because we take good care of ourselves" (Reis and Gir

2009:665). This is explained by the authors as a “denial of risk” which “contributes to the vulnerability of these individuals.”

These examples come from various historical moments in the epidemic, which were characterized by evolving understandings of infectiousness. Yet instances of “normal” like these have usually been treated in one (or a combination) of three ways in the international literature. Often the assertion of normality is simply not analyzed at all, but is offered to illustrate some other point. Alternatively, it may be interpreted as an index of the HIV-negative partner’s “vulnerability” to infection. Finally, it is sometimes offered as evidence of misunderstanding or denial of risk of HIV transmission or serodiscordance more generally. These last two approaches are evident in the examples above. Rarely is there any critical consideration of what “normal” means, or why it would be important to these individuals in these circumstances. There are, of course, exceptions (e.g., Knauth et al. 1998; Persson 2008, 2011, 2013a), all of which share the spirit of Gee’s (2005:93) injunction to “always assume, until absolutely proven otherwise, that everyone has ‘good reasons’ and makes ‘deep sense’ in terms of their own socioculturally specific ways of talking.”

Such an epistemological stance suggests there is much to learn from taking this discourse seriously. Before exploring that “deep sense,” however, let us turn to the etiology of the DON.

Foundations of the Discourse of Normality

As discussed, virtually all couples claimed a negligible role for HIV in their relationship; Renato’s “It doesn’t really come up” was typical. Such non-importance was possible partly because, in five of these six couples, the medical management of HIV was entirely unproblematic. This in itself must be situated as a product of the Brazilian state’s commitment to provide free medical care, including ART, to those living with HIV. The implementation of this policy is what enabled all couples’ experience of good or improving health for the positive partner, a condition seen as corroborated by high or rising CD4 counts, and undetectable or declining viral loads. The role played by these clinical markers raises a further important issue. Though the HIV-positive individuals in this study understood these numbers and what they represented, many Brazilians would not. That is, such concepts were not part of what Gee calls a “lifeworld” discourse, that which is used or produced when people “think, act, and communicate as ‘everyday’ people and not as ‘specialists’ (e.g., physicists, doctors, lawyers)” (2005:63). Instead, CD4 counts and viral loads were components of a “specialist” discourse, for which the clinic served as the primary site of acquisition.

Observation of clinic procedures—patient check-in, dispensation of ART, appointments for routine follow-up, as well as acute health issues—allowed me to document this specialist clinic discourse. Here I will highlight just one element of this: the likening of HIV to other common diseases. Prevalent in the speech of physicians and nurses, this seemed specifically aimed to destigmatize HIV (though this purpose was never explicitly acknowledged). Such constructions also surfaced in the conversations I had with clinic patients. They frequently equated HIV to high blood pressure or diabetes; given the prevalence of such non-communicable, chronic conditions in Brazil (Moura et al. 2012), this essentially served to normalize the virus. They also commented how "lucky" they were to have HIV rather than cancer or H1N1 influenza, which were seen as much more difficult to successfully treat and prevent, respectively.

Because the research participants did not habitually communicate about HIV with many people—if anyone at all—outside of their partners and clinic personnel, medical providers likely served as models for how to do so. Therefore, to the extent that the mixed-status couples in this study felt the clinic discourse (positioning HIV as a chronic disease) reflected their lived experience, we should not be surprised to find these patterns replicated in couples' speech. Felipe even made this influence explicit when he noted that, "[Doctors] say, 'If you do everything just right you can have a life that's close to normal.'"

Within the specialized clinic discourse, however, the need to explicitly link HIV and "normality" suggests the same thing it does in the speech of individuals. It points to friction: dynamics or situations in which these assertions do *not* mesh with lived experience. Gee (2005:93) notes that we are all members of multiple discourses; hence "the analytic task is often finding which of these and with what blends, are operative in communication." The DON is clearly deployed in response to contrary notions of HIV, namely those that construct the virus as a mark of pathological, stigmatized difference. The pervasiveness of such ideas at the time this research was conducted is signaled by the existence of a media campaign, sponsored by the Brazilian Ministry of Health, to combat HIV-related stigma. It employed the slogan "It's possible to live with AIDS. But not with prejudice." Some of these materials featured a heterosexual couple of mixed HIV status, kissing, and the words, "One of them has HIV. The other knows." Fine print at the side read, "This is a real case. One of these people lives with HIV" (image available at: http://www.aids.gov.br/campanhas/2009/38266).

The clear implication was that consumers of this image might assume that the people pictured were merely actors, and the kiss needed to be "real" to have the desired effect. The Ministry of Health chose to have this message plastered on buses, appear on television, and play on the radio—which indicates they must have felt most Brazilians considered serodiscordance to be abnormal. This is the context in which those who dispensed and received care for HIV—and the seronegative partners who lived their own version of the virus (Persson 2011; Crane et al. 2002)—sought recourse in the DON.

Discursive and Embodied Conflicts

Most obviously then, the DON was a way couples in this study represented their daily experiences of HIV as an unremarkable biomedical reality. Social reality, however, was different. As mentioned previously, none of the couples were entirely open about their status and some were quite secretive. They explained this by the persistence of HIV-related stigma, attributed to outdated associations of the virus with socially and sexually "deviant" behavior.[1] Both the positive and negative partners sought ways to avoid or refute these associations, that is, to reject the idea that they were "the kind of person" one might expect to have HIV, or to have an intimate relationship with someone who did. The DON served this purpose well, as it allowed couples to discursively "shadow-box" with stigma—that is, to contest mainstream stigmatizing perceptions of HIV without explicitly stating them. Instead, they could simply say their life or relationship was "normal".

Thus, participants in this research implicitly resisted notions that framed HIV and/or mixed status as a subtle but indelible mark of difference. And yet their talk gave the impression that "normality" and "difference" were in a tug-of-war. In fact, the totality of their discursive production, including both verbal and non-verbal aspects of their participation in this study, suggested that most couples were (on some level, at least sometimes) ambivalent about whether a "normal life" was truly achievable in the context of serodiscordance. This tension should lead us to two questions: Why? and What is at stake?

This ambivalence or inconsistency may stem from several sources. Because participants lived in environments where HIV was stigmatized, some amount of unconscious or internalized stigma may have been at play. Perhaps more importantly, however, these mixed-status couples did not always conceive of themselves as "serodiscordant," or even in terms of HIV at all (much as noted by Persson 2013b). They were also, and even foremost, simply "couples," composed of Brazilian men and women. According to traditional conceptions of couplehood and gender in this setting—which are strongly shaped by heteropatriarchy—this meant they had particular and complementary roles to fulfill. Yet close examination of the clinic discourse reveals specific ways its directives conflicted with these conjugal and gendered aspects of couples' identities. Particularly challenging were some of the embodied practices that evoke Briggs and Mantini-Briggs's (2003) notion of "sanitary citizenship". While norms concerning couplehood and gender are profoundly intertwined in Brazil, for the sake of brevity and clarity I have parsed them a bit in the examples that follow.

One of the practices evangelized by the clinic discourse that undermined any claim couples might make to "normal" conjugality was preventing sexual transmission of HIV. Medical providers' default counsel on this issue was "use a condom every time." As Bibiana made evident, however, her excellent clinical condition notwithstanding, this constituted a notable limit on how closely serodiscordant couplehood could approximate "normality." She remarked, "I only remember [that I have HIV] when I have to use a condom with Felipe … That's when I remember that I'm sick." This makes sense, given the stark contrast between prevention mandates and the "conjugal cycle" that characterizes condom use in most Brazilian couples (Perrusi and Franch 2012:193). The cycle entails frequent use in the beginning of a relationship, followed by "progressive abandonment as the relationship becomes

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[1] In Brazil, as in the U.S., the groups seen as initially affected by HIV included men who have sex with men, injection drug users, and commercial sex workers (Berkman et al. 2005).

more stable.” That is, not only are condoms not part of “normal,” long-term, intimate relationships in Brazil; the disappearance of condoms is actually part of what constitutes those relationships as normal.

Part of the reason condoms disappear from committed relationships is likely their association with sex that is perceived as transgressive in some way (Goldstein 1992, Garcia and de Souza 2010). This association can be especially prejudicial to female partners, about whom condom use may imply that a violation of gendered sexual roles has rendered them symbolically “dirty” (Kerr-Pontes et al. 2004; Douglas 1966). Hence, not only is the non-use of condoms normal within couples, it is also a statement on the socially sanctioned nature of the relationship and the upstanding moral character of each partner within it. In this context, condom use by long-term mixed-status couples may be understood to have an important “cost,” even beyond important questions of intimacy raised by some researchers (Closson et al. 2015).

HIV prevention and treatment strategies impinged in other ways on the respective gendered identities of members of mixed-status couples. For example, protocols for the prevention of mother-to-child transmission include the prohibition of breastfeeding by HIV-positive mothers. Yet motherhood is an important part of femininity in Brazil (Perrusi and Franch 2012), and breastfeeding, in general, is widely recognized as best for babies (http://www.unicef.org/brazil/pt/activities_10000.htm). In essence, breastfeeding is something the country’s health system has encouraged as “normal.”

It was against this backdrop that Adriano answered my question about his “greatest worry” at one point during his partner Rita’s pregnancy:

> The health of the baby. If he’s going to come with [HIV] or not. That issue of [Rita] also not being able to breastfeed. Automatically together with that comes the worry that my family—no one knows [about Rita’s serostatus] and I don’t intend to tell them … sooner or later they’re going to want to know why she’s not breastfeeding.

That family members might ask this question is quite plausible. In a study of postpartum care in a public maternity ward, nursing staff reported receiving such queries when third parties observed women formula-feeding (Araújo et al. 2012). Rita also was anxious about not breastfeeding; it topped the list of the things she worried about once she was pregnant.

Rita: I can’t breastfeed, right? The milk is all wasted. Yeah.
Shana: Is this something that’s important to you?
Rita: It is.
Shana: It’s meaningful?
Rita: Yeah.
Shana: Did you want to breastfeed?
Rita: Oh, if I didn’t have [HIV], absolutely, you know?

Rita’s subdued affect in this exchange was a marked departure from her usual animated, assertive demeanor, and suggested something more than fear of potentially being judged a bad mother or having to reveal her serostatus to Adriano’s family. It bordered on grief. Other research with HIV-positive Brazilian mothers has found that, while they understand why formula feeding is important for their infants' health, some women simultaneously feel sad to miss breastfeeding (Rigoni et al. 2008), an act that would have "completed" their experience of motherhood (Paiva and Galvão 2004). One can understand this sense of loss not only in terms of being barred from a particular type of bonding with an individual child, but also as a reaction to exclusion from a "normal" and valued part of embodying womanhood in Brazil.

Adherence to prescriptions of the clinic discourse could also be destabilizing to traditional conceptions of masculinity. To provide just one example, consider the medical appointments required of HIV-positive patients prescribed ART: in addition to monthly medication pick-ups, patients were supposed to have bloodwork (including CD4 count and viral load) done and see their physicians about four times a year. Brazilian men, however, are most notable within the health system for their *absence*. Machin and colleagues found that medical professionals themselves perceived both structural and ideological reasons for this. They cited lack of appointment times outside of business hours (when men would traditionally be working), the paucity of programs and services oriented to men's health, and the social construction of clinics as "feminine spaces, *par excellence*" (2011:4504) as major contributors. Gomes and colleagues add that hegemonic models of masculinity (2011:988) emphasize strength, invulnerability, and self-sufficiency—all values that may be seen as contravened by seeking care. In essence, they argue that mere presence in the clinic is emasculating.

Hence, there are multiple challenges heterosexual Brazilian men must overcome every 3 months when they attend medical appointments. After observing one of Renato's routine follow-up visits, I asked him how he felt about the care he received. He responded, "For me, it‘s normal! … As you saw, right? My appointment [with the physician] doesn't even last five minutes." Indeed, there had been little to the interaction beyond reviewing Renato's "numbers," which indicated no clinical problems. Thus, he could portray this as being just like any other regular check-up: when one is healthy, there's ostensibly little to extend the process. This construction, however, backgrounds what is potentially the most important aspect of Renato's compliance with his treatment: his presence at the clinic to begin with. Whether the appointment itself lasted 5 min or 50, given his lack of any obvious clinical problem, being seen by a physician, as a gendered practice, can only be considered "normal" within the parameters of seropositivity.

Role of the Discourse of Normality

The foregoing examples illustrate that although the clinic discourse constructs living with HIV as "normal," important components of this specialist discourse require behaviors from seropositive people and their intimate partners that are *abnormal* from the vantage point of other discourses or identities. Using condoms in ongoing, primary sexual-affective relationships, avoiding breastfeeding by HIV-positive mothers, and attending clinic for HIV-positive men, for example, all conflict with conjugal and gendered norms in Brazil. In some sense, there are two conflicting versions of “normal” at work, with biomedical mandates from the specialist discourse posing culturally-specific symbolic challenges for these couples. Partners in mixed-status relationships must thus choose which kind of “normal” they will be: “heterosexual couples” or “sanitary citizens.” Keeping this in mind, it is possible to see the DON as an attempt by the couples to make sense of not only two competing discourses, but also to reconcile contradictory aspects of their own identities.

Couples often oscillated between versions of normality. In some cases, they opted to embody practices from the clinic discourse. Felipe and Jorge had to that point used condoms with their seropositive partners. Rita did not breastfeed. Renato came to clinic regularly and took his ART (as did all the seropositive participants). But such practices did not necessarily predict rigid adherence to the clinic discourse; in other situations, what the wider social world considered normal prevailed. For example, neither Rita and Adriano nor Renato and Milene used condoms consistently. Regardless of the various specific decisions made by individual couples, the notion of “normality” was an important resource for all of them. Attending to the DON makes visible that what was at stake was couples’ very understanding of themselves and their relationship.

Biomedical technologies have played a large role in creating the conditions that structure this dilemma for couples of mixed HIV status. They enable diagnosis and treatment of HIV, extend the lives of those living with the virus and facilitate the formation of serodiscordant unions. Biomedicalization as a disciplining force, however, has also propagated a particular mode of embodied citizenship in which disease prevention is both a primary social responsibility and marker of modernity and morality (Briggs and Mantini-Briggs 2003; Biehl 2007). Nonetheless, I never saw clinic personnel recognize or discuss with patients how biomedical mandates around HIV prevention and treatment existed in tension with other valued ways of being. Without guidance on how to mediate this conflict, the couples in this research creatively adapted clinic discourse, using the key word “normal” to bridge this cultural divide, in defiance of what society more generally might see as a decided lack of fit.

As Bakhtin (1984:202) wrote, “When a member of a speaking collective comes upon a word … the word enters his [sic] context from another context, permeated with the interpretations of others.” Every meaning is thus a situated one. But because language is generative (Gee 2005:67), these meanings can also be re-situated, re-signified, and alter the reality into which they are launched. By mixing the lifeworld and specialist discourses, mixed-status couples redrew the boundaries of “normal life.” We might see in the DON a form of “storytelling as a rally for social and political recognition and legitimacy” (Persson, Ellard, and Newman 2015), as it brings into being—even if only momentarily—a world in which HIV-related stigma around serodiscordance no longer makes cultural sense and serodiscordant relationships can be accepted and valued.

Conclusion: Thoughts on Serodiscordance in the TasP Era

Seropositive people and their intimate partners in this research perceived HIV-related stigma to be pervasive within wider society; this stigma also attached to their relationships. Mixed-status couples sought to contest such constructions. At the same time, medicine played a crucial role in expanding possibilities for serodiscordant partnerships, through the beneficial effects of ART and enhanced longevity of those diagnosed with HIV. Stigma and biomedicine were thus both important influences on the DON. Delving deeper into the sociocultural context of the DON's production, however, it is clear that the behaviors demanded of "good patients" (e.g., using condoms, avoiding breastfeeding, attending clinic, etc.) contradicted culturally specific ideals of conjugality and gender in Brazil. Hence, a critical examination reveals that, as these couples struggled to re-signify serodiscordant relationships, they faced a choice between conflicting identities. I argue the DON is their attempt to reconcile this conflict. This reconciliation is only comprehensible within a particular political-economic and socio-cultural context: one in which strong HIV-related stigma and effective, accessible treatment for the virus collide, and both bump up against strong norms about how to embody gender and couplehood. At its heart, the DON is a powerful marker of ongoing negotiations around HIV and serodiscordance.

This brings us to the issue of what the DON might suggest about serodiscordance in the TasP era. The results of the HPTN-052 study demonstrated that achieving viral suppression in seropositive partners of serodiscordant couples vastly reduces sexual transmission risk (Cohen et al. 2011). Partly in response to these findings, in late 2013, Brazil became the first middle-income country to begin offering ART to any resident diagnosed with HIV, regardless of CD4 count (Ministério da Saúde, 2015). Thus, moving forward, more Brazilians diagnosed with HIV may begin treatment prior to ever experiencing clinical manifestations of the virus. Yet there is little reason to expect this alone to prompt a precipitous decline in HIV-related stigma in the short term. Therefore, serodiscordant couples will still negotiate their lives together in the context of conflicting versions of "normality." Recognizing this, treatment for HIV should provide the opportunity for mixed-status couples to discuss such lived complexities in a holistic frame (whether with physicians, nurses, social workers, or psychologists—variously available in Brazil's public health system).

One particular question raised by the HPTN-052 findings is what advice people living with HIV should receive about condom use in long-term sexual relationships. Already in 2009–2010, various couples in this study voiced doubts about transmissibility in the context of "undetectable" viral loads. These couples did not consistently use condoms. It seemed that, lacking a compelling biomedical justification, doing so was simply too large a concession to the clinic discourse. Instead, they chose the intimacy, pleasure, and symbolism offered by the "normality" of the life-world discourse. As understandings of non-infectiousness become more prevalent, more couples may come to similar conclusions.

The findings from this pre-TasP era study, as well as those from subsequent research in Brazil (e.g., Paiva et al. 2011; Closson et al. 2015) show that the "threat" of HIV transmission was never sufficient to prompt consistent condom use among all mixed-status couples. Other considerations were also in play. Indeed, the truth about serodiscordance is that it is a contingent and fundamentally biocultural lived experience; nothing about TasP alters this. What biomedical prevention may change—albeit more gradually than we wish—is the social world surrounding mixed-status couples, particularly in terms of diminishing HIV-related stigma. Such an alteration could lessen the conceptual distance between lifeworld and specialist perspectives on serodiscordance, leading to less of a need for discursive bridging, and potentially the disappearance of the DON. At that point, couples of mixed status may no longer feel it essential to explicitly state the normality of their relationships; it will go without saying.

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Situating Serodiscordance: Living in Relationships with Mixed HIV Status in Different Local, Historical and Biomedical Realities

Angela Kelly-Hanku

Introduction

> We don't think about it. We forget about it. We are normal and live our life, except when I must remember to check my review date and go to the clinic (Soso, HIV-positive woman in a HIV-serodiscordant couple, Goroka, Papua New Guinea).

In the Australian winter of 1981, the year I began primary school, an epidemic of unknown cause or origin officially began with reported cases of *Pneumocystis carinii* pneumonia in gay men in the USA. Soon after, Australians—mostly gay men and individuals with haemophilia—began to face the epidemic, forced to live with and respond to a new illness that affected not only them, but also their partners, family, friends, and communities. As no members of my family were infected or affected by this new mysterious illness, I remained oblivious to the virus for many years. It would not be for another decade and a half that I would find myself personally affected by HIV, and part of a "key population", as serodiscordant couples are now termed. But this was not how we viewed ourselves, nor how "HIV experts" classified us at that time. This was, in part, because at that historical moment HIV treatment was minimal and the current culture of biomedical prevention was still far in the future.

HIV is most frequently transmitted during "intimate acts in private relationships", making it a "disease rooted in relationships" (Kalichman 2000:175). As Persson (2011, 2013) has underscored in her body of work on serodiscordant relationships in Australia, it is critical to understand how serodiscordance operates relationally. This means enquiring into how HIV impacts upon the social and embodied

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sense of self for both HIV-positive and HIV-negative partners, as well as the diverse ways this shapes how serodiscordance, and risk, is lived in different local realities. At the core of serodiscordance is the issue of intersubjectivity because individuals, as Merleau-Ponty (1973) said, rarely act in isolation from others. Similarly according to Schutz (1973:55), the social world "is from the outset an intersubjective world". Thus, although HIV is a virus physically confined to the body of the HIV infected individual, both the person with HIV and their partner (and others) experience HIV affectively and socio-culturally. In short, lived experiences of HIV are intersubjective, profoundly mediated by both social and biomedical contexts. Such an emphasis on the relationality and intersubjectivity of serodiscordance (within sexual and other familial relationships) has been at the heart of my own work on HIV, particularly as it relates to AIDS dementia (Kelly 2008a, b, c, 2010).

Seeing serodiscordance from this perspective destabilises any effort to essentialise what living in a serodiscordant relationship means. In this chapter specifically, by exploring serodiscordance in different local, historical and biomedical settings, I attempt to unsettle popular discourses of and the meanings ascribed to serodiscordance by illustrating how they are neither universal nor consistent across time or place. I provide historical insights into the "emergence" of serodiscordant couples by drawing on my own story as an HIV-negative woman in a heterosexual serodiscordant relationship in Australia. I also chronicle my experience of the emergence of HIV serodiscordant couples in the national response in Papua New Guinea (PNG), first as an imagined biomedical anomaly and subsequently as a normalized phenomenon of living with HIV. In doing so, I make visible snippets of the realities of couples' lives, bringing to the fore personal stories of HIV and serodiscordance. I thus consider the private lives behind a global health concern, offering an analysis of the effects of biomedicine and living in relationships with mixed HIV status. But first I examine the politics of representation of living with HIV and its impacts on understandings and representations of couples with mixed HIV status.

The Space for Serodiscordant Couples

Long marginalised to the edges of the epidemic (e.g. Kelly 2006; Roman 1997; Van der Straten et al. 1998), HIV-negative partners are now more visible than at any other time in the history of the epidemic, if for no other reason than their role in clinical research on Treatment-as-Prevention (TasP). Results from the high-profile HIV Prevention Trials Network trial have shown that early treatment of HIV reduces HIV transmission in serodiscordant couples by 96 %, as compared with delayed treatment (Cohen et al. 2011). As a result, TasP has become a key biomedical intervention in the HIV landscape, with a very specific goal; to reduce HIV incidence globally.

This new concern with serodiscordant couples, however, has almost exclusively been focused on quantitative understandings of HIV transmission/acquisition risk rather than the intimate practices and daily realities of couples' lives. Their bodies have become a primary focus of the biomedical gaze in large-scale trials. Whether they engage in same-sex or opposite-sex intimate relationships, and whether located in African, North-American or other countries and regions, serodiscordant partners have become central to understanding HIV transmission risk from a clinical and epidemiological viewpoint. But this perspective is only partial and reflects little of living with serodiscordance. It has also meant that serodiscordant relationships have overwhelmingly been framed as sites of HIV risk, as if these couples in all their variances were the same across both time and space. Hence, with the transformation of the biomedical landscape, the recent attention to serodiscordant couples is welcomed, but comes with a level of caution as to the genuine interest above and beyond "risk" and the potential biomedicalisation of these relationships.

People new to HIV could be forgiven however for believing that serodiscordant relationships are a recent phenomenon, a late addition to the HIV epidemic and to "living with HIV". But, of course, intimate serodiscordant partnerships have always been a characteristic of the epidemic; they simply have not been given the attention they now incite, whether biomedical, political or social. This was the reason I referred to the politics of representation in an earlier article where I explored, using visual images, my partner's life and subsequent death from AIDS dementia, a feared and deeply stigmatised AIDS-related condition, arguing that my shadowed face in one particular image at an AIDS Candlelight Memorial was symbolic of my invisible serostatus position as an HIV-negative partner of a person living with HIV (see Kelly and Kerner 2004).

Situated Knowledge

To explore the issues outlined for this chapter I draw on a number of different sets of "data" (knowledge). Along with insights gained through my work as a social researcher on HIV in PNG, my life, like that of many people, has also been intimately impacted by the virus. Jossie and Soso, two women employed in my home to care for my children, live with HIV; both of them have married HIV-negative men in the five to ten years we have known each other. Reaching further into the past, my connection to serodiscordance grows more intimate still. My partner Andrew died from AIDS-related dementia in early 1999, 8 days before my 23rd birthday. Thus my embodied experience of serodiscordance is situated at a very different historical moment than Jossie's and Soso's. I have permission and the blessing of family members, friends, and research participants to draw on all of the stories presented in this chapter. My commentary here should be recognised as, in part, autoethnographic, in the midst of an ongoing HIV journey that is both professional and personal, across highly diverse cultural, linguistic and temporal settings. In this way, I work in the "borderland between passion and intellect, analysis and subjectivity, ethnography and autobiography, art and life" (Behar 1996:174). This perspective offers a unique window onto changes in the biomedical landscape over time—changes which I argue are critical to the (re)framing of serodiscordant relationships in PNG, and likely in other contexts as well.

Intimate Understanding

I met Andrew in my late teens. The night of the day we met I dreamed of our wedding; needless to say I was deeply taken by him. I had never met someone who had intrigued me as much nor whom I shared so much in common with. Diagnosed with HIV in December 1984, Andrew had already lived with HIV for many years before I met him; his resilience, passion and humour were infectious not only to me, but also to all those who met him. I was not intentionally entering into a relationship with "a person with HIV." I was experiencing my first great love. It was a love that would teach me much about the value of life, but also of living with HIV; lessons I continue to benefit from long after his death.

Our relationship posed immediate challenges; in the mid-1990s in Australia, effective HIV treatment was lacking and much fear and discrimination prevailed. Andrew's family carried a hereditary bleeding disorder and was deeply affected by HIV early on in ways most families were not. Andrew was 11 years old when he was infected and 14 years old when diagnosed with HIV. His maternal uncle, who also had haemophilia, was diagnosed in his early thirties. This uncle, who died the year before I met Andrew, left behind an HIV-negative wife and young daughter, born within a year of his diagnosis.

AZT was the only HIV treatment available at the time Andrew and I met. Many people suffered from its toxicity, hence his decision not to risk premature death from treatment side effects. Treatments advanced considerably during our 4-year relationship, though treatment as we know it today simply did not exist. In particular, there were severely limited options for people like Andrew, who had been diagnosed with HIV-related dementia some 18 months into our relationship. At one point, he was granted, on compassionate grounds, permission to commence treatment on a trial drug believed to cross the blood brain barrier.

Soon after Andrew started this trial treatment, however, he stopped. The side effects were unmanageable and intolerable, and ongoing cognitive deterioration suggested that the regimen was not adequately treating HIV in his brain. He wanted desperately to live but not at the cost of being severely impaired by dementia. Andrew and I were never to benefit from the medical advances that were yet to come in the ways many of our friends did and continue to do. With his ongoing cognitive deterioration, the hope for HIV treatments to halt or reverse the damage of HIV to his brain became a hope for death, suggesting the complex and temporal dimensions of hope, treatments and HIV (Kelly 2007).

Situating HIV in PNG

In the almost 30 years since HIV was first diagnosed in PNG in 1987, epidemiological, socio-cultural and political understandings of the epidemic have undergone momentous change. As the country with the largest number of people living with HIV in the Pacific (National AIDS Council Secretariat [NACS] 2010, 2013) and with a rapid increase in diagnoses in the early years, the epidemic in PNG was previously predicted to follow the path witnessed in sub-Saharan Africa (Australian Agency for International Development 2006; NACS 2013).

That said, there is increasing recognition that not all people in PNG are equally at risk of infection, nor is the epidemic evenly felt across the country (Kelly-Hanku et al. 2014a, b; Maibani et al. 2011; NACS 2013). The current epidemic is complex; mixed rather than concentrated or generalized (Kelly-Hanku et al. 2014a, b), and not readily classified into HIV estimate models or epidemiological categories. When I first began working in PNG at the turn of the century, HIV treatments were not yet available. A few years later, they were integrated in a pilot project at the country's largest HIV clinic in the nation's capital. Thus, HIV treatments were late to be incorporated into PNG's response to the epidemic, particularly considering the grim sub-Saharan analogies that were drawn at the time. Fast-forward to the present day and treatments are available throughout the country.

In the past 10 years, a wealth of research (social, cultural, laboratory and epidemiological) has enhanced our understandings of HIV in PNG. This includes my own research studies, such as *The ART of Living*, the first study on living with HIV and treatment in the country (Kelly et al. 2009a), as well as the first study to bring attention to the core issue of this edited volume: couples with mixed HIV status (Kelly et al. 2011). In this study, of participants living with HIV who were sexually active and in a regular heterosexual relationship, 21 % reported being in a serodiscordant relationship; a further 14.3 % did not know their partner's status (Kelly et al. 2011). There was no significant difference in condom use between couples with mixed HIV status, couples with the same HIV status or those where the status of the partner was unknown. In qualitative interviews from the same study, people living with HIV described their HIV-negative partners as playing an important role in their lives in terms of treatment adherence, keeping HIV a secret, nutritional support and a sense of normality through sexual intimacy and care (Kelly et al. 2009a; 2011).

More recent qualitative research on prevention of parent-to-child transmission (PPTCT) programs shows that, with the rapid roll out of antiretroviral treatment (ART), HIV-positive women and their negative husbands are fulfilling reproductive desires, with increasing numbers of couples knowingly entering into a serodiscordant relationship (Kelly et al. 2013). Marriage, pregnancy and parenthood are significant cultural practices and expectations in PNG, and understanding this makes plain how transformative biomedicine can be. It allows people with HIV, and serodiscordant couples, to re-enter society from the margins of contagion and pollution, enabling their claims of reproductive citizenship (Kelly 2012b).

Notwithstanding severely limited second-line treatment and numerous treatment stock outs, the treatment and management of HIV in PNG has progressed significantly in the past few years. Portable point-of-care CD4 machines are now readily and widely available in most treatment centers. But access to viral load testing—critical to determining treatment failure—is non-existent. The absence of viral load testing influences the clinical management of HIV as well as discourses of HIV risk. Excluding the few HIV activists who attend regional meetings, nowhere have I heard people with HIV or their HIV-negative spouses talk about "non-infectiousness", undetectable viral loads or TasP, as found in other studies of serodiscordant couples. Rather, people talk about treatment as putting the virus to sleep or putting a fence around it and enabling them to have "normal" babies free from HIV. While it is not clear if this encodes the same understanding that lies behind more scientific discourses, its expression is certainly different in PNG. As viral load testing becomes available in the future, it will be important to map how this new technology might alter narratives of HIV risk and how the knowledge of viral load might be incorporated into the sexual and reproductive practices of couples with mixed HIV status.

Sero-Silence and Diversity

The current PNG National HIV Strategy (NACS 2010) is the first to mention serodiscordance, and does so only twice. This occurred only because my supporters and I were so intent on breaking the silence that surrounded such couples and, in particular, ensuring their access to Post Exposure Prophylaxis (PEP). The policy on PEP provision at the time the Strategy was drafted named only victims of sexual violence and occupational exposure. I knew that unless serodiscordance was explicitly included, the policy would be left to interpretation, and possibly discriminatory application. To appropriate and re-apply a phrase coined by Persson (2008), our work in those meetings (where the strategy and policies were designed) was to ensure there was no "sero-silence". Another expression of sero-silence is the way global public health discourses frequently frame serodiscordance as homogenous. This muzzling of diversity in mixed-status couples, historically and across different socio-cultural (and biomedical) landscapes, is an ongoing limitation of the extant literature. Here I offer just a few examples of the diversity I have come across in my work and personal experience.

Many marriages throughout PNG, but particularly in the Highlands Region, are polygamous. I encountered a serodiscordant polygamous marriage in early 2008 while in Mendi, the provincial capital of the Southern Highlands, for the ART of Living study. The diagnosed HIV-positive woman, one of two wives, had been enrolled in the PPTCT program, after having tested positive for HIV at her first antenatal visit. She had only given birth within the last 24 h prior to me meeting her. As we talked, her co-wife shared that she too wanted a baby but that she did not know her HIV status. Nor, it turned out, did the husband of these women. He had recently been released from prison for a brutal act of domestic violence. Wanting to know their status, the co-wife and their husband attended the Catholic HIV Center a few days later. Both tested negative for the virus.

Though only a snippet, this family's story has stayed with me, offering a variant narrative to the dominant construction of serodiscordance perpetuated by national and international policy and rhetoric. In prevailing HIV discourse, polygamous unions are erased, despite polygamy being a type of marriage endorsed and codified culturally, religiously and often legally in many parts of the world. In countries such as PNG, serodiscordant polygamous unions are not a socio-cultural (or biomedical) anomaly. Yet such relationships are rarely acknowledged in the literature on serodiscordance more broadly, let alone in the clinical drug trials that have brought biomedical attention to serodiscordance. Polygamous unions with mixed HIV status stretch and challenge our common understanding of serodiscordant "couples". But if we look beyond intimate partnerships, serodiscordance begins to stretch and diversify even further.

At another point during my time in Mendi, a local priest brought a group of people living with HIV from his diocese for their HIV medical review at the local Catholic HIV treatment and care centre. There were two young brothers amongst them. As people waited for their reviews, we all played a game of basketball, laughing and sharing stories. A story of the boys was relayed to me be by another member of the group. Both boys had been infected perinatally, though their middle brother was born without the virus. Their parents, however, had died from AIDS. This chain of infection and death was forged before ART was introduced in PNG; had the family lived elsewhere where treatment was already available, this chain of infection and loss of life may have been prevented.

This story of mixed HIV status between family members is not unique to this family or to PNG. In Australia, prior to the development of more advanced HIV treatments, I knew of families in which parents and children were serodiscordant, or siblings were of mixed-status—including a family with identical twins where one was HIV-positive and the other negative. This kind of serodiscordance also characterized my late partner's family: Andrew's uncle was infected but his wife and daughter were negative. Though not often discussed, intra-familial serodiscordance has only become *more* common as HIV treatment and prevention have evolved. Indeed, because PPTCT programs are designed to ensure that children of HIV-positive mothers are born without HIV, and that HIV-positive men do not infect their spouse and therefore their child, such programs increase rather than decrease mixed-status relationships. Creating serodiscordance within families is the explicit global biomedical aim of PPTCT.

Treatment and the (Re)framing of Serodiscordance

I grasp the concern about the emphasis placed on biomedical technologies to control and manage HIV (e.g., Knight et al. 2014), what some criticize as a "remedicalization of HIV" (Nguyen et al. 2011) at the expense of other socio-cultural and structural interventions. And yet, as someone whose serodiscordant relationship came to a tragic end because existing treatments were incapable of extending my partner's life, I am also compelled to acknowledge the exhilaration and hope that contemporary treatments afford those living with the virus. But rather than debate the promises or limitations of treatment, I want to explore the potential re-framing of serodiscordance in the context of treatment. I note that Persson (2015) uses a similar term—re-imagining—in relation to TasP among serodiscordant couples in Australia. The similarity is both coincidental and speaks of the extent to which biomedicine is affecting the re-framing/re-imagining of serodiscordance across vastly different epidemiological and cultural landscapes.

The absence of treatment played a critical role in how Andrew's and my relationship and lives unfolded, including how our experiences of discordance differed in very important ways from the couple I quoted at the start of this chapter. Life was rarely ever "normal" for us. Our daily lives were constant reminders of HIV, of illness and demise. His disease consumed his life, my own and that of his family. In addition, parenthood was something Andrew and I wanted to experience together. But unlike many mixed-status couples today, even in a low-income country such as PNG, we had no safe means of making a family in Australia in the mid to late 1990s. At the time, it posed significant risks (particularly for me as the female, HIV-negative partner) or required highly intrusive (and expensive) biomedical interventions (e.g., sperm washing). In comparison, PPTCT makes reproduction for couples with mixed HIV status seem almost mundane. Because of advances in treatment and increased global access, those currently living in resource-limited settings are able to achieve something that was not possible earlier in the epidemic for Andrew and me, even in a resource-rich context: they not only survive, they thrive.

Until fairly recently in PNG, particularly when treatments were new and today's sense of living with HIV was not yet evident, considerable stigma and moralisation surrounded sexuality in the context of HIV. However, through both my research and my personal involvement in the lives of people with HIV, I have witnessed the emergence of new sexual relationships that defy earlier HIV narratives of sorcery, demise and discrimination (Kelly 2012a, b; Kelly et al. 2009a, b). With access to antiretroviral therapies now widespread, such narratives have diminished considerably, as evidenced by the stories of two women living with HIV: close friends Jossie and Soso were both supported in their marriages to HIV-negative men by their health care workers. Moreover, Jossie was supported to have four children, all of whom are negative as a result of ART and her determination to adhere to breastfeeding advice.

Serodiscordant relationships in PNG now appear largely accepted by health professionals and, to varying degrees, within families and communities. This does not diminish the difficulties of disclosure, of positive-negative sexuality, of treatment adherence or reproduction. However, with treatment, the quest for relationships and parenthood is not limited to those who can afford expensive interventions or those who live in high-income countries; it is now in the grasp of most mixed-status couples in PNG. The mixed-status couples I know in PNG live a sense of normality far removed from my and Andrew's experience.

God, Risk, and Being Normal

Biomedical discourses homogenize HIV risk amongst serodiscordant couples, failing to account for variances across settings and sexual practices that affect risk. They also tend to overlook the culturally specific dynamics that shape and inform how relationships of mixed HIV status (be they monogamous, polygamous or heterosexual, homosexual or both) are lived in local, historical and biomedical realities. In the context of PNG, one key cultural dynamic to consider is the role of religion. Several Christian churches play an important role in the national response to HIV (particularly treatment and care) (Kelly 2009), and Christianity more generally has a profound impact upon the diverse and sometimes conflicting ways that people perceive HIV treatment and HIV risk (Eves 2012; Kelly-Hanku et al. 2014a). But more than that, Christianity offers those living with HIV an important and prevailing framework for understanding health and personal infection, sometimes alongside or in stark contrast to biomedical models (Kelly-Hanku et al. 2014a; Kelly 2012a). And it is Christianity, as opposed to TasP, or even condoms, which is perceived by those without HIV to provide the greatest protection against infection (Eves 2012; Kelly et al. 2009b), including HIV-negative people in serodisordant couples. Sophie, a participant in the *Art of Living* Study (2008) highlighted this dimension to HIV in PNG when she shared the following comment by her HIV-negative husband: "He told me, 'I love you and we live together; so according to my own faith, your sickness will not infect me'" (Kelly et al. 2009a).

Soso told a similar story, one that highlights the increasing normalization of serodiscordance in PNG in the biomedical age, but also the powerful influence of Christianity on local risk perceptions. Soso and her husband had both been diagnosed with HIV when she was 1 month pregnant. Immediately starting on ART, she gave birth to a little girl free of HIV. Her husband, sadly, passed away and a short time afterward she commenced working in my house to support herself and her three children. Not long after I came to know Soso, Michael, a friend and *wantok* (person from the same village) of her late husband, asked Soso to marry him. Michael knew that Soso was HIV-positive and that his friend had died of the disease. As a church man, Michael believed in several things: that he should be married; that Soso did not create the "sin" of HIV in her body, and; that God would protect him from HIV because he, like Soso, was innocent, for neither of them caused the disease. During a conversation about this book chapter, Soso shared with me what her new husband had said to her at the time of his marriage proposal:

> My belief in God is that I can marry you and not get this disease. I am an innocent man. You are a mother. And your husband is responsible for giving you this disease so I won't get this disease. I believe in God the Father.

Over the years Michael had shared similar comments with me that reinforced the normality of their marriage and the notion that God would decide if he became sick or not.

I asked Soso one morning, as we shared breakfast, about when her next HIV medical review would be; I was worried because she had not said she would be late to work for some time because she needed to first attend clinic in the morning. She dismissed my concern, saying, “Don’t worry, sometimes when I am busy here with the children, I send Michael and they give him my medicine”. When I asked her if there were many other husbands like Michael who were negative and go to the clinic, Soso replied; “When I was diagnosed there weren’t couples like my husband and I. Now there are lots of couples where the man or woman has HIV and their partner doesn’t; it’s normal”. Taking the idea of normal further, she said:

> We don’t think about it. We forget about it. We are normal and live our life, except when I must remember to check my review date and go to the clinic, but the rest of the time we don’t, we just act normal. I don’t think too much about it, I forget about it. We just stay normal and live life. And my daughter [exposed to HIV in pregnancy] is normal. I will see my children get older and have children of their own. I am fit and healthy.

This notion of normal intrigued me, as did the belief in God’s ability to protect a person from HIV; I would never have used such concepts to describe my relationship with Andrew. I clearly saw signs of HIV’s presence in Andrew’s body in ways Michael does not see in Soso. And so we could never forget about HIV in the way Michael and Soso described. Moreover, I was scared of becoming infected in a way Michael does not appear to be. Although raised in the Roman Catholic tradition, I did not believe in or trust that a spiritual figure would ensure my safety from infection. My fear increased when HIV viral load testing came into use, and I was not alone. Andrew and I heard stories of people committing suicide in response to receiving their viral load results. There was, at that time, limited social understanding of their meaning, but the numbers used to express viral load—in the thousands and millions—were enormous. This was in stark contrast to CD4 test results, which were, depending on your stage of disease progression, in the double or, if you were lucky, triple figures. Beyond the figures themselves, there was no biomedical, let alone popular discourse of non-infectivity or undetectable viral load back then. In short, our serodiscordant experience could not have been more different than Soso and Michael’s. Christianity, normality and biomedicine were not frameworks for understanding HIV in my Australian context all those years ago.

Conclusion

As HIV treatments have been re-applied to prevent the transmission of HIV, couples with mixed HIV status have been brought into the biomedical, public health and clinical gaze, most markedly with TasP. But this gaze has almost exclusively been focused on quantitative understandings of risk. Narratives of the daily lives, feelings and practices of couples and individuals in these relationships have not been afforded the same priority as clinical and epidemiological understandings. In this chapter, I have tried to address this imbalance by providing vignettes of actual practices, intimate events and feelings among mixed-status couples, both through my own story and those of others. In doing so I have sought to show that, though the biomedical model makes no space for such a perspective, serodiscordance is an intersubjective experience, an intensely relational and diverse phenomenon.

Despite the existence of diverse serodiscordant relationships from the outset of the epidemic, our understanding of serodiscordance has been narrow. This, I suggest, is in large part because the concept of serodiscordance has been used to understand transmission risk rather than people's lived realities. This has resulted in a systematic erasure of differences in local realities—polygamous unions are a good example. Further, by limiting the concept of serodiscordance to "risk" in couples, we fail to understand the complex and dynamic ways that HIV is experienced and lived in social relationships, above and beyond those of a sexual nature, encompassing broader family relations and community contexts. In places such as PNG, where family and familial relationships are central to identity, these connections are paramount and worth further consideration as we refine and deepen our understandings of serodiscordance.

I have drawn here on my long-term understanding of HIV, ranging from having been in a serodiscordant relationship in Australia early in the epidemic to now living and working with serodiscordant couples in PNG. I have shown that, while living in a mixed-status relationship goes well beyond sex and reproduction, it is nonetheless within these domains that we can most easily observe some of the many changes and new possibilities brought about by HIV treatment. Welcome biomedical advances in the global response to HIV mean that mixed-status couples (and families) in PNG and Australia can now identify as "normal", rather than as a "key population" as global HIV discourses currently in circulation would have them classified. My own early experience of being part of a mixed-status couple in a resource-rich setting like Australia contrasts markedly with the realities of mixed HIV status couples today and the normalisation of serodiscordance that is emerging in PNG and other settings in what is now a very different biomedical landscape.

On a final note, the power of recent scientific discoveries and increased access to HIV treatment notwithstanding, the "end of AIDS" is not (yet) ensured. People still become infected and die from AIDS-related conditions, as my dear friend of almost 10 years Jossie did in late 2015, leaving her HIV-negative husband and children behind. Given that HIV medicine is a rapidly moving field, there is an ongoing need to understand treatment as situated within local meanings and practices, particularly in serodiscordant relationships. We must forego a-historical and de-contextualized conceptions and, instead, engage critically with diverse cultural, temporal, and biomedical realities to understand what living with serodiscordance means and may mean into the future.

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Dedication This chapter is dedicated to my friend and sister Jossie who died from HIV and TB co-infection 17th November 2015 and to her husband and four children.

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Exploring the Relational Complexity of Serodiscordance: Negotiating Violence, Temporality and Diaspora

Annette-Carina van der Zaag and Ulla McKnight

Introduction

> Couples with one person who is HIV-positive and one who is HIV-negative are sometimes called 'serodiscordant' or 'mixed serostatus' … 'Serostatus' refers to whether someone has HIV infection or not (The Body 2012)

The definition of serodiscordance provided above depends on a certain biomedical "truth", namely that HIV is a discrete entity contained in the host's body. In this definition, the virus (as a discrete entity within a body) can be discovered through biomedical testing technologies. Moreover, HIV is, and remains, a separate entity from the body it is housed within and is unaffected by the technologies and practices through which it is made knowable by biomedicine. In this chapter we seek to question this notion of serodiscordance. We will show that, while the definition of serodiscordance provided above may appear straightforward, on closer examination serodiscordance is better understood as a complex entanglement of virus, bodies, power and diasporic positionalities.

The concept of serostatus disclosure is closely related to this conception of serodiscordance. Disclosure always happens prior to serodiscordance (according to the above definition of serodiscordance). That is, serodiscordance is preceded by disclosure; one person discloses to their partner that they are HIV-positive. The partner, in turn (presumably after testing) discloses that they are HIV-negative. Serodiscordance is established. Disclosure assumes *"the real" of HIV,*[1] which exists

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[1] "The real" is a concept we have taken from feminist theory in which it is used to articulate materiality as it appears (and is imagined) to exist prior to discourse (see for instance Butler 1994). The concept is at the heart of Karen Barad's agential *real* ism and has been adopted by Marsha Rosengarten (2009).

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prior to and independent from biomedical investigation and intervention, as well as the host's body within its social environment: "[A] seemingly stable object" (Rosengarten 2009:28) that can be spoken about and accepted/understood as a discrete object that may, or may not transfer between bodies. Our position, in contrast, is that technology is always and already part of the object that is under investigation. Therefore, *the real of HIV* is always and already involved in systems of meaning in the (onto-epistemological) processes through which HIV becomes knowable (McKnight and van der Zaag 2015).

We understand the above biomedical definition of serodiscordance to be symptomatic of the wider remedicalisation of the HIV epidemic. Nguyen and colleagues (2011:291) have articulated this remedicalisation as a "view of the epidemic as a medical problem best addressed by purely technical, biomedical solutions whose management should be left to biomedical professionals and scientists." But although the prevention of vertical transmission of HIV has proven to be highly effective when access to proper care is available (Centers for Disease Control and Prevention [CDC] 2012), the complexities it is embedded in and brings forth go beyond the scope of biomedicine (Doyal and Anderson 2005).

Furthermore, within the above definition, serodiscordance is articulated in close relation to the legal status of disclosure, and as such the criminalisation of HIV transmission. At present, the establishment and maintenance of serodiscordance is understood of as being the responsibility of people who have received a positive HIV diagnosis and are, or intend to be, sexually active. If the person infected with HIV fails to disclose their serostatus to sexual partners they may be accused of grievous bodily harm in the UK (Dodds et al. 2005). Here biomedicine strengthens a legal definition of disclosure (and vice versa) as it is understood as an articulated representation of the real of HIV in the host's body (provided by biomedicine). Although we will not be speaking of the criminalisation of HIV transmission per se, its legal force is present in the clinic, made visible by the ethical-legal necessity for practitioners to encourage disclosure, even though they know the effects of this may be violent to the women involved (Kalichman et al. 2003).

The analysis set out in this chapter is both an articulation of the relational complexity of serodiscordance and an explicit critique of its biomedical definition and its socio-legal effects. In contrast to the notion of HIV that the biomedical definition of serodiscordance evokes, we argue that serodiscordance emerges in relation to, and in intra-action with, its social environment and the technologies that enable its detection and treatment. As such, serodiscordance reveals a set of relations that are not necessarily the same from one body to another. We argue that serodiscordance is a phenomenon that is multiple and this multiplicity directly impacts on the possibility of care and the lives of people affected by HIV. In short, we will set out a novel conceptual approach that foregrounds serodiscordance as a deeply relational state of affairs. To this effect we will provide an agential realist analysis of serodiscordance in the antenatal clinic.

Serodiscordance Within the Clinic

This chapter is premised on material collected, by McKnight, during a 9 months-long qualitative investigation into a once-weekly HIV specialist antenatal clinic housed in an acute National Health Services (NHS) Research Hospital in London. The study explored how HIV prevention occurred in the space of the clinic and in what ways the interests of HIV-positive mothers, babies and health professionals were reconciled, if at all. During the course of the project, McKnight regularly attended the consultations of 21 different patients, conducted unstructured in-depth interviews with nine patients, and held second interviews with three of them and a third interview with one woman. All of the patients interviewed were Black, and originally from countries in Sub-Saharan Africa, with the exception of one woman, who came from a country in the Caribbean. The patients' nationalities reflect the wider UK HIV epidemic, as it pertains to women (Yin et al. 2014). Eight of the patients interviewed spoke about their experiences of being in relationships that (they had assumed) were serodiscordant. All of these relationships had been with Black men from the same countries as the women themselves, aside from one woman who had been in a relationship with a White British man.

Five healthcare practitioners were also interviewed; second interviews were held with the only two practitioners who regularly met with patients in the clinic. Two of the practitioners were women of Black African decent, while the rest were White British. Pseudonyms have been given to all research participants to protect their anonymity. Interview transcripts were analysed in NVivo, using an adapted Grounded Theory approach. Ethical approval to undertake this study was granted by the NHS Research Ethics Committee (REC), the Research and Development office at the Hospital and the REC at Goldsmiths, University of London.

In the clinic the establishment and/or the refutation of serodiscordance was potentially a threat to the successful prevention of vertical transmission. The threat, as the practitioners imagined it, emerged from the way in which their patient's partner might react to status disclosure, and the consequences of his reaction. Patients who were subjected to violence were more likely to have difficultly adhering to their plans for care (including adhering to HIV treatment regimes), hence jeopardizing the practitioners' ability to prevent vertical transmission. While these disruptions were hypothetical (prior to disclosure), the practitioners knew from experience that disclosure of HIV carried a high risk of violence for their patients. Thus, the possible consequences of a partner's hostile response to a patient revealing her status were always and already part of serodiscordance in the clinic. Despite this, the legal imperative of disclosure meant that the practitioners had to be seen to be actively helping their patients towards this goal. In other words, and from the practitioners' point of view, while the establishment of serodiscordance was a legal necessity, it could disrupt the clinic's prime purpose; namely, the prevention of vertical transmission and the provision of good care to the patient and her (unborn) baby, of which strict adherence to antiretroviral therapy (ART) was a key component (de Ruiter et al. 2014:21).

Moreover, from the practitioners' perspectives, the establishment of serodiscordance took place outside of the antenatal clinic and entailed: a patient communicating a biomedical "truth" to a sexual partner, the partner accepting this truth, establishing his own serological status, and disclosing it to the original patient. The patient would then relay the information to her health care practitioners, who would in turn document that the process had taken place. Here it is important to state that we are not dealing with how serodiscordance was enacted outside the clinic by the patients, but with how the outside reality was *imagined* by the practitioners inside the clinic.

Furthermore, while the definition of serodiscordance provided at the beginning of this chapter concerned two people in a sexual relationship, serodiscordance in the clinic pertained to any number of people that were or might become involved in a sexual relationship with a (postnatal) patient. Monogamy was not assumed in the clinic and neither was it assumed that the patient's sexual partner was the father of her (unborn) baby. The practitioners' work of tracing these (fleshy) relations and assessing the (legal) risk and responsibility that may be ascribed to them, became part of serodiscordance. Moreover, as soon as a patient discloses her HIV status, HIV will indelibly be connected to her (within her social relations) and her (unborn) baby, even if the baby is born free of HIV. In this way, the *real* of HIV is not limited to the HIV positive woman's body, even if it is not physically transmitted to another body.

In addition, and as a consequence of the fact that the majority of the clinic's patients were from countries wherein HIV and death were not decoupled, serodiscordance in the clinic was intricately part of what we call an HIV diaspora. We use this term to articulate the inequalities and differences between the effects HIV has on the lives of HIV-positive women in different geographical locations. We argue that the diasporic HIV-positive women involved in this research were simultaneously connected to and affected by the vicissitudes of HIV in multiple geographical locations. In other words, the majority of the clinic's patients were immigrants, and while some of them had become British and/or had permanent residency in the UK, they were all perpetually and intricately connected to their countries of origin. Moreover, these connections were always significantly affected and amplified by (various issues related to) HIV and the meanings, consequences and effects of HIV in their countries of origin *and* in the UK.

From what we have written above, it becomes clear that serodiscordance is not contained within static duos. Rather, what is at stake is a more complex relationality that reaches beyond the relation between two bodies in a sexual partnership. This relationality includes: the (unborn) baby, past, present and future partners, geopolitical locations, biomedical technologies and practices of care. The existence of an HIV-positive (pregnant) patient means that serodiscordance is always a possibility, in the future, even if serostatus-sameness (seroconcordance) is established in the present.

Agential Realism

How can we articulate the complex relationality of serodiscordance in the clinic? We will build on a school of HIV research that engages the performative effects of biomedical interventions and assessment in and of the HIV epidemic (Persson 2013; Race 2001; Rosengarten 2009). This school of thought constitutes a significant critique of the social science approaches currently dominating the field of HIV that foreground the force of "structural drivers" in the progression of the epidemic. Problematically, approaches utilising structural drivers tend to separate the social from (bio)medical practice, where sociality becomes the sphere of power dynamics that fuel the epidemic. However, such an understanding is insufficient to capture the biomedicalisation of the epidemic referred to above. Instead, we propose a materialist approach, which does not exclude cultural causes and people's different experiences of HIV, but does explicitly foreground the differential *materialities* of HIV and biomedicine's constitutive role herein.

Thus, we will turn to Karen Barad's (2007) agential realism as an alternative framework of thought. Karen Barad is increasingly used as a key theorist in the field of feminist materialism, focusing on specific constructions of the body and human/nonhuman relations within and through specific scientific practices. In this chapter, we build on Barad's agential realism to articulate serodiscordance as a phenomenon – fleshed, discursive, imagined and deeply relational. Making this argument has a dual purpose, namely to articulate the relationality of serodiscordance in the clinic with direct consequences for practices of care; and to critique the biomedicalisation of the epidemic.

Barad's agential realism is a performative account of scientific practice that foregrounds the materiality of objects and bodies, always in intimate relation with their discursive constructions. For Barad, "'material' is always already material-discursive – that is what it means to matter" (2007:153). In this account, the primary ontological units are not biological bodies, or scientific objects of any kind, but it is within a *phenomenon* (a more encompassing material-discursive relationality, i.e. "the ontological inseparability of agentially intra-acting components" (Barad 2007:148) that these entities come to be, in relation with one another, as their ontology is an effect of specific, performative, intra-active practices. Within an onto-epistemology of agential realism, (scientific) apparatuses have a central place because boundaries between the component entities of the phenomenon are determined through the apparatus. For Barad, an apparatus is not a mere laboratory set-up, but a complex entanglement of sociality, discourses, politics, ideals, materiality and science. Consequently, the intra-actions enacted within the apparatus are not solely scientific, but include political, social, normative enactments that construct the specific components of these phenomena as they emerge. Following this line of thought, we understand the clinic to be an apparatus, where bodies are made to matter in specific ways: "bodies are material-discursive phenomena that materialize in intra-action with (and, by definition, are indissociable from) the particular apparatuses of bodily production through which they come to matter (in both senses of the word)" (Barad 2007:209). In this chapter, we focus on tracing the material and discursive relations that make up serodiscordance as a phenomenon in the antenatal clinic.

Serodiscordance as a Multiple Phenomenon

> We can't force disclosure, but we do have a responsibility to help [the patient] do that to the husband, but then there could be dangers as well … we've got sort of a lot of evidence that domestic violence is an issue, with disclosure, so it's a difficult path to tread and we also have got to think about the legal sides, because clearly there've been some court cases, where people have gone to prison for not disclosing their status and having unprotected sex with their partner and we have to let people know that that is the case, and document that we've told them that, and then be seen to be working towards it (Interview with HIV specialist midwife, 2009).

What the above quote makes clear is that serodiscordance is not only a deeply relational issue, but that it emerges in very different ways depending on its context, or environment: a clinical phenomenon to be negotiated; a phenomenon in relationships, both sexual and violent; and a legal phenomenon. The different contexts imply different material and discursive components that make up serodiscordance, and as such, the phenomenon multiplies. In line with Annemarie Mol's *The Body Multiple* (2002), we argue that serodiscordance is not only a phenomenon, but that as a phenomenon it is multiple. This does not mean that it is fragmented, that one version is radically different and incommensurable with another – rather, they are in themselves related. For instance, the quotation above shows that the practitioners in the clinic were very aware of the complexity of serodiscordance in women's relationships and that disclosure could result in domestic violence in these relationships. However, because of the criminalisation of infecting a sexual partner without disclosing one's status, legal requirements compel practitioners to be seen to have had a discussion on disclosure. In other words, in the clinic, serodiscordance emerged as a composite phenomenon, its meanings and materialisations differed from one context to the next, but "[hung] together" nonetheless (Mol 2002:55). In the analysis below, we flesh out this multiplicity in more detail by focusing on three "serodiscordances": a violent phenomenon, a temporal phenomenon and a diasporic phenomenon.

Violent Phenomenon

Elisabeth was from a Central African country and was pregnant with her second child. She had lived in the UK for close to a decade, and had permanent residency. Elisabeth had not disclosed her HIV status to her husband, who was from the same country, until she was heavily pregnant with their first child – who was born free of

HIV. She assumed that her husband would react violently. He initially responded quite well, Elisabeth explained. Shortly thereafter, however, her husband began to be extremely violent towards her. Fearing for her life, Elisabeth left him. She spent a year in a women's shelter with her child. She then reconciled with her husband, only to have to go back to the shelter a few years later. She suspected that he might have thought that he had accepted her status, only to become overwhelmed by the consequences of her HIV-positivity, and that these feelings instigated the abuse.

After the HIV-related death of one of Elisabeth's family members, who had lived in Africa, Elisabeth became aware that she was rumoured to be the next person in the family who would die "from AIDS". Elisabeth suspected that her husband had disclosed her HIV status to members of her family. After her first child was born, one of her relatives came to her house and accused her of having AIDS. Elisabeth explained that her relatives assumed that her child was positive as well. They told people to avoid the child and not to handle its belongings. For Elisabeth, this was the worst aspect of being HIV-positive, not being able to protect her child from the consequences of her infection. What worried Elisabeth the most was how to shield her children from the effects of this behaviour. Elisabeth did not think that her older child knew her status, and she was desperate for the child to remain ignorant of it. She believed that the knowledge of her status would be too much for the child to bear alone, and that the child would be tempted to confide in friends. She was worried that this would lead to the child's permanent exclusion and maltreatment.

In our synopsis of Elisabeth's narrative, serodiscordance emerges as a phenomenon in which (unborn) children, husband, family, stigma, HIV and disclosure are brought together in a highly violent manner. We argue that these components are intra-active; as such they are deeply related and mutually constitutive of the violence that serodiscordance *was* in Elizabeth's story. Elisabeth articulates the violence of the husband as being a consequence of the HIV virus in her body, not her husband's agency. As such, HIV was enacted as the cause of domestic violence. Moreover, the violence spread to her child as it got caught up in the violently stigmatising behaviour of the family.

Reminiscent of Barad's argument that matter and discourse are intimately related in the manner in which bodies come to matter, in this story there is a complex relation of "disconnect" between the materiality of HIV and its discursive articulation through disclosure; the materiality of HIV and the discursive meaning of HV are mutually constituted but they do not coincide. In other words, HIV and disclosure are cut together-apart (Barad 2012:46). The child was penalised as being HIV-positive, and marked by the stigma of AIDS that was enacted within the family, even though the child was born free of HIV. Because of the way in which HIV's discursive stigmatising reality was enacted by the family, a certain disconnect was established between the physical materiality of HIV and its social and discursive consequences. Consequently, the knowledge of HIV became something to be hidden from the child, as it constituted the condition of possibility for further disclosure and therefore additional violence. It is important to note that it was the disconnection between the materiality of HIV and its discursive reality that allowed the violence to escalate. If the materiality of HIV had been connected to its discursive stigmatising reality, the child would have been protected from maltreatment because it was born free of HIV.

Importantly, in this case disclosure was not contained within a sexual serodiscordant relationship, but spread to the larger family. As a result the violence not only impacted on Elisabeth, but also her child. Disclosure is understood as something the HIV-positive person has control over within a serodiscordant relationship, a truth of HIV that remains contained within the body of the one who discloses. However, this story shows that once HIV is spoken, and put into discourse, it can be used by other people as a way of controlling, or penalising the HIV-positive person and people connected to her. Neither the biomedical definition of a real of HIV to be discovered nor the legal protocol of disclosure are sufficient to grasp what is at stake in Elisabeth's story. Moreover, this biomedical definition and legal protocol inherently linked to serodiscordance encourage an event that may harm the patient and her (unborn) baby and are, as such, in tension with what good care would entail in the clinic.

Temporal Phenomenon

Celine: When we started a relationship I didn't know how to go about telling him you know, and then he started insisting that we should have sex without condom. I came round to the hospital, I explain it to the doctor, and one of the nurses, they said well if I can't tell him I should bring him round and they will look for a way to tell him … but at the end of the day it's my responsibility, so I got up enough courage and I told him and I was surprised he accepted me, he told me that 'Oh its fine, it's not the end of the world', he is going to provide me with as much support as I need. Even though, a few months down the line he used to use it to insult me, taunt me, you know, at one point he even told that he is going to call the police and to report me that I wanted to infect him with HIV and whatever. So I said to him; 'but it's strange you saying such a thing when you have *been* to the hospital with *me,* in the presence of the doctor you've said you were going to provide me with support, so if you go around and you start saying something like that; if it ends up going to court, I'm sure that doctor is going to come and say; "you said something like this"', you know! But later on he told me that it was just advice from friends.

Ulla: Why do you think? Do you believe that?

Celine: I don't know. I just believe he just wanted to hurt me. And he knew that saying that is definitely going to hurt me. But when he realized that, at the, at the point he realized that it doesn't hurt me anymore, he didn't, he never insulted me. Because when he used to insult me in the beginning, it used to be painful; I would cry, and cry, and cry, then after a while I said to myself; why should I keep doing this to myself? It's not worth it. So every time when he wants to insult me, I even told him, I say 'if you want I can tell all of your friends!' The day I told him that I am going to tell all of his friends he was shocked! He said I shouldn't. Now he's the one who wants to hide it. I said that 'I can tell every member of your family, I can tell all of your friends, it doesn't cost me anything at the end of the day; it is *me*! I'm the one who is sick!' So, so even now, he knows I don't care so he doesn't use it as an insult, anymore (Interview with Celine, 2008).

By re-appropriating the threat of disclosure of her HIV positivity, Celine, who was from a country in West Africa, was able to flip the power dynamics in her relationship. This re-negotiation was possible because Celine had disclosed her HIV positivity to her husband in accordance with legal strictures and allowed the process of disclosure to be validated and supervised by medical professionals. Consequently, Celine was able to invoke the medics as a proxy for the law. By deploying the practitioners in her defense against her husband's accusations, Celine was able to shift the power dynamics and reclaim control over her HIV. Following this, her husband's threat lost its power over time, because Celine had the backing of a more formidable entity, namely the clinic. This is radically different from the role disclosure played in serodiscordance as a violent phenomenon described above.

Serodiscordance is always about a negotiation between people, conceding to or rejecting various kinds of relationships and positions within those relationships. For example, one of the women interviewed had disclosed her serological status to a (former) partner, who in turn tested and revealed he was HIV-negative. Later the patient found out that he had lied and that he had been HIV-positive all along, although he refused directly to admit to being HIV-positive. Thus, the experiences of the effects of and *validity* of serodiscordance can be renegotiated and changed with time. They are not stable and they involve, amongst other things, negotiating partners' sexual expectations. Acceptance/rejection, responsibility, risk assessments, (legal/social) threats, social pressures, access and adherence to treatment and the (social/legal) support of medical practitioners – the ways in which these components intra-actively come together (or apart) constitute a materialisation of serodiscordance in which power dynamics can be renegotiated. More specifically, the manner in which serodiscordance is put into discourse (or not) and the effects this has, have the potential to change over time. This renegotiation signals the temporality of serodiscordance. Not only is serodiscordance a deeply relational phenomenon, the manner in which these relations are intra-acted are not stable over time.

Diasporic Phenomenon

> *Kessie:* *[H]e didn't leave me!* The reason why I'm not so angry with him is that he didn't abandon me in Africa; I would have been dead by now. But he brought me here and he stood beside me and he helped me and I thank God for that. Many, many girls like me has been abandoned like that, and they are dead! … He just couldn't leave me there, that's why he brought me here and I think he has given me a second chance of living; it would have killed me, but he let me live. So I don't get angry with him … Sometimes I get angry, but then I have to see it the other way, like he helped me. He gave me a second chance to live in life (Interview with Kessie, 2008).

In the extract above, Kessie, who was from a West African Country, discusses her feelings towards her first husband: a white British man. She started dating him in her country of origin, when she was a teenager. Kessie now knows that he was

HIV-positive when they commenced their relationship. Moreover, he never made any attempts to disclose his HIV status to her or "protect" her from HIV. But he facilitated Kessie's relocation to the UK and helped her acquire permanent residency. Kessie, her new (presumably HIV-negative) partner, their children and Kessie's extended family, were all financially entangled with the first husband. This should be thought of in relation to the fact that Kessie felt her first husband was the person who put her life at risk. However, as she explained, if he had not facilitated her relocation to the UK, she would have died. Consequently, even though she blamed her infection on this man, she also viewed him as the person who saved her from death.

Kessie's story is premised on two opposing positions, namely: that biomedical developments have enabled a decoupling of HIV from death; and that an HIV diagnosis is tantamount to a "prognosis of death" in some countries, because of the expense/unavailability of HIV treatments and care (Flowers et al. 2006:110). At the time of the interviews, the decoupling of HIV and death was at stake for Kessie. In her lived reality as an HIV-positive woman, she simultaneously negotiated what she thought the effects of HIV would be if she were in her country of origin. That knowledge complicated Kessie's feelings of anger towards her first husband for knowingly exposing her to HIV. Thus, she acknowledged that he took advantage of her, while being simultaneously grateful that he had extended his privilege (access to biomedical technologies and care through citizenship) to her. Interestingly, and problematically, the criminalisation of HIV infection is absent here. Hence, while Kessie had a legal responsibility to inform her current partner of her HIV status, she had not been afforded the same protection during her previous relationship. This is because UK law could not *protect* Kessie when she commenced a sexual relationship with her first husband outside of the UK. And by the time Kessie did find out that he had exposed her to HIV, she was financially dependent on him, and could therefore not seek restitution, had she wanted to. Here too we see a certain temporality to serodiscordance, an entanglement of past/present/future that the criminalisation of HIV transmission and its sole focus on the HIV-positive person's responsibility for another's future occludes. As such, the past/present of the HIV positive person escapes legality and its assumed protective function.

The interview extract brings to mind Flowers and colleagues' argument that even in geographical locations where treatments and care are available, the meanings of an HIV diagnosis are variable. This, they argue, is because of the risk of deportation that many HIV-positive immigrants constantly live with and the complications that may arise from living with a chronic long term illness (Flowers et al. 2006:118). These observations are important, as they ask us to pay attention to the ways in which the circumstances of people living with HIV in the same geographical locations can vary drastically, depending on – as in Flowers and colleagues' example – the ways in which resources and privileges (permanent residency and citizenship) are allocated or denied. This directly impacts on how serodiscordant relationships are negotiated.

Women located within the HIV diaspora who disclose their HIV status to their sexual partner(s) do more than fulfill a legal and moral obligation in negotiating their serodiscordant relationships. Instead, the practice of disclosure has the potential to forever subject the women and their children to the consequences of HIV in multiple geographical locations. Thus, in fulfilling a UK-specific requirement to disclose, the women will (potentially) be subjected to effects of HIV from places outside of the UK. Hence, the components of the HIV that are disclosed are connected to (unknown) components elsewhere, in places where HIV may be something very different than it is and has the potential to be in the UK. This in turn changes the effects of the serological status of both the patient and her partner and the manner in which their serodiscordance can be negotiated. Again we see that serodiscordance does not only concern the relationships between patients and their sexual partners. Instead serodiscordance concerns all of the people who are, have been or may be in the geographical spaces wherein serodiscordance emerges. To return to Barad's language, the clinic as an apparatus of bodily production exists in relation to a wider geopolitical positionality, in that the bodies that are produced and the serodiscordant relationships they are in will be intensely affected by their location within the HIV diaspora.

The point of stating that serodiscordance is multiple is not to say that it is fragmented. Regardless of its multiplicity, it is a composite "entity". We argue that it is in light of the HIV diaspora specifically, that the explicit relations between the various composites of serodiscordance become visible. At the time of the interviews, the violence women and their dependents were subjected to and compelled to justify was related to the practices of care that were available in the UK and the decoupling of life and death that ART afforded.

Importantly, we argue that while domestic violence can be part of serodiscordance as a violent phenomenon, domestic violence is always overshadowed by the violence that constitutes the HIV diaspora, and the temporality of life and death for women incorporated in it. Thus, the HIV diaspora is intimately connected to each of the serodiscordances we have explored. What these serodiscordances are, the effects they have within and on the bodies/lives/futures of women who are part of the HIV diaspora, and everyone connected to them, are entirely constituted within the inequalities the diaspora constitutes.

While significant progress has been made in relation to universal access to ART in many African countries since these interviews took place (Joint United Nations Programme on HIV/AIDS [UNAIDS] 2012:9), the kind of care, interventions, (bio) medicines and technologies that were available in the antenatal clinic in the UK, are still not accessible for the vast majority of HIV-positive women in sub-Saharan Africa. This becomes clear when considering the difficulties in eliminating vertical transmission of HIV (de Wit et al. 2011:385; UNAIDS 2012:43). Therefore, while there is a temporal element to our data, our arguments are still highly relevant.

Conclusion

> [T]o recognize that HIV is a phenomenon affected by the process of its identification does not take away from its palpable presence, its insistence as a force to be contested. Nor does this recognition take away from the ability of medical science to intervene – although not

> as directly or neatly as it may be anticipated – in the biological substance of its imaginary. But it does highlight the performative nature of science and how science achieves more than is usually assumed. To put it another way, a performative account of the materialization of matter makes apparent the contributory work of science *in* the substance of its study (Rosengarten 2009:32).

The prevention of vertical transmission of HIV is indeed effective, when access to good care and appropriate biomedical technologies and medicines are available (CDC 2012). Consequently, the provision of good care is the modus operandi in the specialist antenatal clinic. However, the provision of care is negotiated amidst myriad complexities that beg for a negotiation of relationality. We have argued that this is exactly what happens in the clinic. However, the understanding of HIV and serodiscordance provided by biomedicine and put forward by legal protocol is in serious tension to the aforementioned relationality and the painstaking work the practitioners in the clinic undertake. This tension has direct consequences for good care to be provided in the clinic, as it impacts both on the patient and the (unborn) baby, and its chances of being born free of HIV.

Thinking of serodiscordance through an agential realist lens has three main advantages. Firstly, agential realism highlights the intimate relations between discourse and materiality. Importantly, as apparatuses are material-discursive, the manner in which serodiscordance is done in the clinic does not only contain the manner in which its materiality is measured and negotiated; it also includes the meanings it is given, the manner in which it is spoken and/or silenced. In the clinic, the materiality of serodiscordance is intimately related to specific discursive practices: in this chapter we were concerned with how serodiscordance exists *as* disclosure in the clinic and as such constitutes a material-discursive phenomenon. Thus, from the practitioners' perspectives, disclosure was a *threshold* from the materiality of the virus to the social discursiveness of HIV their patients had a (legal) responsibility to traverse. The establishment of serodiscordance as a material-discursive and temporal phenomenon emerged from this moment of passage. The inclusion of the discursive establishment of HIV into the materiality of HIV provided by biomedicine allows for a more encompassing and multiple notion of serodiscordance – indeed, more in line with the complexity of care that is provided in the clinic, patient by patient. The conceptualisation of serodiscordance we are proposing could then replace the deceptively straightforward definition of the term provided at the beginning of this chapter.

Secondly, agential realism highlights the imagination that is at the heart of the biomedical real. From the practitioners' perspectives, serodiscordance (as disclosure) entails that a patient communicates a biomedical "truth" to a sexual partner. This "truth" is provided by a biomedical discovery of virus through various measuring techniques. Within agential realism, this truth is not discovered by these techniques, but constructed by them. This is in line with Marsha Rosengarten's use of agential realism to make visible the generative effects of biomedical practices, interventions and imaginaries on its object of intervention – HIV (2009). The constant possibility of serodiscordance, its suspension into the future, indeed reveals a certain imaginary at the heart of serodiscordance in the clinic. Therefore, while the process of establishing that a patient is in a serodiscordant relationship might initially appear to be simply about acquiring and coordinating information, it is also about different understandings of HIV and how these different understandings are part of serodiscordance in the clinic. On a practical basis, the generative effects of establishing serodiscordance were imagined by the practitioners as having the potential to both harm and protect their patients and people connected to them. Thus, the successful provision of good care in the clinic demanded that the practitioners were able to anticipate and negotiate the possible materializations of these generative effects.

Thirdly, and most importantly, agential realism enables an articulation of serodiscordance as deeply relational. The antenatal clinic becomes a space of intraaction between the various components that make up "serodiscordance" which are temporarily determined in specific ways. This articulation of relationality is significant, because "relationality" is precisely what practitioners engage with in the clinic, by negotiating the women's relations to their partners, families, their unborn baby, ART and HIV. (The possibility of) serodiscordance in the clinic extends beyond the couple and encompasses other wives, their children, the legal connections between these fleshy relationships, the de-coupling of HIV and death in some geographical locations but not others, (the threat of) violence, disclosure and its possible consequences, access to HIV care and treatment, relationships between patients and medical practitioners, and practitioners' moral and legal obligations to everything and everyone involved. While this complexity is not easy to negotiate in practice, we argued that the practitioners in the clinic enact this complexity, although they would not articulate it as such. Agential realism enables such an articulation of complexity and allows serodiscordance as disclosure to be an inherent part of the clinic's prime purpose: preventing vertical transmission and providing good care to the patient and her (unborn) baby, instead of disrupting this purpose by foregrounding legal protocol and the threat of violence that may result from a focus on disclosure while neglecting the (temporal) web of relations in which this occurs.

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Part II
Stigma, Culture & Gender: Contextualising Serodiscordance

Conversations with an African-American Woman and an Indian Woman

Sunshine After the Rain & Red Reminds Me

Stacy Jennings

Sunshine After the Rain: A Conversation with Stacy Jennings

How and when did you meet your HIV-negative partner?
About two years ago, I was ending a relationship with an HIV-positive man. The relationship was going downhill rapidly and I was very unhappy. I'd been HIV-positive for a long time and had no problem taking my antiretroviral medication—I've been undetectable for nine years! But I wanted to start taking care of myself in other ways, too. Then, while involved in an exercise program, I met the love of my life—I'll call him Mr. Smith (a pseudonym). He was my knight in shining armour—and still is, even though we have our ups and downs.

When did you decide to disclose your status? How did you decide?
After meeting Mr. Smith things happened so quickly. I met him in May 2013 and he was open and honest right from the start, including about his previous substance abuse problems. We went to church together, and I sensed he was different from other partners who had passed through my life. Still, I wasn't sure where the relationship was headed, and when things heated up between us physically, I wasn't ready to disclose my status to him—my plan was to protect him by using condoms. When I mentioned condoms, though, he refused. I almost stopped breathing—'What now?' I thought. In the heat of the moment, I couldn't find a way to tell him. I fell back on thoughts of my undetectable viral load and trusted it would be ok. This happened a couple times: I kept telling him to use a condom, but he kept refusing.

It was only a few weeks after we became intimate that Mr. Smith relapsed on drugs. You might think I would take this as a sign to end the relationship, but I'd already fallen for his kindness and commitment. I stuck by him, and through two

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very intense weeks, our bond was strengthened. We had serious conversations about the future, and I felt like I had to tell him about my HIV status, even though I just knew he would leave me.

I grabbed the opportunity the next time he wanted to have sex with me. I told him that I had to tell him something first. He thought I was going to tell him that I had decided to get back with my ex; little did he know I was going to share with him something that could change his life. Upon sharing my status with him, Mr. Smith was very angry and I don't blame him. He told me he was through with me and wanted to know how I could have done that to him. He wouldn't talk and turned his back on me, but didn't leave.

I must have fallen asleep, because I woke to him staring at me and "admiring my beauty", so he said. He said he hadn't slept, but had prayed on things. He said he admired me for my strength in telling him because most women would not have done so. He then stated that I could have kept my status a secret because he would have never known. We talked it through and decided to try to go forward. Oh! And by the way, we ended up having sex after all.

Did your disclosure or does your mixed status bring up any special needs, issues, conflicts, or challenges that the two of you had to confront or are still dealing with?

No, not between the two of us, but other people have reacted to my status in ways that brought tragedy into our lives. We both have grown children, and very early in our relationship we'd discussed wanting to have a child together. Around the time of my disclosure, even though I'd been told I couldn't have any more babies, and it had been 20 years since I'd had a child, I found out I was pregnant. We both were excited.

Mr. Smith had a lot of questions, especially about the possibility of him contracting the virus from me, and if it would be possible for us to have a child that was HIV-negative. I did a lot of educating about my status and what "undetectable" means. I explained that the chance of him contracting the virus from me was slim to none. He felt a little better after hearing that, which I felt was rare, because most men would not be so understanding. Mr. Smith relapsed on drugs a few times during the pregnancy, which made me think I might be better off leaving him. Then I thought about how he had been, and still is, there for me and I decided to stand with him through it all.

Our baby boy, whom we called KJ, was born early, in March of 2014. I needed a C-section, which was delayed for hours. Our son passed away that same day. Because a court case is pending, I won't go into all the details, but I believe (after a lot of research) that discrimination based on my HIV status and a series of medical errors led to his death. His life was ripped away from us due to *stigma*. We are still dealing with it.

What role does treatment play in your relationship? That is, what emotional/social/sexual impact does it have, if any?

Treatment plays a huge role in our relationship because I take extremely good care of myself. Mr. Smith tells me all the time that he admires how well I take care of myself. We even talk about getting pregnant again someday. Emotionally I don't think I'm quite ready and he gets angry at the disease and blames the disease for taking our son's life. As far as for our social and sexual lives, let's just say that it is "off the chain." I really love this man and I know that he loves me. The one thing I like the most is that he supports me in everything and he is not ashamed to meet my other HIV-positive friends. He really fits in like family. They love him and he loves them back.

How do you and your partner think about HIV and your mixed status nowadays?

I've decided that, for me, HIV stands for ***H**eaven **i**s **I**n my **V**iew.* This reminds me daily that that I have a lot to live for. I strive to live for my son KJ. I strive to fight for him every day, so that no other woman has to experience what I had to experience. We live for peace, love and unity, and our son's death has allowed us to grow stronger for one another. We admire the fact that we are different and believe wholeheartedly that opposites attract. I believe that me being positive and him being negative makes us great for each other. He's the Yin to my Yang. He's caring, spiritual, and of course the man after my own heart. Mr. Smith doesn't care about my HIV; what he does acknowledge is the fact that I am still human.

What's something that might surprise people who have never been in a mixed-status relationship?

Something I feel may surprise people is that it doesn't bother him to not use a condom, and that he's not afraid of me. Mr. Smith has said, "God has not given me the spirit of fear." He enjoys being intimate with me and accepts me just as I am; that's what makes us click. He's learned a lot about this disease called HIV, and also sees first-hand that it's manageable—I'm the living proof.

Based on your experience, are there differences between mixed status vs. seroconcordant (the same status, whether positive or negative) relationships?

As I mentioned, I had an HIV-positive partner before. But as far as the differences are concerned, I feel they come from my ex's and Mr. Smith's personalities. Relationships are relationships. I feel that, if there's an understanding on both parts, whether the relationship consists of two positives, one positive and one negative, or two negatives, there must be open communication, an understanding, and education. I feel that the most important thing when it comes to relationships and HIV is that both persons should know their status, get and stay in treatment if they need it, and still maintain the option to use condoms and other forms of protection.

The term "HIV serodiscordant" most often gets used to refer strictly to a relationship between two intimate partners with different statuses. Is this term useful to you? Is it relevant to your relationship? Are there other areas of your life where mixed statuses become important?
My mate loves and accepts me with or without my HIV. When we as a society start placing labels on statuses, it can get out of hand; people think they understand but they don't really. I am human and my status has nothing to do with it. I can't say that the term "serodiscordance" is useful to me, but it does pertain to my relationship status. I don't use the term. I've never used the term, and even though it pertains to my relationship, that doesn't change who I am and how we live our lives. There are indeed other areas in my life, as well as in all of our lives, when it comes to mixed statuses. For instance, I work, own my home and my mate lives with me, but he does not work right now because he receives disability insurance. Once again, that makes for our "statuses" to be of mixed entities, but still, just because our HIV statuses are different, and our statuses in society are different, we still strive to be there for one another where the other lacks. Where I am weak, he is strong and vice versa.

Red Reminds Me

Red reminds me of 19 years ago,
October 17, 1995
After receiving a devastating
diagnosis of HIV
Of wanting to end my life
Of hating I was me
Red reminds me
Of a whole lot of pain
It reminds me of agony
Of a life now slain
Red reminded me to give up hope
Red broke me down
And took away my ability to cope
Red reminded me to cover my face,
in shame, to run away and hide
To keep others from slandering my name
Red reminded me to turn and walk
away, to waddle in my misery for
yet another day

But now Red reminds Me
That I must stand strong, to bring
down stigma, in order to get along
Red now reminds me to HOPE,

TRUST, and have FAITH
That I must Fully Allow It To Happen
And Hold On Peacefully through
Each and Every day

Red reminds me that everything is
going to be alright
That I must not lose focus,
That I must hold on with all my might
Red reminds me,
That even though STIGMA robbed me of my son K.J.
Red Reminds Me to hold on anyway.
Red Reminds Me!!
Red Reminds Me!!
Red Reminds Me!!

Be the Change You Want to See

Jyoti Dhawale-Surve

Tell us a little about yourself
I'm 40 years old and live with my husband in Mumbai. I was diagnosed with HIV in 2005 when I was pregnant. In India, being HIV-positive is very stigmatised and is linked to either sex workers or injecting drug users. Even though other sources of transmission are known, such as mother-to-child transmission and blood donations, most people don't know that you can contract HIV through medical negligence, as happened in my case. When you tell people, they look at you with doubt and disbelief, no matter how hard you try telling them. They won't believe you until you furnish a proof. Thankfully I did have some proofs that helped me convince those I cared about that I had contracted the virus during a blood transfusion in relation to one of several abortions my ex-husband forced me to have.

How and when did you meet your HIV-negative partner?
We knew each other via Yahoo Chat. Then we met face to face after six months, on the day my father died. My best friend was in Dubai, so the man who was later to become my husband was my only emotional support around that time. It was him I could look to at that very difficult time.

When did you decide to disclose your status? How did you decide?
I didn't think it was necessary for him to know my status at the beginning of our friendship. We were just friends, so what has my illness got to do with us being friends? And I didn't need any pity or sympathy, so for four months I didn't tell him. But later, when I found that we were falling for each other, it was during that time I had the responsibility to disclose – because he should know that the woman he is thinking of spending his future with is HIV-positive.

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How did your partner react? How has his feeling about it evolved over time?
Initially it was both a shock and surprise for him. It took him some time to adjust to the news and fact that I was HIV-positive. He disappeared from my life for three months. Smallest of things bothered him, like an itch or a cough or even a headache; minor issues. He thought he must have contracted the virus as he compared each and every symptom to those listed on Google. We had hugged. And we had French-kissed. We had shared food from one plate, and we even used to drink from the same glass. And for those who are ignorant about HIV, all of those practices can seem as though they might potentially transmit HIV.

That's how most people in India think: even if a drop of blood from an HIV-positive person falls on another person, even without an open wound or anything, they would be mighty scared and would think that they will get HIV from it. No one would come and touch the person with HIV or help them apply an ointment or tie a bandage. Such are the fears and misconceptions that revolve around HIV.

Although he didn't meet with me during those three months, he used to text me, saying he didn't want to die. I had to keep my patience and educate him that hugging, kissing and sharing food or liquids don't cause HIV. He came back in my life after three months only because of love and the special bonding that we shared. After two years of dating and courtship, we got married.

Does your mixed HIV status bring up any special needs, issues, or challenges that the two of you have to confront or deal with?
He adjusted to my needs very well. I am usually not an early riser. Most of the time, I rarely cook. And I tend to sleep a lot because I easily get tired. He understood all these needs and never pushed me about anything. These needs are probably not only related to being HIV-positive, but also to lifestyle and personality. There are days when I work all the time, which makes me feel tired and drained the next day. It could possibly also be the HIV medicine at play. Sometimes the medicine makes me feel tired, at times sleepy depending on the day, time, place and activities. But a short catnap can recharge the energy level to the fullest and I'm raring to go again!

My husband is very supportive and even remembers my medicine dosing-time and reminds me about it. Even if I've already had my medication, he never fails to ask me if I have taken it. Although he wanted a child, he understood that I'm not capable of raising a child. So he never complained and accepted me wholeheartedly. After three forced abortions and a one delivery, my child was taken away by my ex. I still haven't come out of the trauma. Hence, I don't want to be pregnant again. I already have a child whom I'm yearning for. I want to fight for the rights of my own child, for his custody or visit. I don't know if my ex took him away because he was born a boy. There is a cultural difference between the birth of a male child and female child in India. Male children are mostly preferred by a husband's families to carry on their name, while female children are considered "other's property" to be given away. Sometimes I used to think; what if my child had been a girl? Would he have taken her after divorcing me? Or would he have left her under my care?

What role does treatment play in your relationship? What emotional, social or sexual impact does it have?
For us, we know that it is just a virus that needs to be kept under control with proper care and medication. Just like a diabetic person taking insulin shots to keep blood sugar under control. It's not at all hard – just pop a pill (ART medicine) and go about your daily life.

Strict adherence to medication and half-yearly lab tests helps to monitor my health and keep the virus at bay. My CD4 count is high, over 800, and my viral load is undetectable. Which means I'm as good as any other person. Healthy eating and daily exercising helps to keep my body fit. I try to stay away from negativities as it impacts my CD4 count. Stress is not good for health. I listen to music, which is my stress-reducer and read books that help me feel more relaxed. Sometimes we go for a holiday and it brings us even closer. All this enables me to have a healthy sexual relationship with him and once in blue moon even without a condom. Having condomless sex is entirely a couple's own decision provided that their CD4 is of a good level (more than 600) and the viral load is undetectable. Since I am educated about HIV in-depth, I know the dos and don'ts and when to have condomless sex. I wouldn't advise this to others who are *not* well-versed in HIV. But since I know when and how to practice it, my husband and I are very much comfortable with it and it is a kind of trust and bonding we share.

How do you and your partner think about HIV and your mixed status nowadays?
We are used to getting queries and surprised looks from people when they discover our mixed HIV status. As I mentioned, people with HIV are heavily stigmatized and discriminated against in India. As a couple, we try to be a "role model" for them, because we live, preach and teach by example – by showing our faces and talking about our life – and in that way we educate the general public regarding HIV.

What's something that might surprise people who have never been in a mixed-status relationship?
A person with HIV getting married to someone who is not HIV-positive, having sex, having a baby – all these things surprise people. We are often asked how it is possible that the virus isn't transmitted, or how I appear to look so healthy when, in their mindset, an "HIV person" is supposed to look thin, frail, weak. In India, when it comes to HIV, it is a big hush-hush topic. Many NGOs are trying to change this by educating people. But it's difficult, because in my country people don't talk about themselves openly, especially about their sex life.

You and your partner are very open and public about your relationship, which makes you different from other serodiscordant couples in India. Tell us why you decided to live that way?
Because India is very conservative and orthodox when it comes to HIV and that needs to change. Except for Mumbai, in most areas, especially in rural areas, HIV is considered a "taboo" topic. Women from villages and town-sides are married off

to men by their families, without even knowing their husband's HIV status. In rural areas, if the husband dies, the wife and her children are ostracized by society when they come to know of her HIV status. People think of her as a "characterless" woman. Even her husband's family would throw her out of their matrimonial home just to save their face and prestige in society, despite knowing the fact that their son was HIV-positive and passed the virus onto his wife, who might in turn have transmitted it to her kids during childbirth. In villages, childbirth mostly happens through normal delivery under supervision of the village's midwife. Those who can afford hospital care would get to know their status instantly, as nowadays HIV testing is compulsory in every hospital before going in for delivery, and some could prevent transmission if they could adhere to the medicines that are provided to them. Government hospitals do give free medication, but it isn't easy for the patients, especially those in villages who have to travel miles to collect it. Most of the people aren't even aware of how important adherence is.

The government has done well in trying to educate certain sectors regarding HIV; how it is contracted and how people can protect themselves. But not enough emphasis has been given to teaching people with HIV to understand their treatment or lab reports, adherence, resistance and even PEP or PrEP, which is unheard of by most people. Only doctors know about it. Isn't this an irony; that many lives would have been saved if deeper understanding of HIV had been shared with the population to prevent stigma and discrimination and to let them know that HIV can be kept under control and that it's no longer a "death sentence" as they used to believe?

Therefore, my husband and I beat our drums for this cause – by showing our faces and being the "real-life example". We even encourage others to come out of their closet and share their stories. We need more and more people to come out to fight for the cause and to change the mindset of society – by talking and sharing. For sharing is caring, and knowledge is power! Thus, to share knowledge can illuminate much darkness. Just like our names; my name Jyoti means "ray of light". And my husband's name is Vivek, which means "wisdom" or "knowledge", in Hindi.

Intimacy, Support and Social Connectivity: Experiences of HIV Serodiscordant Relationships Among Black African People Living in England

Adam Bourne, John Owuor, and Catherine Dodds

Introduction

In England and Wales, recent census data show that 3.3 % of the total population describe themselves as Black African, or use a similar term to indicate African descent (Office for National Statistics 2012). Further data from Public Health England (Yin et al. 2014) indicate that this group is disproportionately affected by HIV, with more than 26,000 Black African people having been diagnosed with HIV infection, and an estimated further 13,000 who remain undiagnosed. Those involved in regular sexual partnerships where one partner has diagnosed HIV and the other does not (serodiscordance) had previously been considered at a higher risk of involvement in HIV transmission, however emerging evidence (Rodger et al. 2014) indicates that HIV treatment and viral suppression may limit the likelihood of this occurring. Regardless, individuals within, or connected to, serodiscordant relationships can face significant psychological and social challenges, often arising as a result of continuing HIV related stigma (Weatherburn et al. 2009) as well as ongoing concerns about HIV transmission and acquisition.

In this chapter, we present data arising from a qualitative study undertaken in 2012 among Black African people with HIV and their sexual partners without diagnosed HIV, regarding some key elements that contribute to (and detract from) wellbeing and intimacy. While focusing on the serodiscordant couple, we are also attentive to how intimacy is experienced in a range of other social relationships that link to, influence or support these dyads.

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Conceptualising Intimacy

In everyday terminology, intimacy may be taken to only refer to sexual relationships between people or, alternatively, may refer to a "deep knowing" between people that brings them into a particular closeness (Giddens 2013). In the late twentieth century, leading Western social theorists pursued the question of modern intimacy by primarily using either the romantic couple, or the nuclear family as their central unit of analysis (Giddens 2013[1992]; Bauman 2003; Beck and Beck-Gernsheim 1995). These works argue that love and intimacy arise as key aspects of late modernity as individuals are forced to respond to changing social environments that have deprioritised kinship and community bonds. In the face of disconnection and risk, they argue, people now seek connection through romantic and sexual intimacy, and by extension within the nuclear family unit.

These theories of intimacy have been critiqued by those who, for example, point to the alternative intimacies constructed by members of LGBT communities in response to heteronormativity (Roseneil et al. 2013; Weeks et al. 2001; Roseneil and Budgeon 2004). In addition, writers such as Jamieson (2011) point out that heavily individualised conceptualisations of intimacy are culturally bound, and that across many eras and in many places still today, understanding "intimacy" requires situating relationships within their cultural and material circumstances. Instead of valorising what is often considered the virtue of "high romance" in modern Western cultures, these authors argue that a century of social science has silenced and "othered" a range of intimate practices that deserve consideration.

Furthermore, Rhodes and Cusick (2000) have examined how love and intimacy were bound up with risk management for people who injected drugs in serodiscordant partnerships. They found that couples continually managed risks, and that this included negotiating a balance between those that existed within and outside of their partnership. How HIV was conceptualised by each individual played a crucial role in this balancing act, and couples' understandings and practices relating to intimacy and risk were likely to change over time. Rhodes and Cusick's work features those outside of the HIV serodiscordant couple, as well as within it, and this expansive consideration of intimacy is central to our findings discussed here. In a similar vein, Obermeyer and colleagues (2011) describe how individuals living with diagnosed HIV, and their family members, selectively conceal their status from their social contacts to avoid the risk of stigmatisation. Such decisions may be based on either previous negative personal experiences or anecdotal evidence of their peers' experiences.

Acknowledging these multifaceted conceptions and manifestations of the balancing acts of intimacy in everyday life, this chapter examines notions of intimacy among people from black African communities in the UK who are in serodiscordant relationships. We explore how intimacy evolves or develops within and outside of HIV serodiscordant sexual relationships following HIV diagnosis or disclosure. In light of the literatures referenced above, we allow for a pluralistic examination of relational intimacies in context and examine the construct of intimacy at various levels of romantic and social interaction. In doing so, we seek to expand the traditional conception of serodiscordance framed as operating only at the level of the couple. We do so by illustrating serodiscordance as it is perceived or experienced through broader social relations that might have been considered intimate prior to the HIV diagnosis or the disclosure of HIV, but that have since had to be renegotiated or reconsidered. In this way, we are not only interested in examining HIV serodiscordance between two people in a primary sexual relationship, but also the HIV serodiscordance that is experienced between that couple and those in their immediate, intimate circles.

Methods

This chapter draws on data collected as part of the *Plus One* study, conducted in 2012, which explored HIV serodiscordant relationships among black African people living in England (Bourne et al. 2012). Sixty people (39 women; 21 men) who had experience of being in a relationship where one person had HIV and the other did not participated in in-depth interviews. Of these, 44 were HIV-positive and 16 were HIV-negative or untested. In order to be eligible to participate, individuals had to: be over 18 years of age; be in a relationship where one person had diagnosed HIV and the other did not *or* have been in such a relationship within the previous year; self-describe as black African (or use a similar term to describe their ethnicity) *or* be an HIV negative/untested primary sexual partner of a black African person with HIV. It was not a requirement that both partners in a relationship took part, but four such couples (i.e. eight participants) volunteered to do so and were interviewed separately by different interviewers. This sampling approach allowed us to speak to people who had experience of being in a serodiscordant relationship that had ended as well as those that were ongoing. The demographic characteristics of participants are displayed in Table 1.

Participants were recruited by HIV community-based organisations (CBOs) in areas of England with a high prevalence of HIV among black African people (Public Health England 2014). Staff or volunteers at the CBOs made an initial approach to eligible participants to explain the study. Those who were interested in taking part were asked to contact the lead author for further discussion of the research and to arrange a convenient time for the interview. These took place either in the offices of the collaborating organisations or in private rooms at municipal facilities. Participants' confidentiality was assured and all were reimbursed travel expenses of £20. The interviews explored: issues surrounding HIV status disclosure (or lack thereof) to partners, family and friends; the broad impact of HIV on the relationship; sexual behaviour; understanding of HIV treatments, viral load and infectiousness.

While authors AB and CD conducted a small number of the interviews, the majority were conducted by a team of trained and closely supported peer educators from the black African communities, including author JO. These interviewers were

Table 1 Participant demographic characteristics

Age		**Gender**	**N**	**Relationship status**	**N**
Mean	40	Male	21	Currently in SD[a] relationship	52
Range	22-58	Female	39	No longer in SD relationship	8
Country of origin	**N**	**Area of residence**		**HIV status by gender**	**N**
Zimbabwe	20	London	27	Female with diagnosed HIV	32
Uganda	9	Leeds/Bradford	20	Male with diagnosed HIV	12
Nigeria	7	Nottingham	4	Negative or untested female	7
Zambia	6	Huddersfield	4	Negative or untested male	9
Other African nation[b]	17	Others	5		
European nation	1				
Education	**N**	**Time in relationship**		**Time living in the UK**	
Primary/elementary	4	Median	3 years	Median	11.3 years
Secondary/high school	27	Range	1 month–12 years	Range	2–55 years
University/college	29				
Ethnicity	**N**	**Employment status**	**N**	**Immigration status**	**N**
Black African	54	Full-time employment	11	Indefinite leave to remain	18
Black African- British	3	Part-time employment	8	Asylum seeker	16
Mixed African Arab	1	Voluntary work only	10	British nationality	11
White European	1	Education or training	5	Compassionate/exceptional leave to remain	3
Other	1	Carer/homemaker	3	Student	3
		Casual/cash-in-hand	1	Citizen of other EU country	1
		Not in education, employment or training	22	Visitor	1
				Don't know	2
				Other	5

[a] Serodiscordant

[b] Other African nations included Malawi, Kenya, Democratic Republic of Congo, Sierra Leone, South Africa, Somalia, Liberia, Angola and Rwanda

recruited via HIV CBOs and were often existing staff or volunteers of these organisations. Participants were given the choice of having a male or female interviewer. Interviews were digitally recorded, transcribed verbatim and subject to a thematic analysis (Braun and Clarke 2006). Quotes, shown in *italics*, are followed by the gender and HIV status of the participant. Ethical approval for the study was granted by the Faculty of Humanities and Social Sciences Research Ethics Committee at the University of Portsmouth (the host institution at the time of data collection).

Results

Within this section we explore three main themes that emerged relating to the broad domain of intimacy and relational wellbeing. The first theme focuses on intimacy between serodiscordant couples and how communication about HIV-positive status influenced the development or maintenance of such intimacy. The second theme examines the notion of intimacy within the wider family and other social relationships, including how communication about HIV status by the interacting parties within the wider social network informed their resultant experience of intimacy. Finally, we examine interviewees' perceptions of the viability of serodiscordant relationships and their potential for longevity.

Overall, the findings must be interpreted as a product of transnational context—that is, with awareness that interviewees simultaneously occupied two different sociocultural worlds, and negotiated intimacy and wellbeing with reference to their host society as well as their countries of origin. Participants' understandings of romantic relationships, social relationships, "family" and "community" were influenced by their experiences of the dominant models in both their countries of origin and in England. Additionally, these HIV positive individuals were living with HIV stigma layered onto other stigmatized attributes arising mainly from their immigration status, lower socioeconomic status and minority ethnicity in their host society, making them liable to perceived "outsider status or tainted identity" (Goffman 1963). Managing that tainted identity to reduce its impact on their relational dynamics in the UK and in their countries of origin thus influenced their experiences of intimacy within romantic relationships and beyond.

Intimacy Within Serodiscordant Couples: Disclosure, Communication and Negotiation

Communication of an HIV diagnosis to a romantic partner was a carefully considered act, evaluated in terms of its merits and potential impacts on relational intimacy and the wellbeing of the relationship more broadly. The most commonly cited rationale for HIV disclosure in this context was the desire to be honest with one's partner. Hiding one's status was often considered deceitful, which added to the emotional burden the interviewees described as resulting from their positive HIV diagnosis. Some participants considered disclosure to a partner as soon as possible to be a responsible act not only because it could help in the negotiation of safer sex, but also help to ensure they were in a relationship with someone who was willing to deal with the realities of HIV.

> I disclosed my status to him early on because I loved him so much and couldn't be free knowing that I was carrying such a secret. I had to tell him to know if he really wanted to be with me. (Woman with diagnosed HIV)

The above extract illustrates how secret-keeping was perceived by the participant as a significant burden, from which freedom was obtained through disclosure. The absence of secrecy was regarded as vital in developing or maintaining a close relationship. However, while many participants articulated positive possible consequences of HIV status disclosure, nine of the HIV-positive participants said they had not revealed their illness to their partners. Their reasons were often complex and multifaceted but typically related to a fear of rejection or stigmatisation, or fear of losing partner support and ensuing loneliness.

> It's a big challenge to say to somebody that you are HIV-positive … Because the African community, most of the people have that negative attitude on you when you are HIV-positive. They just think that maybe you have been careless, maybe me as a woman I have been a prostitute or whatever, that's how I got the disease. (Woman with diagnosed HIV)

On the opposite side of the HIV disclosure equation, immediate responses from partners following disclosure were often confused, complex and contradictory. They were also shaped by the longevity of the relationship and the broader social or economic circumstances of the couple. The most "fortunate" HIV-positive participants were met with a supportive reaction and a commitment to explore the meaning of the diagnosis (or disclosure) in a constructive fashion. While startled, several HIV-negative or untested participants emphasised that their primary concern had been for their partner's well-being.

> We treat each other the same. Even when she told me. We still treat each other the same you know. […] I love her because she was upfront [about her HIV status] … she's a lovely person; you know, she's loving, she can cook, she's a real woman [laughs]. I love her ever since, no matter what she got. I just care that she okay. (Man whose last test was negative)

Such responses, however, were not in the majority. Most participants with diagnosed HIV experienced more negative, or even hostile reactions at the point of disclosure, which had long term consequences for intimacy within existing and future relationships. HIV-positive participants often felt that such reactions were shaped by conceptions of people with HIV as promiscuous and highly infectious and a perception of HIV as a terminal disease. These reactions often exacerbated internalised feelings of shame experienced by some participants.

> 'I can't go out with someone who's sick, no, I can't be seen with someone who is' […] Yeah, that's what he said, he said, I asked him, 'Are you comfortable going out with someone who's HIV positive?' He's like, 'No, why would I?' (Woman with diagnosed HIV)

However, with time and regular, in-depth conversation about HIV treatments and prognosis, some romantic partners were able to shift their understanding and acceptance of the person with diagnosed HIV.

> I think relationships can work whether with a negative partner or a positive partner. Both can work […] it's based on keeping the conversation going and the interest of the other partner as well, if the partner is really interested in the condition then they will be able to know how to react to different situations that the positive partner will be going through. (Woman whose last test was negative)

However, communication about HIV was loaded and appeared to require careful management. A fear of hostile reactions – or fear of re-introducing a topic that had caused hostility in the past – meant that some avoided active discussion of HIV within their romantic relationship altogether. Others felt it important not to discuss HIV too much lest they afford it undue prominence within the relationship or simply felt that, with time, other factors in life took priority for discussion. These options were described as mechanisms for preserving a damaged and fragile intimacy.

> It was difficult the first days but now he is normal to me. I am just being my normal self. If he say yes [he loves me], he says yes, if he says no he says no, because I've decided if I put [emphasis on] this [HIV], it will be like a third person in this relationship. (Woman whose last test was negative)

The challenges for the nine participants with diagnosed HIV who had not told their current sexual partners were different. They aspired to the same sense of intimacy (through bonds of trust) as those who had disclosed, but were confronted by feelings of dishonesty as well as greater complexities in negotiating safer sex, such as struggling to explain why they still wanted to use condoms within longer term relationships.

> She is always putting on me to stop [using condoms]. What do I say? What can I say? But I cannot [stop using condoms]. I cannot, but she does not understand. What would she say? (Man with diagnosed HIV)

In terms of the impact of HIV treatment on a couple's experience of intimacy and wellbeing, two thirds of the participants with diagnosed HIV had initiated antiretroviral treatment, and those who had not were maintaining a healthy CD4 count, with the exception of one individual. The consequence of this stabilising medication meant that the topic of HIV could often be sidestepped in many aspects of everyday life. However, all participants believed that their HIV serodiscordant status required attention in the context of sex; a domain which typically plays a significant role in the development or maintenance of many romantic relationships. All described an initial short term, detrimental impact of HIV diagnosis or disclosure on the sex they had with their partner. While some were able to move past this over time, others still harboured serious concerns about the possibility of HIV transmission.

As explored further in other publications (Bourne et al. 2012), around three-quarters of participants were familiar with the concept of treatment as prevention, however most were skeptical of how it may offer sufficient protection from HIV transmission. The vast majority of participants depended upon condoms to make sex safer but, as has been documented in previous studies (e.g. Flowers et al. 1997; Bourne and Robson 2009), condoms were also described by these participants as a barrier to intimacy development, especially in new relationships. For our participants, discontinuing condom use signified trust and commitment whereas its continued presence contributed to a sense of both physical and emotional distance between partners.

> When it comes to being together you have to use rubbers all the time and that is when he got fed up […] And you know, when someone is not happy in the bedroom, every small issue becomes a big issue. Like you are always arguing about even small things because someone already has this, what should I call it? Anger? (Woman with diagnosed HIV)

Sexual relationships do not exist in isolation and all of our participants negotiated, or desired, connections or friendships with others, people whom they turned to (or wished they could turn to) to discuss such problems or challenges within their relationships.

Intimacy Within the Family and Other Social Relationships

Participants in our study talked of HIV affecting their relationships with family members, friends and members of their close community in myriad ways. Within these networks were individuals from whom many participants sought, or already received, both practical and emotional support. While non-romantic in nature, participants articulated feelings of intimacy (both implicitly and explicitly) with individuals from these wider social and familial networks. Within this section we examine how participants' proximity to HIV had influenced these wider intimacies.

The main motivation for disclosure of HIV to people beyond the sexual partner was for support, be that social, emotional or spiritual. However, it was a carefully weighed process to ensure that existing support was maintained. Selective disclosure and concealment therefore played a vital role in maintaining intimacies with social networks in the UK, especially as it was common for participants to have particularly strong social links with people from the same country of origin. Disclosure and concealment to others was carefully judged on forecasting whether such knowledge was likely to then cascade to family members and friends "back home", to whom the participants were not yet ready to disclose.

> But I don't even tell my family that I'm HIV actually, because with our African [community], you will be neglected and they don't want to see you. And even like holding their baby they will say, it would just be better for the baby [not to be held by someone with HIV]. So I just decided to keep it quiet to myself. Only have a few people around me know, my friends, my boyfriend, but my family, nobody knows. (Woman with diagnosed HIV)

Our participants' perceptions about the potential reactions of their family members and friends back home was largely informed by their awareness of how people perceived HIV in their countries of origin. While many had not visited their countries of origin for a significant period of time, they expressed a sweeping view that most African people (at home and abroad) were ignorant about HIV transmission, treatment and prognosis. As a result of the close transnational social bonds they perceived among African migrants living in the UK, and the ease with which news and gossip spread, information about HIV status was carefully guarded by both partners within the serodiscordant couple.

> There's a girl I used to work with before [I was] diagnosed, she is a friend from my country … and I thought she was my best friend so I told her this is what is happening [disclosed]. But then I heard from people that this person was telling other people … and people from Africa they don't understand this thing … I don't have friends that I can discuss it [HIV status] with. (Man with diagnosed HIV)

Many participants described being continuously cautious of the risk of being "found out" and this often adversely affected the degree of closeness they experienced, or desired, with friends (both as individuals and as couples). This situation also persisted with family members. While a majority of participants had disclosed their serodiscordant couple status to their siblings, mainly to draw upon social and emotional support, only a small minority had disclosed to their children, citing a need to protect them from perceived risks such as stigmatisation or a fear of burdening them with caring roles.

> I will not tell her [my daughter]. I won't. She thinks a lot when she should be just free and not worrying about it […] When you get a slight headache, she will be asking, 'are you ok? Are you sure you are alright?' (Woman with diagnosed HIV)

Many participants had also not told their parents because, in most cases, they were still living in their country of origin and participants perceived they would worry considerably and be unable to offer material or constructive emotional support. Concern for social censure and being seen as "irresponsible" by family members for putting a partner at risk of infection dissuaded many from disclosing. In making this decision, couples and individuals were pained by the separation they experienced from these highly valuable sources of kinship support, which are traditionally seen to play a key role in helping to manage and maintain partner relationships.

Those participants who had told family members and friends of the mixed HIV status within their relationship – and who had received a broadly supportive reaction – reported satisfactory intimacies in this wider social circle. However, some found themselves frequently bombarded with questions about their own (or their partner's) health status, particularly by family members who lived in their countries of origin. While these can be viewed as genuine concerns that would naturally arise from cases of illness within intimate relationships, some participants viewed these as unwelcome reminders of HIV. They also believed the main cause for such expressions of concern arose from the contextual differences between geographic settings. They believed most of their friends and families "back home" still held stigmatising views about HIV, and were overly worried about the wellbeing of the participants (a notion that was possibly false since improved access to HIV treatment in their countries or origin might have modified attitudes towards HIV during their absence). In exchanges with friends to whom disclosure had taken place, participants described difficulties in balancing conversations, trying not to place undue emphasis on HIV while still accessing support when it was required. While some were able to navigate the secrets they held and (re)establish intimate family and social relationships over time as they became accustomed to HIV within their lives, others struggled and expressed profound isolation.

Imagining Intimate Futures: Visibility and Viability

A sizeable minority of participants, both HIV-positive and negative, were plagued by uncertainty as to the longer-term viability of their primary intimate relationship. While many sought to overcome doubt and anxiety relating to transmission, participants struggled to understand how a relationship could remain serodiscordant, believing either that the strain of navigating mixed HIV serostatus would ultimately lead to separation, or that the undiagnosed partner would inevitably seroconvert.

> Living with a person who has got HIV, there is a part of you which is like you become a spy on your own life. You spy on your own life because you're always looking like, 'Shall I get it, do I have it, when?' You're always thinking at the back of my mind, 'One day I'll catch it'. (Man whose last test was negative)

Illness or lethargy associated with HIV medication (particularly at the point of treatment initiation) sometimes threatened traditional relationship or familial roles, which tended to be gender normative. Women with diagnosed HIV expressed distress at the times they felt unable to adequately care for their husband or children, and some male partners similarly lamented their absence from household responsibilities and/or economic productivity. Difficulties regarding conception in serodiscordant relationships often dominated the research interviews; both men and women with HIV had a sense that they were not performing their traditional role within the family if they could not conceive, and do so safely (bearing in mind that at the time of writing pre-exposure prophylaxis remains inaccessible outside of clinical trials in the UK). This distress was exacerbated by a lack of awareness or access to supportive conception technologies and, as previously mentioned, limited understanding of the impact of ART treatment in reducing the risk of HIV transmission.

Several participants described how daily reminders of HIV in their lives, such as taking medication or clinic visits, also challenged their attempts to not allow HIV to dominate their relationships. Such reminders also posed a risk of social exposure for those participants who had not disclosed their status to partners or family. Others, though, were keen to stress that these reminders could diminish in significance. With time, and within supportive relationships, some participants said it had been possible for HIV to assume a much diminished role in their relationship, which ultimately required only fleeting attention.

> One is reminded by maybe some … letters coming through the door [from the HIV clinic]. Or by some TV programme. Or occasionally when you are wading through the drawers …

> you see some medicines there. But otherwise, [if] it's not in the sight, it's not in the mind. (Man with diagnosed HIV)

However, given concerns about transmission, the challenges of providing (and gaining) sexual satisfaction, and experiences of physical and emotional distance in the relationship, some participants with diagnosed HIV were haunted by fears of abandonment. For some women, this situation was sometimes compounded by financial or material dependence on their male partners, which resulted in them feeling trapped in unhappy relationships and with only limited social and familial support (given concerns relating to HIV status disclosure).

> I think the person living with HIV—because we often tend to take responsibility and carry the burden around with the relationship—I think we tend to stay in bad relationships because you think at least it is acceptable, he has accepted my status. I think a lot of time people tolerate a lot more than they would do normally if they didn't have the HIV. (Woman with diagnosed HIV)

This gives us further cause to reflect on the range of work that intimacy can "do", including meeting essential needs and creating a stable external status, beyond the concept of romantic intimacy (Hunter 2010).

Fundamentally, many participants struggled to perceive serodiscordant relationships as viable in the long term because they simply did not know anyone in the same situation. We can consider the extent to which the cautious guarding of intimacies has contributed to this outcome on a population level. While many could point to examples of openly HIV-positive advocates within their communities who were external to their intimate social circle, very few knew another serodiscordant couple personally or were aware of any such public role models. When questioned as to why this might be the case, most participants revisited a common discourse that both sex and HIV are sensitive topics to discuss within African cultures and referred again to the significant stigma within their close-knit communities. The lack of belief in a shared future often had a serious and detrimental effect on the relationships and left some questioning the extent to which theirs could ever truly be intimate.

Discussion

Serodiscordance is established by an individual with diagnosed HIV when they reveal their condition to someone who does not have, or is not yet diagnosed with, the virus. The moment of disclosure (or witness of diagnosis) represents a critical juncture in the relationship and, in this study, had the potential for long-lasting influence over the experience of relational intimacies. Those participants who, because of stigma, felt the need to conceal their HIV status from sexual partners and others with whom they had shared their lives, almost always experienced some degree of decrease in the intimacy they had previously relied on or enjoyed. In this sense, HIV stigma, present since the beginning of the epidemic, was observed in this study as having significant and deleterious consequences. It should be noted that this stigma was layered with other stigmatised attributes such as ethnicity, lower socioeconomic status and immigration status (Obermeyer et al. 2011). This stigma had a profound effect on how all participants conceptualised and sought to preserve a diverse range of intimacies that they considered essential to wellbeing.

Communication about HIV represented a significant challenge within serodiscordant relationships, as both partners often strove not to make the condition a dominant factor. Those who were experiencing solid, satisfying relationships had, over time, managed to balance their need to explore worries and anxieties with their partner with a firm desire that HIV not become what one female participant termed a “third person” in their relationship, a presence that is known but unspoken with continuing potential and actual intrusion on relational intimacy. Sex presented an arena in which concerns about onward transmission did negatively impact some relationships. Principally, the need (articulated by most participants) to maintain physical barriers in the form of condoms reminded couples of their serodiscordance on a regular basis, with detrimental effects on intimacy. Increased knowledge and understanding of how HIV treatments function to make an HIV-positive individual less infectious have the potential to radically reduce such concerns, and thus better facilitate deeper sexual intimacies.

Participants in our study typically socialised and lived within relatively small, geographically concentrated communities where there is limited epidemiological awareness of the UK HIV epidemic (Bourne et al. 2014) and where stigmatising views were perceived as pervasive. Previous research has also identified that migrants maintain close connections with their countries and extended families (Falicov 2007). As our findings show, this can hamper communication about a couple’s serodiscordant status to friends or members of the community, as there was widespread fear (or indeed experience) of negative reactions, as well as concerns that this information would filter through to social networks back home. Secret-keeping served to deny participants emotional or practical support relating to their serodiscordant relationship, because it created a sense of distance from others in their close circles. In this way, the notion of difference, of discordance, should be understood as applying not only to the serostatus of sexual partners, but also to their social and familial relationships.

Our findings suggest that communication about HIV-positive status and subsequent intimacy was based on the “awareness contexts” (Glaser and Strauss 1964) that existed between the participants and their social contacts. Where participants were uncertain about the HIV status or HIV literacy of their social contacts, communication was restricted, which in turn severely curtailed the development or maintenance of intimacy.

While most studies have tended to report serodiscordance in single sociocultural contexts, or fail to consider sociocultural context altogether, our findings highlight serodiscordance in transnational contexts where risk perceptions and intimacy are moderated by dominant views in at least two sociocultural settings. Given convenient and expedient intercontinental communication, intimacies between people living in different countries can be more readily maintained or, indeed, disrupted.

Despite the obvious distance from family and friends in their country of origin, many participants were on edge and guarded about what they shared with their tribal and national diaspora communities in the UK, because those communities may serve as conduits of information to those who are held nearest and dearest, but who do not live nearby.

Finally, the invisibility of other African people in secure, serodiscordant relationships meant it was hard for many study participants to conceptualise their own intimate relationship as viable. Both partners needed time to come to terms with HIV as a part of their lives, and while some had managed to successfully integrate it into their relationship, many also stressed a desire for HIV not to cast a shadow over everything. While much prior research on serodiscordance has focused on sexual behaviour that risks HIV transmission, the findings of this study highlight how mixed HIV status is integrated with many complex social and structural factors, including geographical, that shape health and well-being, as well as expand our understanding of "intimacy" in the context of serodiscordance.

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Stigma, Sex and Family Life: Serodiscordance in Henan Province, China

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Introduction

In this chapter we challenge the more common conceptualisation of "serodiscordance" by showing that, in rural China, mixed status relationships concern not only intimate partners, but also affect broader social relationships, including extended family or in-laws. We examine personal narratives of HIV serodiscordant partnerships in rural Henan province to identify ways in which the profoundly family-oriented nature of traditional Chinese society (Li et al. 2008; Ho and Mak 2013) renders inseparable the individual experience of living with HIV from that of their family members We therefore refine our definition of serodiscordance to mean both the mixed HIV status of sexual partners, as well as that of individuals and their family members. Examination of this novel interpretation within the appropriate

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contextual framework allows us to understand HIV as a social construct that sits at the intersection of the individual and the family, providing new perspectives on the landscape of HIV in Chinese society.

In the mid-1990s in central China, the commercial blood and plasma collection industry began targeting farmers in poor rural areas as prospective blood donors. The compensation of 50 RMB (about 6 US dollars) for the donation of plasma and 200 RMB (about 25 US dollars) for whole blood provided famers with a tempting means of supplementing their meagre incomes (Wu et al. 2001). As demand grew from farmers wishing to donate, illegal collection stations proliferated, where inadequate regulatory oversight allowed dangerous collection procedures at these stations to continue unchecked. The most dangerous of these practices was the pooling of blood from multiple individuals of the same blood type for collective centrifuging, from which the left-over red blood cells were re-injected back into the contributing donors. This was done in order to prevent anaemia and therefore allow donors to give plasma far more frequently than the 15-day interval required by national regulations, in some cases as often as every other day.

This practice also lead to the mass transmission of blood-borne infections, including human immunodeficiency virus (HIV) and hepatitis C virus (HCV) (Dong et al. 2011; Qian et al. 2006). The resulting HIV epidemic eventually became the largest known cohort to date of persons infected through commercial blood selling (Dou et al. 2010). By the time government crackdowns put an effective end to these practices in 1997, entire villages of former donors had been infected with HIV and other pathogens. In the hardest hit Henan province, a mass screening campaign in 2004 estimated that the total number of HIV-infected people ranged between 50,000 and 170,000 (Anon 2007; Wang 2007).

Despite early denial about its HIV epidemic, since the early 2000s the Chinese government has taken decisive steps to control the disease spread, particularly among former blood and plasma donors. Beginning in 2002, a free, national antiretroviral therapy (ART) program was piloted to address the dire need in this population (Wu et al. 2007). The program is now widely noted both for its scale and its success. In the first six years of the program (2000–2006), mortality rates among treated patients fell from 30 deaths to 5 deaths per 100 person years (Zhang et al. 2009), and as of 2011, 76.1 % of the estimated population of eligible patients are on therapy (Ministry of Health of the People's Republic of China 2012). In addition to expanded treatment access, preventing HIV transmission in "serodiscordant households" has become a priority of local public health departments in settings such as Henan. Such couples, in which only one partner is infected, are tracked by local health departments, and uninfected spouses are annually tested for HIV infection. The resulting cohort of over 5000 serodiscordant couples in our study region of southern Henan province has provided rich epidemiological insight into the dynamics of HIV transmission in such settings (Wang et al. 2010a, 2013; Smith et al. 2015).

In the course of epidemiological research on the efficacy of ART in preventing sexually-transmitted HIV in rural Henan, our team conducted semi-structured interviews to better understand barriers and facilitators to accessing HIV care. As respondents began sharing their experiences of living with HIV, however, unanticipated themes emerged suggesting that "serodiscordance" as it is lived in rural China describes the state of not only sexual partners but also of their family members. The frequent recurrence of this theme underscored its merit as a dedicated topic of analysis; the family is the basic unit of society and, as such, plays an important role in people's experiences of living with HIV. In the following, we present our efforts to understand ways in which HIV is perceived and experienced within both intimate partnerships and family relationships. This chapter also seeks to give voice to a population with little political agency, both due to their poverty and their HIV-positive status.

Methods

Study Setting

Zhumadian Prefecture is located in the south of Henan, a rural province in the central plains region of China. Figure 1 shows the relative location of Zhumadian Prefecture within Henan Province and the provincial level spatial distribution of all HIV cases attributed to blood and/or plasma selling practices (Dou et al. 2010). Following mass screenings in 2004, Zhumadian had the highest number reported cases of all prefectures with reported HIV cases. Its nearly 20,000 cases represented 38.1 % of all cases reported in Henan at the time (Wang 2007).

In 2006, officials at the Zhumadian Centres for Disease Control (CDC) began formal monitoring of new HIV infections in all HIV serodiscordant couples living in the prefecture. The HIV-negative spouses of infected individuals were contacted annually for routine HIV testing and to provide basic demographic and behavioural

Fig. 1 Relative location Zhumadian Prefecture within Henan province, pictured in *yellow* in the *left* image, and outlined in *black* in the *right* image. The right image also shows the geographic distribution of HIV cases among former donors of blood and blood plasma in the province. 1 dot equals 20 infections (Adapted from Dou et al. 2010)

information. Beginning in 2008, the Chinese National Centre for AIDS/STD Control & Prevention (NCAIDS) introduced a more formal epidemiological survey that was then annually administered to couples meeting study criteria: those over 16 years of age, in a stable marriage (i.e. no separation or divorce), in which both partners were aware of the infected partner's HIV status, and willing to provide informed consent.

All individuals who provided interviews for this research were recruited through their local HIV treatment clinics from among respondents of the NCAIDS annual epidemiological survey. The interviews were conducted by the authors in two waves, the first between July and September of 2012; the second from May to December of 2013. The study objectives of each wave varied slightly, with the first focused on the treatment experiences of the initially-infected (or index) partners, and the second on the experiences of both partners in the small subset who had experienced a transmission event in the prior two years. All respondents included in this analysis were therefore HIV-positive, but some had previous experience of being an HIV-negative member of a serodiscordant couple. Twenty-three (23) individuals participated in the first wave of interviews, and 28 in the second.

All potential respondents were first approached by their HIV care provider to gauge initial interest, after which interested individuals then met with study staff, who provided more information about the study. Sampling was conducted to maximize representation across high and low HIV prevalence counties within Zhumadian Prefecture. Respondents willing to provide informed consent (written or verbal) then took part in one-on-one interviews in closed, unmarked clinic examination rooms, conducted in Mandarin Chinese and audio recorded (in the case of two respondents who declined audio recordings, notes were taken). Interviews explored respondents' experiences with infection, disclosure of HIV status, stigma, and engagement with healthcare entities, as well as their attitudes and opinions about preventing HIV transmission to sexual partners.

Before initiation of the study, preliminary interview guides were pre-tested with two patient volunteers at the Zhumadian City infectious disease hospital. Pilot interview content was reviewed and discussed by the study team to edit the interview guide for improved flow, culturally appropriate phrasing, and possible probing questions for key content areas. Data from pilot interviews were not included in the analysis. In accordance with locally acceptable practices, respondents received a 33ML bottle of cooking oil valued at about 70RMB (about 11USD) for their time and effort.

Each set of audio recorded interviews was transcribed verbatim, de-identified and translated into English by two native Chinese speakers. Substantial differences in translations were reviewed by the first two authors for validation and to build a consensus transcript. Analyses focused on general themes such as sexual behaviours, care taking, access to care and treatment, and experiences with HIV stigma within the family and community. After an initial review of each of the 51 interviews, a preliminary code book was built by the first two authors containing key concepts and categories. These codes were then applied to interviews, allowing for modification of the preliminary code following any discrepancies in coding between the first two authors.

This study was reviewed and approved by the Institutional Review Boards of NCAIDS and the University of North Carolina.

Results

Study Population and Characteristics

A summary of the socio-demographic and behavioural characteristics of the 51 respondents who participated in this study appear in Table 1. The median age of the 40 index partners was 46 years (range: 33–71). Forty-two point three percent (42.3 %) were male. All but one respondent reported having children; in only one case had a couple experienced mother-to-child transmission. The 12 respondents who were the initially uninfected partners did not differ from index partners in terms of age (median, 46; range 33–62), but were overwhelmingly female (72.2 %). Though we did not collect individual level data on purported routes of HIV transmission among initially infected partners, the most recent epidemiologic study of this population suggests that about 60 % of infections were acquired through blood contact (blood/plasma selling; blood transfusion), another quarter through sexual contact (nearly all heterosexual), and most of the remainder were of unknown origin (Smith et al. 2015). The majority (82.2 %) of respondents were taking ART at the time of interview.

Table 1 Characteristics of the 51 HIV infected members of serodiscordant partnerships

Characteristic	%
Initially infected (%)	76.9
Sex (% male)	42.3
Age (median, range)	46.1 (32.5–70.6)
ART status at time of interview	82.4
Change in sexual behaviors after diagnosis	
Decreased at first, now normal	3.8
No change	28.8
Decreased	32.7
Stopped having sex	9.6
Missing	25.0
Monthly frequency of sex in past year (%)	
Never	21.2
Once a month or less	59.6
2–3 times a month	13.5
At least 4 times a month	3.8
Condom use in the past year (%)	
N/A (no sex)	21.2
Every time	63.5
Sometimes	3.8
Almost never	9.6

The sections below explore themes that emerged around HIV serodiscordance as it was experienced between married partners and within the larger familial context. Themes include perceptions and management of HIV risk within a sexual partnership, as well as how mixed status was implicated in wider social dynamics involving whole families. Of note, anecdotal evidence from the aftermath of the blood selling scandals suggests that dissolution of married couples upon HIV diagnosis of one partner was not uncommon. The serodiscordant couples included in this study therefore likely only represent a subset of the original population of serodiscordant couples.

Serodiscordance and Marriage

Marriage and HIV as Fate

Respondents' self-perception of living in a serodiscordant partnership was often couched in their conceptions about fate. When reflecting on their relationships, for example, several respondents expressed their decisions to stay together as a commitment to each other and the marriage. "We have already been together so many years," said one female respondent (S1–25). A 54-year old man said, "Until we are old we will not be apart. We're both old now, and we will only part when we move on [die]" (S1–14). Diagnosis of one partner was also seen as a shared fate, as in the case of a 46-year old respondent who described her husband's reaction to her HIV diagnosis in the following way, "What could he do? If I've become infected there's nothing that can be done … after all, he and I are family" (S1–17). One 49-year old man had tried to separate from his wife after learning of his own HIV infection. He had hoped to do this so that his wife might seek out a new life without him, but as he related:

> When I first tested positive I said that we should be divorced. But she wouldn't hear of it. Sometimes it can actually be the woman who refuses to leave her husband. So then I thought, once I have my health back I will insist on it again. But she still refused. She said that what has happened has happened. We're nervous [about transmitting], of course, but it's actually not so big a problem (S1–05).

Sexual Behaviors and Gender

Forty-two (82.4 %) respondents provided data on sexual behaviours following HIV diagnosis of the infected partner, the majority (76.2 %) of whom reported that they now had sex either less frequently (40.5 %) or at the same frequency (35.7 %) as before they had learned of the index partner's HIV infection. An additional 4.8 % reported that they had stopped having sex right after the index partner's diagnosis, but that over time frequency returned to normal, most often due to learning about safe sex measures from health care providers at the disease control stations where condoms were often supplied for free. About a tenth (11.9 %) of respondents reported that they had no had sex at all after diagnosis, though many explained that this was partly due to their advanced age and not necessarily a precaution against transmission.

Not every respondent volunteered information about prevention measures to stop HIV transmission, but among those that did, emergent patterns suggested that precautions adopted by couples may have been in part shaped by the gender of the seropositive partner. The defining aspect of gender dynamics of sexual behaviours was the agency exercised by male partners to dictate the couple's preventive measures—or lack thereof. Those who reported using condoms framed it in terms of concern for their partner, as in the case of a 54-year old HIV-positive man who explained why he had never had condomless sex since his diagnosis: "If I gave it [HIV] to my wife, well that's just not right … I've already endured so much, how could I put her through the same?" (S1–14). Among others, vigilance about condom use eroded over time as respondents shed their fear of a transmission event. Even in such cases, however, it was the male partners who maintained decision-making power over condom use, regardless of whether or not he bore the risk of infection. One HIV-positive man who reported only occasional condom use explained that he had become "less afraid and less worried" about infecting his wife given how long she had remained uninfected during their years of condomless sex before his diagnosis (S1–19).

Faced with their husbands' disregard of transmission risk, uninfected women may have had few means of self-protection, as in the case of one woman infected by her husband who felt she had had no choice but to submit to condomless sex: "had I refused him, he would have become agitated" (S2–11). In other cases, however, male partners refused condom use even when it was in their own best interest, as in the case of an initially HIV-negative man who attributed his lack of fear to his disease-free marriage to his first wife who had died of AIDS. When he became infected by his second wife, another HIV-positive woman, he reasoned, "My thinking had been that when I was with my previous wife, I had never gotten infected, so I guess I figured I wouldn't get infected with my second wife, either" (S2–181).

A second aspect of these gender dynamics was that, for HIV-positive female respondents, protecting their husbands from disease for the sake of their family and children was a primary concern. One HIV-positive woman whose husband refused to use condoms lamented, "If he got infected our family is finished. Right now we depend entirely on his work. How could I not be scared?" (S1–17) Other women echoed this fear, saying that infecting their husband would mean "our family would die" (S1–13) or, "If he became infected, how could our children survive?" (S1–20) Underlying these concerns was a belief that men played a more central role in family survival, best articulated by one initially-uninfected woman who later seroconverted, when she described her reaction to her husband's diagnosis:

> I thought it would have been better if I had been the one infected. Women don't leave the house to go out to work in manual labor, we're not as physically strong to do this. When I learned that my husband had been infected, it felt like the skies had fallen (S2–02).

In these ways, partners' concerns about maintaining HIV serodiscordance were couched in gender specific priorities. For many male respondents, lifelong condom use was not seen as a feasible trade-off for reducing what was perceived to be a minimal risk of transmission. By contrast, concerns about transmission among female respondents centred on the primacy of the family's well-being as embodied in her husband's physical health. Of note, respondents interviewed in the first wave of this study were asked if they were aware of the fact that suppressive antiretroviral therapy could reduce sexual HIV transmission risk; none were.

Serodiscordance and Families

Most research on HIV serodiscordance has traditionally focused on couples; however, our respondents' narratives suggested that serodiscordance in rural Henan was also a family-level phenomenon. Our respondents frequently constructed serodiscordance as an issue intimately tied to concerns such as maintenance of family unity, children's marriage prospects, and relationships with other family members.

Fragmentation of the Family

Respondents' anxiety regarding their own or their spouse's HIV status was often expressed in the form of fear that members of their family might move away or otherwise abandon them in an attempt to disassociate from the stigma and shame of being related to an HIV-positive individual. Many respondents were therefore very cautious about disclosing their own or their spouse's HIV status to family members. One 42-year old woman described her concerns about her family dissolving after hearing a rumour of another serodiscordant couple whose daughter-in-law had fled upon learning of her in-law's HIV status, taking their grandchildren with her. She related:

> My daughter-in-law does not know about my disease. Once she knows, she will not [want to] live with my son … and I need to consider the children. If my daughter-in-law knows, she will leave the family, and then what can we do about the children? (S1–03)

In another case, a 46-year old respondent's son who knew of his mother's HIV infection asked his mother not to reveal her condition to his new wife out of fear that this would prompt her to leave him. The respondent was not only sympathetic to her son's concerns, stating: "Well, it is not easy to find a wife these days" (S1–17), but she also apparently agreed with her son that her HIV status could give a daughter-in-law probable cause to flee.

Four cases surfaced in the course of these interviews of families that had been broken apart by news about the respondent's HIV status. Three respondents reported daughters-in-laws leaving the family. In one such case, the daughter-in-law fled with her children, in the second case she fled with only one child while leaving the others behind, and in the final case, the daughter-in-law left all her children behind. Respondents whose grandchildren had been taken away expressed shock and sadness at the loss. Those who had been left with the grandchildren were hurt by their daughter-in-law's departure, and also expressed concern at their ability to take on the added responsibility of child care, particularly as there was now one less working-age adult contributing to the household income and helping around the house.

The fourth case in which a family had been broken apart as a result of a negative reaction to the respondent's HIV status, was relayed by a 45-year old HIV-infected woman whose son had broken with tradition by opting to move in with his wife's family rather than raise his children in his ancestral home. This act, which would in effect cut short the lineage of his own family, was a source of great disappointment for the respondent:

> Even my son is afraid of my infection. He married into another village. I am so angry with it. It is as if I raised him for another family! He wouldn't come back, because I am infected. He wouldn't let me take care of his children, won't even let me hold them (S1–08).

These cases of fleeing daughters-in-law confirmed respondents' fears about the potential damage of their HIV status on their families, further illustrating the impact of HIV serodiscordance on relationships beyond dyadic couples. The effect of this stigma on parent/daughter-in-law relationships in particular also highlights the complexity of marital ties in rural China. On the one hand, daughters-in-law regarded their familial ties to the HIV infected respondents as strong enough to trigger fears of stigma by association. On the other hand, as a patrilineal society in which married women are "adopted" into the husband's family (Riley 1994), daughters-in-law may have regarded themselves as outsiders enough to reserve them the option of severing ties with their husband's families for the sake of their own or their children's reputations. These phenomena therefore underscore the value of exploring serodiscordance in rural China as a construct operating at both the level of the couple as well as the extended family. It was family-level serodiscordance that prompted stigmatizing and fearful reactions that unravelled familial ties and threatened the traditional family structure at the heart of rural life in China (Wang et al. 2010b; Liu et al. 2005; Yang et al. 2001).

Marriage Prospects of Children

Another way in which serodiscordance could be seen to operate at the family level was in respondents' fear of the impact of their HIV status on their children's marriage prospects. As one 60-year old woman described it, "I told him [my son] that he could marry someone from here [from our home village]. But then again he can’t. People here all know [about my HIV], so they would never agree to it” (S1–11). Another respondent who had been diagnosed with HIV around the same time as her son’s engagement, worried that her HIV status might jeopardize the union. She exercised great caution in sharing her status lest news of her infection spread and her daughter-in-law found out: “I was afraid if this happened she would not marry my son” (S1–12). Similar fears had prompted a 50-year old woman to reconsider the timing of her first HIV test. Despite her suspicions that she was infected, she delayed getting an HIV test because her son was engaged to be married at the time, and was “afraid [a positive result] would be bad for our reputation, so I didn’t dare” (S1–15). It was only after her son was married and had a child that she sought testing, which confirmed that she was in fact infected.

In only one case did a respondent fully disclose her HIV status to a prospective in-law. As this 41-year old respondent recalled, “When my son and daughter-in-law were about to marry, I had my son talk to her first and tell her about my HIV. If she still wanted to marry him then she could. So she knew.” In this instance, the future bride accepted the son’s marriage proposal and eventually married into his family, in spite of his mother’s HIV infection. As the respondent described it, “No one in her family has HIV, but her parents had said to us, ‘Even those without this disease also die’” (S2–11), implying that they did not see HIV as such a taboo cause of death.

As these anecdotes convey, HIV-positive parents were often concerned about the stigma their children might face as member of an “AIDS family.” They therefore put great effort into shielding their children from potential stigma by being very circumspect about disclosing their HIV status, both to their children and to other family members and social connections. These “mixed-status relationships” between parents and children reveal the fact that serodiscordance is lived and experienced at the family level and beyond. The centrality of marriage in the lifeline of traditional Chinese families also means that the HIV infection of a single individual affects not only intra-family dynamics but also those with families joined by marriage.

Discussion

Qualitative interviews with these 51 HIV-infected individuals from Henan province provide insight into the experiences of HIV serodiscordance among the rural poor in China. Key emergent themes included the role of gender in the management of sex and condom use in serodiscordant marriages, and the centrality of the family in experiences of serodiscordance in this setting. In particular, family-level serodiscordance played a role both in the fracture of existing families as well as an impediment to the formation of new ones, both threats to this core unit of traditional Chinese society.

At the couple level, HIV serodiscordance was often described as a shared experience that bound partners more tightly together once they had accepted their mixed status. Condom use was the most widely reported prevention strategy in this population, however, consistent use waned over time in some couples as they became accustomed to their serodiscordance. Attitudes towards prevention of HIV transmission in the marriage also appeared to diverge along gender lines. For example, male partners expressed a wide range of attitudes about the possibility of an intracouple transmission, from active fear to complete resignation. Female respondents, on the other hand, were unanimous in their fear of transmission, which they frequently articulated in terms of their family's collective welfare in the event both parents were to become infected. Women's concerns for their family following a partners' potential infection may be rooted in the reality of the barriers women would face trying to support a family in settings like rural China where men possess far higher income-earning potential.

At the family level, themes emergent from these interviews illustrated the centrality of the family in traditional Chinese society. The social role of the family unit laid at the root of several stories of "courtesy stigma," or the stigma acquired through association with a stigmatized person, as described by Erving Goffman (2009 [1963]). Children and grandchildren were often shielded from knowledge about their relative's infection so as to guard against courtesy stigma in the form of being ostracized at work or school. As described by Li and colleagues, HIV infection of one family member is often experienced by the entire family in the form of communal shame and loss of face (Li et al. 2008). Such phenomena stem from beliefs common in rural China that the family is responsible for any "immoral" behaviour that may have resulted in HIV infection (usually drug use or sexual promiscuity), as well as the belief that HIV is highly contagious (Li et al. 2008).

However, nowhere was the phenomenon of courtesy stigma more apparent than in the cases of daughters-in-law who had abandoned their husband's family upon learning the HIV status of a parent-in-law. The patriarchal structure of Chinese rural society dictated that these women became members of their husband's family. However, rather than remaining a part of an "AIDS family," some of these women sought to shield themselves from HIV stigma by severing their marital ties and returning to their biological parents. Children born of these marriages could still be considered blood relatives of the HIV-positive family member, which might have led some of the daughters-in-law to leave their children behind with her husband's family. On the other hand, those women who took the children away with them may have done so in an attempt to renounce ties with the "AIDS family" and claim the child as a member of her own family.

Interpretation of these results should be considered in light of several important limitations. By design, this sample only represents couples who managed to stay together even after the difficult process of one partner's HIV diagnosis; the common experience of couple or family dissolution due to HIV—known to us anecdotally—therefore remains unexplored in this analysis. Our analysis is also limited to the experiences of HIV-positive individuals who we interviewed exclusively. However, several respondents had seroconverted during their existing relationship and therefore provided valuable insights into their previous experience of being the uninfected partner in a serodiscordant relationship. A final and related limitation is that serodiscordance was not the original focus of the interviews conducted. The first wave of interviews (N = 23) sought to explore issues surrounding access to HIV-related healthcare among HIV infected partners. The second wave (N = 28) investigated the experiences of partners who had recently experienced a transmission event, whether from the point of view of the initially infected partner (N = 17) or the newly infected partner (N = 11). As a result, many topics related to the central themes of this analysis were left unexplored during interviews, as the subject matter was considered peripheral to the original research objectives. Nevertheless the consistency and frequency with which topics on serodiscordance were volunteered by respondents lent these themes greater reliability across our sample.

Findings from this study provide important context for meaningful interpretation of epidemiologic findings from rural China that are playing a key role in shaping domestic HIV policy. First, complacency about preventing HIV transmission may be inevitable in couples who have lived with long-term serodiscordance. Ongoing behavioural counselling to help such couples identify feasible and sustainable prevention strategies may help avert future transmissions. Second, condom-based prevention strategies rely heavily on male compliance, highlighting the need for alternative strategies such as female microbicides (Karim et al. 2010), pre-exposure prophylaxis (Grant et al. 2010), or treatment-as-prevention (Cohen et al. 2011) to provide women with options for exercising greater agency over HIV transmission risk, regardless of which partners is infected. That many respondents were not aware that suppressive HIV treatment can prevent transmission further suggests that such methods could substantially impact couple-based approaches to prevention, regardless of the gender of the HIV-positive partner. Third, severe prejudice and social exclusion of persons living with HIV persists in rural China today. The negative effects of HIV stigma are compounded by its multilevel effects both on individuals and their families, serving to unravel a key element of the social fabric of Chinese rural life. Though educational campaigns have attempted to address HIV stigma in affected communities in China, such efforts to date have been limited to a handful of specialized studies (Wu et al. 2008; Li et al. 2010, 2013) whose effects have only been measured in post-intervention awareness surveys. Future interventions with evidence of improving substantive health outcomes associated with HIV prevention and treatment (Sengupta et al. 2011) are still needed in these communities.

Though HIV has affected diverse groups within China, for historic and epidemiological reasons the epidemic has disproportionately affected poor rural communities. People living with HIV in rural China face additional burdens of poverty and lower quality of healthcare, evidenced by higher HIV related mortality in rural areas (Wang et al. 2015). The needs faced in this community are complex and multifaceted, and interventions to address these issues will need to be similarly multi-layered and contextually informed about the experiences of HIV serodiscordance in such settings. By extending our understanding of serodiscordance beyond the couple to the level of families, this analysis can help highlight a broader social domain in which HIV serodiscordance is lived in rural China.

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Reconciling Serodiscordance: Lived Experiences of Mixed HIV-Status Relationships in Ethiopia

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Introduction

About two-thirds of total HIV incidence in Sub-Saharan Africa occurs among stable couples (Chemaitelly et al. 2014); most partners are unaware of each other's HIV status (Matovu 2010). Estimates suggest that about half of all HIV-positive persons in stable relationships in Sub-Saharan Africa have HIV-negative partners (Chemaitelly et al. 2012; Coburn et al. 2011), making these relationships serodiscordant. Such couples have long been recognized as a potential target population for HIV research (Guthrie et al. 2007), and remain a key context for seroconversion under certain conditions.

Much research on serodiscordant couples remains overwhelmingly quantitative and focused on HIV status (Eyawo et al. 2010), sexual risk behavior and transmission (Attia et al. 2009; Loutfy et al. 2013; Reynolds et al. 2011), and testing and counseling (Desgrées-du-Loû and Orne-Gliemann 2008). Comparatively little work examines how these couples make sense of their relationships within a wider sociocultural context, or navigate specific social and behavioral factors informing risk perceptions and negotiations (Persson 2013). This remains the case despite the demonstrated clinical efficacy of the biomedical strategy called Treatment as Prevention (TasP) for serodiscordant couples (Anglemyer et al. 2013; Baggaley et al. 2013; Cohen et al. 2011). TasP protects HIV-negative individuals by achieving viral suppression in their HIV-positive partners, reducing the likelihood of transmission even in the absence of other risk-reduction efforts.

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Knowledge of TasP's effectiveness has not, however, translated into new treatment protocols for HIV-positive members of serodiscordant couples in Ethiopia, where this research was conducted. Thus, the situation there remains much the same in terms of lived experiences. This paper provides insight into these experiences, exploring how couples in such relationships conceptualize serodiscordance in a resource-limited setting. Our findings are organized around three core themes: conceptualizing serodiscordance, negotiating daily life, and managing transmission risk. Although the phenomena corresponding to these themes intersect in practice, the themes yield important insights when explored separately.

Methods

Data reported here come from a larger study of seropositive people receiving care in an HIV/AIDS clinic at a specialized referral hospital in Addis Ababa, Ethiopia that took place between May and October 2008. Our chapter focuses on 20 HIV-positive partners in serodiscordant couples (married, cohabiting, or partnered for at least a year), who were recruited from the study clinic during routine visits. Clinic nurses informed eligible participants about the study and the research team gave detailed explanations to potential participants. All participants were 18 years or older and self-reported as living in mixed HIV-status relationships. Written consent was obtained from all study participants. The Institutional Review Boards of Northwestern University and Addis Ababa University and the National Ethical Review Board in Ethiopia approved the study.

Semi-structured in-depth interviews were conducted with 15 HIV-positive people (nine women and six men) living in serodiscordant relationships. A group interview with three men and two women, all HIV-positive, complemented the individual interviews. All interviews were conducted in privacy in Amharic (the official language of Ethiopia) at the study clinic. Interviews covered infection and diagnosis; risk perceptions; intimate relationships; experiences with serodiscordance; and various challenges they reported facing as they managed their condition. All interviews were audio-recorded with participants' permission and translated into English. Interview recordings were replayed and transcripts read multiple times to increase familiarity with the data. Transcripts were then imported to NVivo 10 software (http://www.qsrinternational.com/) for analysis. Statements conveying common sentiments and experiences were identified with inductively derived codes. This chapter reports on three core themes that emerged during the analysis, describing participants' lived experiences of serodiscordant relationships (Creswell 2007; Starks and Brown Trinidad 2007).

Results

Before addressing the three core themes in detail, we provide information to characterize the study sample. The mean age of participants was 38.8 years (range: 29–52), with educational attainment ranging from elementary school to graduate degrees. All had known of their HIV status for at least two years and were receiving antiretroviral therapy (ART) at the study clinic. Eighteen participants had sought HIV testing due to severe illness, pregnancy, or international travel. The other two had sought HIV testing shortly after engaging in what they perceived as "risky" sexual activity.

Nearly two-thirds of participants were still with the partners they had before discovering their mixed status. However, four were in relationships that began after diagnosis. Three participants, though not formally separated or divorced, reported feeling their relationships were all but "over," so great was the disruption caused by serodiscordance. Many participants found disclosing their HIV status to partners a daunting and stressful process. Yet most, especially those who established new relationships following diagnosis, exhibited a strong sense of responsibility to disclose. Though none of the participants had undergone couples-based counseling and testing, all but one had disclosed their status to their current partner at some point in time.

Conceptualizing Serodiscordance

Most participants' first reaction to learning of their mixed HIV status was denial or skepticism, often leading them to seek multiple tests. One participant remembered:

> I had [my husband] tested in three … places and I was told that I was positive and he was negative. I asked the doctor how that could happen. I told him that I do not know any other man in my life (woman, aged 35).

As evident in this quote, participants struggled to understand how they had become infected while their partners had not. No participant had accurate scientific information about serodiscordance and most reported being desperate for such information, claiming they had never received a convincing explanation of serodiscordance from care providers. This lack of understanding led participants to assume or conclude that their spouses/partners had likely already been infected with HIV, removing the urgency of disclosing their HIV-positive status. This was particularly true in relationships that predated the diagnosis. As one 38-year old man explained:

> I did not tell my wife [then my girlfriend] about my HIV status. My knowledge by then was, 'we were together for about two years and I am positive so she would be HIV-positive as well.' I knew before we got married but I told her long after we had our first daughter.

In addition to not understanding that their relationships might still be serodiscordant, some participants, mostly women, kept their status to themselves for fear that negative reactions from their partners would put their relationships at risk or because they thought other challenges in their relationships needed to be resolved first:

> When [my husband] asked me if I had a test or not, I told him that I had, and [that] it was negative. This is because I didn't want him to know my status. I do not have peace of mind ever since [four years] … we had a disagreement and I wanted that to be taken care of first (woman, aged 37).

Narratives about the discovery and disclosure of mixed HIV status frequently reflected the widely held belief that HIV is a punishment for sexual immorality. Some participants made sense of contracting the virus by admitting their responsibility, especially if they thought risky sexual behavior, such as having multiple partners or unprotected casual sex, was involved. Several made such comments as, "This was somehow my fault," or "I made a mistake." As one 37-year-old woman put it:

> With regards to this disease, I consider myself as a sinner … I had another boyfriend without my husband's knowledge … He is not alive now. I had a feeling and knew that [the boyfriend] was not a good person. He had money and took me to all luxurious places … I knew that it was not a good thing … but I wanted to be with him, thus I had the virus.

In Ethiopia, religion plays a significant role in accepting an HIV diagnosis and provides a source of comfort when coping with the many challenges associated with living with HIV. It also kindles hopes of forgiveness and cure. A 52-year old man explained, "I promised God that I will not see any other person except my wife when I become free of the virus. I have to learn from my mistakes." A 35-year-old woman framed the possibility of a cure in terms of her spiritual beliefs: "God would bring the cure … People might say whatever they want; as for me God will provide me solutions for my sin … My hopes are only from God".

Spiritual explanations were also instrumental in shaping how participants made sense of serodiscordance, with several using the saying "God does not punish those who are trusted to him" to explain continued mixed-status within a relationship, as well as an HIV-negative partner's decision to stay in or commence a serodiscordant relationship. One 30-year old woman explained her partner's decision to establish a relationship with her after learning of her HIV status: "I assume he believes that God would not let … [transmission of the virus] happen while he is risking his life for somebody else". Likewise, spiritual understandings of serodiscordance also helped maintain relationships as people found it immoral to leave or abuse their partners given the protection they received from God: "We may have disagreements here and there but we never raise the disease. Because God has protected her, she won't dare say anything about it" (man, aged 41).

Overall, participants' feelings about their diagnosis, their conceptualizations of serodiscordance, and their status disclosure decisions were informed by their own knowledge of HIV transmission, their spiritual beliefs and their awareness of wider social perceptions of the virus. However, this initial situation was modulated by their lived experiences, as made clear in the data explored below.

Negotiating Daily Life

However participants conceptualized serodiscordance, coping with HIV in daily life meant facing emotionally uncomfortable realities of intimacy in the context of mixed HIV status. Irrespective of the timing of disclosure, some participants reported blame, moral judgment, anger, and stigma as consequences. The following two quotes illustrate instances of verbal abuse from partners:

> We had a disagreement once and my wife said: 'You brought the disease because of your reckless behavior,' and I cried like a baby (man, aged 58).

> When I told … [my husband] about my status, he was disappointed and scolded me … He used to come home drunk and he used to insult, belittle, and yell at me every single night (woman, aged 42).

Verbally abusive partners eventually tempered their language and tone, although stigma and accusations of sexual immorality persisted in some couples. Most couples chose to hide their status from others though some disclosed selectively, and not all were in agreement about appropriate limits. As a 37-year old woman reported:

> [My husband and I] have conflict on disclosure issues. My husband discloses my status to people. He used to say, 'Why should you hide it?' and 'How long do you want to keep it a secret?' But I did not want anybody to know … My husband once had a disagreement with his friend and his friend said, 'Leave me alone; you are sick people' … my husband was so hurt. Now that the stigma is extended to him, he felt so bad.

Thus, partly due to the general lack of awareness of the possibility of serodiscordance, couples often found that HIV-related stigma extended beyond the positive partner.

Even as they moved forward in their lives together, participants expressed considerable uncertainty about their survival, their financial independence, and the fate of their relationships. Most believed that life was meaningful despite HIV, but they vacillated between pessimism and hope for the future, regardless of their overall health:

> [My partner] asks me … how long someone can live on ART. He encourages me to read about it and … I saw the life expectancy with ART is about 13 years and I started to worry (woman, aged 29).

Both men and women voiced such uncertainty primarily in terms of its effect on their families. Those with children frequently expressed a strong desire to live longer: "I want to see the future of my son and that is the only thing that worries me" (woman, aged 36). Male participants, often primary breadwinners, were worried about not being able to support their families. In Ethiopia, this is seen as an important responsibility of manhood: "I feel bad about not being able to provide for my family… I had two jobs before but I can't do that anymore because of my illness" (man, aged 38). Even financially secure participants worried about what would happen to their families if they were to die. Some were preparing their "healthy halves" for this eventuality by sending their partners to school or finding them jobs, as another 38-year old man explained:

> As I have a very good job … everything is good now. But I am concerned about … what would happen to [my family] if something happens to me … My wife and I discussed this and she is … preparing herself to take care of the family.

One of the most vexing aspects of serodiscordance, as revealed in the interviews, was sexual intimacy. Participants who had stayed in their relationships post-diagnosis described having to manage new terms and conditions of sexual intimacy. Most reported reduced frequency of sex, while others abstained altogether: "We are trying to lead our life and take care of our daughter; nothing else [sexual]" (man, aged 40). Some HIV-positive partners explained that their HIV-negative partners had lost interest in sex after receiving serodiscordant test results. In other instances they attributed changes to their own loss of interest. One 42-year old woman observed, "I make love with my husband maybe once in three months. I lost interest in it. I just want to take care of myself".

Some participants' narratives reflected an attempt to reconcile a loss of sexual interest with a desire to fulfill marital/romantic expectations and preserve relationships. As a 38-year-old man noted: "Our relationship is good from my wife's side. But … I couldn't treat her as I should … because I do not feel like having sex anymore." No matter what form their post-diagnosis sexual intimacy took, participants invariably no longer considered their sex lives to be "normal." Yet, most also described their relationships with terms such as "it is all the same," "nothing has changed," and "we are like what we used to be." As one man explained: "We are [a] normal husband and wife. Apart from having separated our bedrooms and taking extreme care [when having sex], there is no change for my wife and me." Such apparently contradictory statements suggest a struggle on the part of participants to normalize their relationships post-diagnosis. In this "new normal," sexuality's importance was often eclipsed by emotional intimacy, companionship, and a sense of sticking together, especially for families with children. On the other hand, childless participants tended to openly air differences in needs, even questioning the sustainability of the relationship:

> There are times I say that I should look for somebody of my type [HIV-positive]. He … fails to understand what I am going through … Sometimes, my partner likes me to stay up late and spend more time with him [sometimes to satisfy his sexual demands] … He misunderstands me. And such moments make me think that I should actually be in a relationship with somebody who has the same problem as I have (woman, aged 29).

It is perhaps unsurprising that sexuality would prove vexing in serodiscordant couples given the common association between HIV and sexual behavior. Nevertheless, despite the frictions reflected in some participants' responses, most of the couples in our research persevered in their relationships by deemphasizing sexual intimacy. The presence of children was an especially strong motivator in this respect.

Managing HIV Risk

The de-emphasis of sexual intimacy did not mean that sexual relationships were unimportant, however. In addition to the more general ways sex figured in couples' negotiations of the vicissitudes of daily life, HIV transmission was a particular and considerable concern for most participants. Although (as previously noted) few understood the scientific explanation of serodiscordance and many were skeptical about it, their mixed HIV status remained on their minds. Indeed, the most frequently expressed theme among participants in sexually active relationships was fear of HIV transmission:

> [I] didn't want to get married; I even brought her [to the clinic] for advice, but she said we have to be together. It is very tough … if [she gets infected], the psychological scar it will leave on me will be huge (man, aged 38).

Many participants mentioned that they hoped their partners would remain free of the virus, in some cases perhaps to avoid blame for being the source of infection, but also out of genuine concern for their partner's welfare. In addition, avoiding transmission was described as beneficial to the relationship, because it would allow the HIV-negative partner to fulfill familial and social obligations, such as caring for children or for the HIV-positive partner should he or she become sick: "I am constantly anxious about his well-being … It won't be to my benefit if he contracts the virus. Who will take care of me? I am better off if he is free from the virus" (woman, aged 29).

Although both men and women reported such anxieties, there was an important gendered difference in the perceived ability to translate fear of HIV transmission into prevention efforts. Most men reported being in control of their relationships and often made their own sexual decisions. Some took charge by offering to leave if their partner was not happy in the relationship:

> I have told [my wife] candidly about my problem [HIV infection] and from that time on, we have had to take care [sexually]; if she likes it she can live [with me] and if she doesn't like it we have to separate (man, aged 38).

Such men were often independent, physically or economically, and none reported that their partners had left them. The HIV-positive women, however, often lacked the power to negotiate safer sex or to decide whether or not to have sex. While this reflects gendered power relations in the general population, this imbalance is more pronounced for HIV-positive women. Nevertheless, most of them wanted to maintain their relationships regardless of stress, loss of intimacy or, as one 37-year-old woman explained, suspected infidelity: "I haven't said anything as I am living with the virus and have to live with him … I can't live with anyone else". Another 30-year old woman elaborated:

> He is not interested in having sex these days. I do not exactly know why. But I do not dare to ask him and I do not want him to be bothered about this either … If I ask why we are not having sexual relations anymore, that would be calling for trouble … His decision to live with me is a big enough sacrifice by itself.

Still, despite such asymmetry in negotiating the terms of sexual intimacy, most couples, as suggested above, tried to avoid transmitting the virus to HIV-negative partners. Thus most of the participants who were sexually active reported using condoms as an HIV-prevention strategy, although in some cases inconsistently. The most common explanation for inconsistent condom use was the desire to have a child. A 35-year old woman mentioned her husband's choice thusly: "[My husband] forced me to have sex without a condom, knowing my HIV [status], because he wanted to have a child with me, and was willing to die with me". Some participants had conceived children through condomless sex after learning of their serodiscordance.

The desire to have children was more frequently mentioned by younger participants who had no children and by individuals who had experienced significant improvement in health due to ART, reflecting the cultural expectation in Ethiopia that young people get married and raise families. For some, however, the hope of parenthood was dashed by their HIV-positive status and a lack of understanding of safe conception: "Previously, I used to wish for lots of things, like having a baby. Not anymore. I may adopt but I have decided that I won't have a biological child" (woman, aged 29). Advances that make it possible to have a baby without transmitting the virus were not clearly communicated to HIV-positive partners of reproductive age. Personal communication with healthcare providers in the study setting revealed that the clinic staff was neither informing patients about safe conception options, nor did they regularly monitor the health of HIV-negative partners.

In some cases, the dream of having biological children drove participants to try to conceive irrespective of whether they knew about safer conception options. As one 38-year old man explained, "Our first daughter was born accidentally. But my wife wanted to have a second child and said … 'God … will keep me safe', and we had our second daughter. Luckily [my wife] is still negative". Such practices indicate that, for some couples in this sample (according to the HIV-positive partners' reports), having biological children together was worth the risk of transmission.

Discussion

This study explored the lived experiences of HIV-positive people in serodiscordant relationships in Ethiopia, revealing a series of psychological and sociocultural challenges. Our findings supplement the literature on HIV serodiscordance, which has been largely dominated by HIV transmission factors and lately by biomedical aspects of prevention, particularly the role of TasP in reducing the risk of HIV transmission. In what follows we discuss the findings on the core themes (conceptualizing serodiscordance, negotiating daily life, and managing transmission risks) with an eye to informing HIV-prevention strategies.

First, we found that serodiscordance was inadequately understood by most participants, who reported that it was poorly explained by healthcare providers. In particular, the misconception that a partner in an established relationship must already be infected was prevalent. Participants' difficulty in conceptualizing serodiscordance led many to fall back on spiritual explanations. The related notions of HIV as punishment for sexual immorality, and God's protection for negative partners caused some participants to be ambivalent about the necessity of prevention efforts (Bunnell et al. 2005). On the other hand, though similar findings have yet to be reported with frequency in the literature, spiritual beliefs represented a major coping mechanism (Mahoney et al. 2015) in accepting the illness and reducing anxiety around HIV serodiscordance (Cherayi and Jose 2015). Thus, HIV prevention education should include scientific explanations of serodiscordance and emphasize the need for consistently protecting the HIV-negative partner while also acknowledging the benefits of spiritual values.

Though nearly all participants eventually felt compelled to disclose their status to their partners, the lack of couples-based counseling or testing for HIV meant they faced this challenge alone. The process was often complicated or delayed by inaccurate understandings of HIV. For example, the assumption that partners were already infected with HIV made some reluctant to disclose their status immediately, as they felt the news could provide little benefit and was potentially hurtful to the partner. This desire to protect others from the psychological burden of HIV has been reported in other qualitative studies (Jarman et al. 2005). Fear of stigma or negative reactions from partners generated anxiety for HIV-positive people when contemplating disclosure. Thus some chose to delay disclosure of their status, as evidenced in another study in South Africa and Tanzania (Rispel et al. 2012).

Obstacles to disclosure are a significant public health concern, as non-disclosure fails to encourage changes in sexual behavior that could reduce the risk of HIV transmission (Kumarasamy et al. 2010). It can also preclude positive outcomes such as stress relief, improved health-seeking behavior, and support in managing illness, among others (King et al. 2008). A study in South Africa revealed that providing couples voluntary HIV testing and counseling improved their knowledge about HIV serodiscordance and prevention strategies (Kilembe et al. 2015). Post-testing counseling sessions should provide accurate, practical information on serodiscordance and promote dialogue using strategies that reduce the risk of damaging relationships (Desgrées-du-Loû and Orne-Gliemann 2008).

These strategies could help mitigate the instances of post-disclosure verbal abuse reported by both men and women in our study. Though these instances diminished over time, as documented in another study of multiple African countries (Were et al. 2011), eliminating such trauma is a worthy goal. It may also be more feasible than expected, since people who conceived their serodiscordance in spiritual terms found it immoral to leave or abuse their partners. In addition, our study and others in Ethiopia have found that HIV-negative partners were mostly supportive (Kassaye et al. 2005), encouraging medication adherence and assisting with social, financial and familial responsibilities (results not reported here).

Our findings echo those of other studies that highlight challenges faced by sexually active serodiscordant couples. The couples in our study struggled to manage sexual intimacy, in some cases foregoing sex while maintaining the relationship for the sake of children or because they found it better to remain together despite the absence of sexual intimacy. In terms of negotiating sexual intimacy, female participants reported feeling restricted while males expressed few such concerns. Although some HIV-positive partners sought to avoid transmission for the sake of their HIV-negative partners, some did so to ensure that someone would remain to care for them or the children.

Similar to other studies, tensions built as partners sought to avoid transmitting HIV, felt unable to live up to sexual expectations, lost interest in sex, or found themselves less able to negotiate the terms of their sexual relationships (Beckerman 2002; Hailemariam et al. 2012; Rispel et al. 2011, 2012). This potentially poses considerable psychosocial and public health concerns. First, the struggle to cope with the ongoing uncertainty of life with HIV and address relationship dynamics underscores the need for psychosocial support for people in serodiscordant relationships. This can be accomplished by integrating mental health into the care continuum, as evidenced by a recent study in Uganda (Pasipanodya and Heatherington 2015), and ensuring continuity of care. Second, some participants chose abstinence as a risk-reduction strategy, reflecting a social responsibility to keep their HIV-negative partners safe. However, this choice could compromise relationships in the long run and potentially lead the negative partner to seek sex elsewhere, posing another HIV acquisition risk. This is of particular concern in light of recent estimates that a substantial portion of incident HIV infections in Sub-Saharan Africa occurs in members of stable couples, but is related to extra-conjugal sexual contact (Chemaitelly et al. 2014).

We noted that men had greater negotiating power in serodiscordant relationships, while most women expressed the desire to safeguard their relationships irrespective of the emotional or financial costs. On the other hand, some HIV-positive men were especially anxious over their (potential) inability to provide for their families, as this detracted from their masculinity. Care providers need to understand the dynamics and social norms governing intimate relationships to help reduce tensions and better target counseling messages. Policy efforts to liberate women from dependency and loss of agency through structural interventions such as income-generating activities (Buchacz et al. 2001) might be helpful, but would also have to negotiate men's sensitivities. This could be achieved by linking care and support services with community organizations and other stakeholders.

Despite participants' express concern with preserving their HIV-negative partner's status, many nevertheless engaged in condomless sex. The socially-important values of maintaining relationships and having children noted in other studies (Beyeza-Kashesya et al. 2009; Hailemariam et al. 2012), were perceived as being in competition with the desire to prevent transmission. Participants were largely unaware of safer conception strategies, and did not seek advice from medical providers. In their assessment, the risk of practicing condomless sex was minimal compared with the social benefits of having children (McDonald 2011).

Such findings call to mind Asha Persson's (2013) argument that HIV "risk" is perceived differently across cultures, and risk-reduction strategies should be adapted to socially-situated perceptions and competing risks. Specifically, social settings where having children is highly valued will require patient-centered approaches sensitized to conception-related priorities and risk perceptions among serodiscordant couples (e.g., Gona and DeMarco 2015). It is important to start ART as early as possible (Anglemyer et al. 2013; Cohen et al. 2011; Kumarasamy et al. 2010) and encourage strict medication adherence (Fowler et al. 2014) to reduce the risk of HIV transmission.

Although TasP has not yet been implemented in Ethiopia, HIV guidelines have been modified to raise the CD4 threshold for initiating ART to 500 cells/μL (World Health Organization 2013), which seems a step toward early treatment. However, special attention to people in mixed HIV-status relationships is lacking. We advocate offering timely testing of partners in stable relationships, early treatment of HIV-positive partners in reproductive age groups, and incorporating family planning in HIV care. Regarding the latter, an individualized approach (Mahoney et al. 2015) to informing reproductive decisions should use couples counseling to factor emotional needs into cognitive appraisals of risk and social values (de Bruyn et al. 2006; Hernando et al. 2009; VanDevanter et al. 1998). Although such an approach will not overcome social pressures that deprioritize HIV prevention in every case, it will equip serodiscordant couples with the tools to evaluate competing demands.

Limitations of the Study

This study has several limitations. First, we recruited only the HIV-positive partners of serodiscordant couples and thus did not directly capture the experiences of HIV-negative partners. Second, we conducted the study in an urban setting, where knowledge about HIV and access to HIV-related services is relatively better than in rural areas. However, the research team's knowledge of both the language and culture of the community under study helped us recognize subtle nuances in participants' lived experiences as members of mixed status couples, including misconceptions about serodiscordance, gendered differences in negotiating the terms of sexual intimacy, and social pressures to have children. Though ongoing contact with the study site suggests that little has changed on the ground, our findings may not reflect the most recent advances in knowledge about serodiscordance or services newly-available to serodiscordant couples there.

Conclusions and Directions for Future Research

Finally, as HIV becomes more easily managed, understanding the social, behavioral, and psychological landscape of stable, intimate, serodiscordant relationships represents an important dimension of HIV prevention. Our understanding of serodiscordance and its effects will benefit from a shift from an individual-based to a couples-based approach. This study strongly recommends couples counseling and education regarding testing, comprehensible scientific explanations of serodiscordance, early disclosure, early ART initiation, and sensitive management of intimate/sexual relationships. Strategies for reducing the risk of transmission should be aimed at both genders and reproductive services need to be integrated into routine HIV care to address fertility desires. Illness experiences and management are socially constructed and, therefore, further qualitative studies are warranted to understand additional psychological, behavioral, and cultural factors in a range of social settings. Future studies should include both partners of serodiscordant couples to better understand differential risk-management strategies and relationship qualities.

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Dialectics of Gender and Health: The Case of HIV Serodiscordance in Uganda

Robert Wyrod

Introduction

In the last two decades our understanding of how gender relations affect health has advanced considerably. However, much less attention has been given to the ways in which health, and especially illness, can in turn affect gender relations. This study uses the case of HIV serodiscordance, where one person in a relationship is HIV positive and the other HIV negative, to examine how gender and health are intertwined. This study allows us to explore both how gender relations shape health risks, such as HIV infection, and how living with HIV then influences gender dynamics in intimate relationships. As such, it provides a way of thinking about the interrelationship of gender and health more holistically.

This focus on serodiscordant relationships also has timely implications for HIV prevention. Recent studies have indicated there are dramatic reductions in new HIV infections in serodiscordant relationships when the HIV-positive individual receives antiretroviral therapy (Anglemyer et al. 2011). Relationship dynamics play a key role in the success of such interventions. However, there is limited research on how discordance alters gender power relations. This article addresses these pressing empirical issues while providing a more complete conceptual understanding of what I refer to here as the dialectics of gender and health.

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The Interrelationship of Gender and Health

Although much research on gender disparities in health remains rooted in problematic notions of gender differences as static and fixed, critical examinations of gender and health have increasingly been informed by an understanding of gender as a dynamic social structure (Springer et al. 2012). Such research conceptualises gender as a multidimensional structure of embodied social relations that encompasses material, discursive and affective relations and operates on cognitive, interpersonal and institutional levels (Connell 2009; Risman 2011). Central to this framework is an emphasis on how gender identities and norms are continually reproduced in historically specific ways. Gender as a social structure is an aspect of social reproduction more generally that both shapes, and is shaped by, other social processes (Connell 2009).

A well-developed aspect of the study of gender relations and health is research examining how everyday social interaction links gender and health. Drawing on West and Zimmerman's (1987) notion of doing gender, this literature has shown that the routine ways we do gender are deeply intertwined with health behaviour, health self-perceptions and illness itself. An early contribution is Saltonstall's (1993) examination of how men and women account for their own good health. Gender played a key role in how individuals constructed their bodies as healthy and differences in health activities were strongly "influenced by social norms related to gender" such that "the doing of health is a form of doing gender" (Saltonstall 1993:12).

This insight is echoed in much of the gender and health literature, from research examining how doing gender affects misperceptions of women's heart problems (Emslie et al. 2001), women's treatment for cosmetic surgery (Dull and West 1991) and young women's sexual health (Jewkes et al. 2005). There is also a growing body of research focused on how doing masculinity affects the health of men and women. This research reveals the largely, but not exclusively, deleterious health behaviour associated with enacting normative masculinity ideals (O'Brien et al. 2005; Oliffe 2006; Springer and Mouzon 2011; Williams 2000).

Yet Saltonstall's conceptualisation of gender and health is important in another, less well acknowledged way. Her framework implies not a simple, one-way causal arrow from gender to health but instead presents gender and health as mutually constitutive. For Saltonstall, health actions are "social acts" that are a form of "practice which construct the subject in the same way that other social and cultural activities do" (1993:12). Her research revealed that health practices were not wholly determined by gender relations but instead "gender was emergent in health doings" and such health actions were how the self as gendered was constructed (Saltonstall 1993:12).

There is, therefore, a dynamic interplay between doing health and doing gender. Normative gender relations shape ideas of appropriate health behaviour, and health practices play an important role in producing gendered social relations. This intertwining of gender and health is implied in other conceptualisations, including

Courtenay's (2000) influential theory of masculinity and health. For Courtenay, health actions are not simply a manifestation of gender relations but are in fact a means of constructing gender, such that "health behaviour and beliefs that people adopt simultaneously define and enact representations of gender" (Courtenay 2000:1388; see also Williams 2000:395). This tight coupling of doing health and doing gender underscores a more fundamental issue raised by Connell, namely that health and gender are both about bodies and embodiment and we "cannot logically treat gender as an independent variable and health status as a dependent variable" (2012:1678).

While the interconnection between gender and health is suggested in these frameworks, empirical research has largely examined how doing gender determines health behaviour and outcomes. The other part of the dialectic has received relatively scant attention, even though the literature provides examples of how changes in health behaviour can challenge, undermine or subvert normative ways of doing gender. Saltonstall, for example, notes in passing how some women who adopted health behaviour perceived as masculine explicitly "regarded their health actions as challenges to existing gender norms" (1993:12). In their review of female-controlled HIV/sexually transmitted disease protection methods (such as the female condom), Mantell et al. conclude that "female-initiated methods could contribute to shifting the state of gender relations" (2006:2005).

Studies of men and masculinity provide additional evidence that health crises can catalyse alternatives to dominant, hegemonic masculine ideals. Emslie et al. found that a minority of men coped with their depression by resisting "culturally dominant definitions of masculinity" and "explicitly reflected on different models of masculinity" (2006:2246). Another study of a group of young men found that the death of a peer prompted a shift in the group's attitudes such that "each man's thinking about what it meant to be masculine was adjusted and, eventually, served to reconfigure the group's new norms" (Creighton and Oliffe 2010:415). Additional examples highlight the complex ways serious health issues result in reassessments of masculinity, with men rejecting certain hegemonic ideals while relying on others to cope with illness (O'Brien et al. 2005; Oliffe 2006).

Such findings underscore the need to examine explicitly how gender and health are intertwined and mutually constitutive. This is a crucial extension of gender relations theory in health because it foregrounds the way in which gender as a social structure continually interacts with other social forces. This perspective further undermines notions of gender (and sex) difference as a fixed binary and provides an avenue for exploring how doing health can be both doing and *undoing* gender. As Deutsch has noted, West and Zimmerman's (1987) notion of doing gender has become a theory about the persistence of gender inequality "despite its revolutionary potential for illuminating how to dismantle the gender system" (2007:106). Deutsch calls for greater attention to the potential of human agency to undo gender in everyday social interaction. Health practices and behaviour, I would argue, are especially rich domains in which to observe such undoings.

This study focuses on the case of HIV serodiscordance and builds on a growing literature on discordant relationships, especially research examining the interplay between gender, living with HIV and relationship power dynamics (Bunnell et al. 2005; Davis and Flowers 2011; Orengo-Aguayo and Perez-Jimenez 2009; Persson and Richards 2008; Stevens and Galvao 2007). Serodiscordance allows us to explore key questions related to the dialectics of gender and health. Under what conditions can an illness subvert or challenge normative gender relations? Does doing health differently have the same potential to undo both femininity and masculinity? Answering such questions allows us to grasp more fully the dialectics of gender and health and the potential that new ways of doing health have for undoing gender.

Context and Methods

Research for this article was conducted in Kampala, the capital of Uganda. As a country noted for its success in reducing HIV prevalence in the 1990s, Uganda is an important setting in which to examine the interplay between AIDS and gender relations. Current epidemiological trends in Uganda, as well as several other African countries, suggest that most new HIV infections are occurring within long-term relationships, especially serodiscordant ones (Uganda AIDS Commission and UNAIDS 2009). In addition, preliminary results from the most recent AIDS survey indicate that national HIV prevalence may have risen from 6.4 % in 2004 to 7.3 % in 2011 (Uganda Ministry of Health 2012). These trends make understanding the interpersonal dynamics of serodiscordant relationships a pressing concern for HIV prevention.

Kampala is located in the southern part of Uganda, in home of the Baganda people, and nearly all this study's participants were Baganda. Historically, the Baganda have been primarily patrilocal and patrilineal, with polygyny associated with male status. In contrast, female monogamy was strictly enforced through social sanctions and this remains largely true today. Thus, while women's agency among the Baganda has been and remains significant, established gender relations today have strong patriarchal aspects and within intimate relationships men are largely seen as the ultimate authorities.

In contemporary urban Uganda several forces are at work reconfiguring these established gender power relations. Chronic male underemployment, women's increasing education and participation in the workforce, and the institutionalisation of women's rights have all challenged notions of innate male authority (Wyrod 2008). In addition, ideas of proper sexual behaviour for men and women are being reworked by ideas of romantic love and companionate marriage, as well as by the many HIV prevention interventions. It is in this complex and dynamic context that discordant couples cope with living with HIV.

Methods

This article incorporates data collected from a broader study of changing gender power dynamics in intimate relationships in urban Uganda. In 2009 I conducted three months of research with cohabiting couples living in Kawempe Division of Kampala, Uganda. Because formal marriage was uncommon, couples were defined as a man and woman who described themselves as married and had cohabited for at least six months. Couples were recruited with the goal of creating a diverse sample based on age, relationship type (monogamous and polygynous), religion, education, income, HIV serostatus, woman's work status and partner age difference. This article focuses on couples that are in HIV serodiscordant relationships.

With the assistance of two local research assistants I identified couples appropriate for the study and continued approaching prospective participants until sufficient sample diversity was attained. Recruitment of HIV-positive participants required the additional assistance of the nurses and counsellors at the local health clinic. My prior research at this clinic facilitated this process and ensured that the HIV status of these participants had been verified within the past six months.

The fieldwork research combined in-depth interviews with all couples and ethnographic observation in the homes and workplaces of half the couples. The formal interview protocol began with an interview with the husband and wife together (conducted twice for polygynous couples). These interviews were deliberately short (30 min) and focused on basic background information to minimise the chance this initial interview would dictate what participants discussed in the individual interviews. At a later time (typically two days later), interviews with individuals alone were conducted. These interviews were significantly more intensive, lasting between 1.5 and 3 hours. As the findings presented below indicate, informative and insightful discrepancies between couple and individual interviews can emerge through this interview method.

The interviews were conducted with the assistance of two research assistants, one man and one woman. Both were Baganda and fluent in Luganda (the language of the Baganda) and English. I was present for all interviews with the couple together and approximately three quarters of the individual interviews. The female research assistant often, but not always, conducted the individual interviews with women. All interviews were conducted in the homes of the participants. Approximately 80 % of the interviews were conducted in Luganda and the remainder in English. Prior Luganda language training allowed me to participate in the Luganda interviews. All interviews were recorded and transcribed, with transcription and translation provided by a native Luganda speaker for all interviews in Luganda.

The interviews focused on three areas: (i) the nature of intimate relationships, including notions of ideal partners, proper husbands and wives, and trust; (ii) power dynamics within relationships, including attitudes toward women's rights and detailed descriptions of decision making; and (iii) sexuality and HIV/AIDS, including ideas of proper sexual behaviour and challenges of living with HIV/AIDS.

Data were analysed using a thematic analysis approach. During the fieldwork an initial summary of each couple was drafted by the research team after the couple completed the entire interview protocol. After the fieldwork, a detailed couple narrative was constructed from close readings of, firstly, the interview of the couple together, then the man's interview and then the woman's interview. Close attention was paid to points of convergence and divergence in these three interviews. This narrative was supplemented by any observational data from the fieldwork and then compared to the initial couple summary created by the research team in the field. Polygynous couples required an additional round of analysis comparing the relationships between the husband and each wife.

The final stage of analysis involved grouping the serodiscordant couples based on whether the man or the woman was HIV positive. Comparisons were made both within and across these two categories. Special attention was paid to how living with discordance affected gender power dynamics in these relationships and the implications for HIV prevention.

A total of 19 couples (40 individuals) participated in the study, including two polygynous couples in which the man was cohabiting separately with two different women (all three individuals in the polygynous relationship were counted as one couple). Seven of the 19 couples were serodiscordant, including one of the polygynous couples. In five of the seven couples the man was HIV positive and in two the woman was HIV positive. These seven discordant couples are the focus of this article. This is a small, non-random sample, yet the fine-grained, experience-rich data on living with discordance generated by this study are unusual.

Findings

In order to present the dynamics of gender and health in serodiscordant couples in some detail, this article presents data on four of the seven discordant couples who participated in the study. While all seven couples generated rich material for analysis, these four couples encompass the range of interpersonal dynamics revealed by this study.

A summary of key background characteristics for these four couples is presented in Table 1. Most of the couples were struggling financially, some quite seriously, but two were significantly better off. Unless noted otherwise, all the couples were married informally and had not had any formal introduction ceremony or wedding.

To illuminate the dialectics of gender and health, key findings are presented here in two parts. Firstly, data on how the HIV-positive person in each couple became infected is briefly outlined. The aim is to illustrate how gender relations affected the ways these men and women were vulnerable to HIV infection. Secondly, a more detailed analysis of how living with HIV serodiscordance affected the gender power dynamics in these relationships is presented.

Table 1 Background characteristics of serodiscordant couples

	Age	Education	Occupation	Monthly income ($)
Woman HIV Positive				
Couple A				
Man	23	Primary 5	Motorcycle taxi	30
Woman	21	Primary 7	Housewife	0
Couple B				
Man	26	University degree	Accountant	200
Woman	25	Studying for degree	School teacher	150
Man HIV Positive				
Couple C				
Man	50	Primary 6	Casual labourer	50
Woman	42	Primary 5	Sells from home	5
Couple D				
Man	52	Primary 7	Auto parts trader	300
Woman 1	46	Secondary 4	Sells from home	20
Woman 2	45	Primary 6	Sells from home	10

The Effect of Gender Relations on Vulnerability to HIV Infection

Couple A had discovered they were discordant only one month before they were interviewed. The husband had decided the couple should test when the wife was several months pregnant and it was then the wife discovered she was HIV-positive. She suspected her infection had occurred in a prior relationship in 2005 when she was 16 and still living in her village. She described the relationship as a youthful love affair with a schoolboy her own age that lasted for about a year. The relationship ended when she moved to Kampala and she claimed she did not have another sexual relationship until she met her current husband. Thus, it was her one prior sexual relationship that she believed was the cause of HIV infection. Her husband was adamant that he had used condoms in his prior relationships and the wife said she was inclined to believe that his recent negative HIV test was correct.

Couple B had known about their discordance for eight months when interviewed. Again, it was the man who encouraged the couple to test after they had been together for a year. After testing positive, the woman concluded she was infected by her one and only previous sexual partner. This previous partner was a serious boyfriend in secondary school – a man she considered marriage material. She described herself as disappointed when he ended the relationship and then deeply hurt again after testing HIV positive. When her current partner tested with her, he was HIV negative and claimed this was his very first sexual relationship, which the woman believed was the case.

In contrast, the route to HIV infection for the men in couples C and D was quite different. Couple C had been together for 20 years and this man detailed the relationships he had held with other women during this time. He openly discussed how he became infected in one of these concurrent relationships, and he took responsibility for the problems he and his current wife now faced as a discordant couple. In addition, he spoke of his fear that his current wife would leave him if he disclosed his HIV status to her. It was, in fact, a serious illness that he experienced that prompted him to finally discuss the issue with his current wife, after waiting for approximately two years.

The route to HIV infection for the man in Couple D was similar. This was a polygynous marriage where the man had two wives living in two different houses. This man, aged 52, had little formal education but had become wealthy from trading used auto parts. He had been with his first wife (to whom he was officially married) for 25 years and with his second wife (who he had not officially married) for 18 years. In addition, this man also had two less formal long-term relationships. He described one of these women as his third wife and said they had children together. She was HIV positive and after she died of AIDS in 2005 the man tested for the first time and learned that he too was positive. He saw himself as the innocent victim and, unlike the man in Couple C, he only reluctantly took responsibility for the problems with discordance he and his wives now faced. While both wives said they were aware of the third wife and her HIV status, neither was informed of her illness by the husband until long after she had died of AIDS.

The Effect of HIV Serodiscordance on Gender Relations

I now turn to a more detailed analysis of how living with discordance affected the relationship dynamics, beginning with the two couples where the woman was HIV positive. Couple A had been together for one year and they had no children but the woman was pregnant. They were struggling to get by on the husband's modest income as a *bodaboda* (motorcycle taxi). Both had limited education and the woman did not work. The husband said an ideal wife was one whom he could control and he described his current wife as ideal because she was submissive, not demanding, had few expectations and was an orphan with little extended family who could interfere in their relationship. While the wife seemed content with this more conventional power dynamic, she was also intimidated by her husband who, she said, could be physically abusive.

As noted above, this couple was just coming to terms with living with serodiscordance. They were very concerned about keeping this issue private and did not want anyone to know they had spoken with me about their problem. The man said "being sick is our secret" and was particularly worried about his family discovering his wife was HIV positive. He said he feared "my relatives will hate her because she is sick and I am not sick". He also noted that if he disclosed his discordant relationship his male peers would pressure him to leave his wife, saying, "they would tell me to leave her. They think like that. They cannot be faithful and they cannot use condoms regularly".

This man did, in fact, concede that if his wife was not pregnant he would have left her. However, he chose to ignore the family and peer pressure and stay with his wife. “I know am the one who made her pregnant”, he said, “and when you look at her situation it is not good. She doesn’t have anybody to look after her, so I shouldn’t just dump her”. What most preoccupied the man, therefore, was weighing his desire to maintain his relationship with his ideal wife and future child against the complications and dangers that serodiscordance presented. After learning his wife was HIV positive, he said:

> I became sad because I thought things were very good and I had found someone who doesn’t have parents … you know, someone without a parent can withstand any situation but a woman with a parent is always thinking about going back to her parents whenever some small problem [in the relationship] happens.

For the moment, marital status trumped HIV status and the man remained committed to the relationship.

This man was actively seeking information on how to continue having sex without becoming infected and how to have uninfected children (issues that largely accounted for his willingness to participate in this study). He said in the future, if he had more money, he would “like to stay with her but I would like also to get another child with another woman”. The wife seemed resigned to this possibility, saying, “He often says that he is going to marry a second wife and I tell him to do so because I won’t lose anything if he does”. Importantly, it was clear from the interviews that it was the man’s decision to either stay in this relationship or to end it. As he phrased it:

> I can stay with her if it’s possible to find medicine to prevent a man from getting infected after sleeping with an infected woman. [Otherwise] I will just continue taking care of her as the mother to my child.

Couple B was facing similar challenges but differed from Couple A in many important ways. Both the man and the woman had university-level education and were earning more money than other young couples in the area. They had been together for two years, cohabiting on and off, and about to take the step to live together full time. They had no children and no immediate plans to have children.

What most distinguished this couple was the strong emphasis they placed on collective decision making. More than any other couple in this study, both the man and woman stressed the importance of making decisions, both large and small, together as a team. The man was also very supportive of the woman working and finishing her university degree. In addition, he was an outspoken supporter of women’s rights, more so than his fiancée. Overall, they both described their relationship as involving very little conflict and both said they were strongly committed to each other and their future together.

Having lived with discordance for eight months when interviewed, the woman described herself as “very happy” and lucky to be in a relationship with such a man. Both the man and woman said they were using condoms 100 % of the time and, while this was not ideal, both said it was not a major issue. More than anything, the man seemed preoccupied with his fiancée’s health, so much so that the woman gently complained the man was overprotective now. Overall, then, this couple appeared to be coping with this issue surprisingly well and compared to other couples, their relationship seemed uncomplicated.

Yet in his interview it was clear this man was more conflicted about this relationship. He was in fact not completely committed to staying in this relationship but instead was carefully weighing all his options. When asked if he planned to marry his fiancée, he said, "I hope. That is a question that is actually puzzling". Unlike the man in Couple A, this man clearly articulated how much he cared for his partner and her wellbeing but, like the other man, he too was seeking information about his options, including by participating in this study.

He and his fiancée received much support from counsellors at the local health clinic and were seen as a special case that the counsellors hoped could overcome this challenge and stay together. The woman clearly appreciated her partner and suggested that staying in this discordant relationship was not something most of his male peers would do, saying:

> Someone has to have courage to do that, actually. Those who do it actually have to be courageous. Not everyone can be … [other men] have problems with dealing with such issues, but those who are courageous, yes, they can deal with them.

The man also discussed how in the eyes of some of his male peers he could legitimately leave this relationship. When he first learned his partner was positive, he said:

> I thought: should I just get rid of this person? I had friends I asked and everybody was like 'Run away. Run away for your life!' And I am like, I was hesitant … Up to now it is a question which is puzzling me.

Having children was also part of the puzzle for this man. While he was aware drugs could help them have a HIV-negative child, he did not rule out eventually taking a second wife but only for having children, saying:

> If it is for sex I would say it is wrong because somehow you might conceive this HIV from this person you are with. Aren't you then spreading it to the second person? So I think it is not okay.

At the close of the interview he made his ambivalence clear, turning to me and asking:

> Would you abort the whole relationship or would you continue with it? The truth is I don't know. She is not a bad person and you cannot get someone who is 100 %. So if someone can give you 80 per cent of what you ever desired you take it, because when you look for the 20, you have the 80 per cent at home and you are looking for the 20 outside the home. There will be implications.

Thus, couples A and B were different in many key aspects, including their socioeconomic status and relationship dynamics. Nonetheless, both men were carefully considering their options and weighing the intimacy and social status that comes through marriage with the stigma and challenges posed by their partner's HIV status. Ultimately, the decision to continue the relationship was the man's and these men remained largely in control of their own risk of HIV infection.

Living with Discordance When the Man Is HIV Positive

The second set of couples (C and D) indicates how different the implications of living with discordance can be when the man, not the woman, is HIV positive. Couple C had been together for 20 years and had four children together, including the youngest, who was four years old. The man was a casual labourer and the woman sold produce from home, and their combined income provided only the basics for this family. This couple saw the man as the leader of the home, and while they claimed they discussed issues together, both said the man was the ultimate decision maker.

The man tested positive in 2003 and, as noted above, believed he was infected by a partner in another, more informal long-term relationship. His wife had been pregnant in the meantime and had therefore been tested for HIV and knew she was negative. Although the man was slow to disclose his status, both the husband and wife stated the man did eventually take full responsibility for bringing HIV into their relationship. When discussing this, he criticised his male peers, saying, "That is why you still see AIDS. Because a man is not able to tell a woman that he is HIV positive. Then he keeps on loving other women".

Living with discordance proved challenging for this couple in part because the woman did not want to use condoms, fearing they could break or provide inadequate protection. Instead, the woman demanded the couple stop having sex completely. The man agreed to this arrangement under the condition he could still have sex with the woman who infected him, as well as with another woman he also saw more casually. Thus, since 2005 this couple had abstained from sex altogether. The wife described the logistics of their relationship this way:

Wife:	The good thing is that I made a gap between the two of us. He sleeps here [chair] and I sleep on the other side with my children [between us] … I think he feels good about it.
Interviewer:	Has he ever demanded sex from you?
Wife:	No, because we no longer have sex together. I tell him to go and have it with his second wife or maybe the other one will be interested.

When asked why he consented to this agreement, the man primarily emphasised the need to look after their children:

> I am HIV positive. I got it and my wife is HIV negative. If I spread it to her, where will this leave our children? What makes most people in Africa so sick is the worry about their children … so if you can identify a person who can remain with your children, like their mother, then you can be hopeful that even though you may die you have left your children with someone to care for them.

Living with discordance, therefore, provided the woman in this relationship with new leverage – leverage she used to negotiate a sexual agreement that protected her from HIV infection. While this arrangement appeared successful in this regard, the agreement had also changed the nature of their relationship. The woman was now ambivalent about the relationship, saying:

> I no longer trust him … I am no longer interested [in the marriage]. I am here just for the sake of the children. I am fed up with him.

The end of the sexual relationship was a facet of her ambivalence, and she said that, "I do love him but the other bedroom love is now gone but I still like him".

These changes were also evident in how the man now described the relationship. When asked if their relationship was still strong without sex, he said, "she is now my sister". Their agreement also remained a sensitive issue for this man and he was reluctant to discuss the logistics of their relationship, saying:

> Do you know what a bedroom is? It is a place where secrets are kept. If you quarrel and if she refuses to have sex with you, you leave the bed and sleep somewhere down on the floor. But it is not a matter of shouting to inform everyone that your wife has refused to have sex with you.

Clearly, not being able to have sex with his wife was stigmatising for this man, a fact that may make maintaining this agreement over the long-term difficult. Thus, the woman in this relationship negotiated some degree of protection from HIV infection but her safety remained tenuous.

Couple D was a polygynous marriage where the man had two wives living in two different houses. The interviews indicated this man was quite controlling and he believed men were innately superior to women. The wives expressed some ambivalence about such notions of men's natural superiority, with the second wife saying, "men should remain with such rights but if it was possible it would be better for women to be with some responsibilities". Both wives, however, were critical of aspects of the husband's domineering behaviour. In addition, it was evident that the wives were not friendly with each other and competed for favoured wife status.

Although he agreed to participate in this study, the husband did not want his HIV status widely known, saying:

> It is not good to talk about it because it is not good to say, 'So and so has this type of disease'… you keep it as a secret.

Neither wife said she cared to discuss the husband's status with him. Both said they had forgiven him and were now focused on maintaining peace in their marriages. As the first wife said:

> He didn't want to get the disease but it just happened to him so you leave it and you take it as an accident … So that is how I changed, I am no longer getting angry … Even if I get angry, I just go somewhere so he cannot get to know.

The second wife, however, claimed when her husband disclosed his status he feared she would divorce him. This gave the second wife new leverage which she used to get an official introduction ceremony with her husband, a major step towards a formal marriage. This woman had always resented that her husband was formally married only to the first wife and now claimed she was, in fact, the favoured wife. When asked why her husband agreed to the introduction ceremony now she said:

> For me I think, according to the period we have been together, and the AIDS issue also happened. OK, first you have to get angry because of the fear but I forgave him about it and secondly about those children [from the wife who died]. I am the one who has taken care of them.

Like the woman in Couple C, this woman utilised her new leverage to obtain something that would have otherwise been difficult to negotiate. Safe sex was a concern but she also used her leverage to improve her social status by having a formal introduction ceremony.

The second wife also claimed that only after her husband disclosed he was positive was she able to get him to agree to always use condoms. Everyone in Couple D claimed to be using condoms 100 % of the time. However, the man was adamant that he disliked condoms, saying:

> Sometimes I agree to use condoms but I hate them so much … it makes me feel bad and I think one time I will run away from my wives, that is what I think.

The safety of the women from HIV infection, therefore, was again tenuous in this discordant relationship. It is possible the husband may eventually grow tired of using condoms and one wife may acquiesce and agree to unprotected sex to secure her status as the favoured wife.

Similar relationship dynamics were evident in two of the three additional discordant couples with HIV positive-men. In one, the woman used her new leverage to get what she most wanted, namely love and greater affection from her husband. In the other couple, the wife attempted to use her leverage to make her husband use condoms and remain monogamous. Unfortunately, unlike Couple C this proved quite difficult and the woman was contemplating leaving her husband out of frustration and to safeguard her health.

Discussion

These discordant couples reveal how deeply gender and health are intertwined. The impact of gender relations on health is evident in how all four of the positive individuals became infected with HIV. Both women described having limited sexual experiences that largely conformed to normative expectations of proper monogamous female sexual behaviour. However, both became infected by men who either did not know, or were unwilling to disclose, their own HIV status. Their monogamy, therefore, did not protect them from HIV infection and may in fact have created in them a false sense of security about their vulnerability to infection.

For the HIV-positive men, both became infected as they too pursued sexual experiences that largely conformed to normative expectations. Entrenched notions of male sexual privilege, especially having multiple sexual partners, made these men especially vulnerable to infection, probably in ways these men themselves did not fully grasp. In addition, both had trouble disclosing their status to their wives, which too can be seen as tied to dominant notions of masculinity in this context (Wyrod 2011).

Once in discordant relationships, the experience of discordance shaped the gender power dynamics in the couples. Discordance worked to either consolidate or moderate male power, and the effect of discordance on power dynamics was primarily determined by who in the relationship was HIV positive.

When the woman was positive, the men's power was largely strengthened, although this new health problem did prompt some reassessment of certain hegemonic masculine norms by both men. They both made it clear that they felt pressure, especially from male peers, to leave their HIV-positive partners. Staying in the relationship was a challenge to this simple solution to their problems, even if the men posed such challenges privately, kept their discordant relationships secret, and were ambivalent about their path forward. It is important to underscore, however, that in both relationships the men's control over decision-making was intensified by discordance, even in Couple B who, when interviewed together, stressed their collective decision-making.

In contrast, when the man was HIV positive, both men were eager to maintain their relationships for both social status and the care and support the relationships afforded them. This resulted in the women gaining new leverage in what had been largely male-dominated relationships. This is not to suggest, however, that men's power was significantly challenged but it was moderated in important ways. In addition, this new leverage did not guarantee that these women were safe from HIV infection, and both remained more vulnerable than the men in couples A and B.

These findings resonate with other research on masculinity and health, including how subtle reworkings of masculinity emerge in response to significant new health problems (Creighton and Oliffe 2010; Emslie et al. 2006; O'Brien et al. 2005; Wyrod 2011). Shifting conceptions of appropriate male sexuality were especially evident in both of the couples where the man was HIV positive. All three women in these relationships voiced criticisms of the husband's sexual behaviour and expressed anger or resentment that their partner's sexual behaviour had brought HIV into their relationships. In turn, both men had accepted aspects of this critique to varying degrees. While neither questioned that men had a right to multiple sexual partners, they both reflected on the consequences of their actions. In the process, both men abdicated some power and control in their relationships. This was especially true of the man in Couple C who agreed to stop having sex with his wife. This couple's sexual agreement was premised on the man recognising that his wife's demand to end sexual relations and her right to some degree of sexual autonomy were legitimate and should be respected.

A useful way of framing the effect of discordance on femininity is to consider the implications for women's agency. While the agency of the HIV-positive women was constrained by discordance, it had the opposite effect for the HIV-negative women. Coming to terms with this new health problem provided a rare opportunity for women to renegotiate some of the terms of their relationships. In line with gender relations theory that posits multiple and dynamic femininities (and masculinities) in any given gender order, the renegotiations advanced by women in couples C and D were quite different. The former focused on greater sexual autonomy while the latter was intent on being publicly recognised as an official second wife who dutifully accepted her husband's authority. In this sense, acknowledgement of serodiscordance was a key moment for these women to exert agency in otherwise largely unequal relationships and diverse notions of femininity animated how they directed their agency.

Serodiscordance and the Dialectics of Gender and Health

Overall, this study indicates that a serious health issue (living with HIV discordance) did prompt changes in the gender dynamics of these relationships. These changes included (i) a degree of critical engagement with dominant masculine norms on the part of the HIV-negative men, especially whether a man should abandon an HIV-positive partner; (ii) an opportunity for some heightened agency and control for the HIV-negative women and (iii) a willingness to accede some power in the relationship by the HIV-positive men. None of these shifts was transformative of conventional gender power dynamics and, in fact, tensions were at times resolved in ways that reinforced conventional gender roles, such as the responsible husband and the dutiful wife.

Nonetheless, the way these couples responded to a serious health issue did prompt a reassessment of their relationship dynamics and destabilised certain normative aspects of gender relations. I would not suggest that living with discordance resulted in these couples fully *undoing* gender. However, their experiences do indicate that a health crisis has the potential to change relationships dynamics, and these changes have important implications for both doing and undoing gender.

These conclusions are supported by other research on serodiscordant couples. In another study in Kampala, Bunnell et al. (2005) found discordance could destabilise gender norms and power dynamics. This included men refusing to abandon an HIV-positive partner and an HIV-positive man agreeing to a sexual contract with his wife that allowed her to find a new male partner provided she continued to care for her husband. Beyond Africa, research on discordant heterosexual couples in Puerto Rico also found that living with HIV prompted critical reflection on gender norms, especially among men, such that "all men in this study expressed a need to change their traditional dominant ideals … [and] the need to incorporate some non-traditional male gender roles" (Orengo-Aguayo and Perez-Jimenez 2009:37).

My findings on discordance and women's agency are also supported by other related research. Stevens and Galvao (2007) found that in the USA HIV-positive women struggled and largely failed to enforce safe sex with their negative partners. In this way, discordance also worked to consolidate male power in these relationships and the authors similarly conclude that the effect of discordance on power dynamics is dictated by the partner who is positive. In addition, the new leverage that HIV-negative women gained in my study finds an interesting parallel in a study of gay Scottish couples living with discordance. Davis and Flowers (2011) describe how HIV-negative men gained an upper hand in the relationship and could use this leverage to ask for unprotected sex to prove their devotion to their partner.

This resonates with the complex ways the HIV-negative women in my study used their newfound agency. It also underscores a key point made by Persson and Richards (2008) in their study of discordant couples with HIV-negative women. They stress that the interrelationship of serodiscordance and gender is multifaceted and that "analyses that hinge on generalised gender power relations may hinder rather than help our understanding of the diverse, complex ways HIV-negative women negotiate serodiscordance in their sexual lives" (Persson and Richards 2008:800).

My study also has important implications for HIV prevention, especially given the intense new focus on antiretroviral treatment as a form of HIV prevention. Biomedical interventions cannot be focused on drug distribution alone and need to address how living with HIV shapes gender dynamics in discordant couples. These dynamics determine when a couple seeks treatment, how they adhere to a drug regimen, and how they maintain their relationship as a discordant couple. While discordance threatens relationships, my research indicates that some men with HIV-positive partners are eager to remain committed to their relationships if they receive appropriately discrete counselling. Similarly, a woman with an HIV-positive partner may be able to use her new leverage to convince her husband to adopt health practices that ensure she does not become infected. This study also makes clear, however, that women may use this leverage to buttress their relationship, thereby prioritising the social risks associated with a failed marriage over the biological risk of HIV infection.

While AIDS is in many ways a unique disease, this case study of HIV serodiscordance reveals more fundamental insights about the dialectics of gender and health. Like living with cancer, heart disease and depression, AIDS can prompt reassessments of health behaviour that may then destabilise, undermine or explicitly challenge conventional ways of doing gender. Such reworkings are complex and often entail contradictory processes that undermine certain normative aspects of gender relations while reinforcing others. Yet, as this study and others make clear, there is a potential to undo gender in doing health differently, and understanding how gender and health are intertwined requires remaining attentive to the dialectical nature of these processes.

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Planning to Be a Parent in HIV Sero-Different Relationships: A Critical Gender Analysis

Carmel Kelly and Maria Lohan

Introduction

Effective HIV treatment has improved individual health outcomes for those living with HIV, reduced the risk of mother to child transmission and, importantly, also reduced sexual infectiousness to negative partners, making pregnancy an achievable goal for couples affected by HIV. The data presented in this chapter were drawn from a qualitative study of reproductive decision-making and experiences of pregnancy and childbirth following HIV diagnosis (Kelly et al. 2011, 2012, 2013), conducted in Northern Ireland during 2007–2010.

Of note, these interviews were undertaken before results of the HIV Prevention Trials Network [HPTN052 study] and PARTNER studies provided unambiguous evidence that a person on effective HIV treatment was essentially uninfectious to a sexual partner (Cohen et al. 2011; Rodger et al. 2014). At the time of our study, there was growing evidence of the effectiveness of antiretroviral treatment in significantly reducing the risk of transmission, prompting the publication of the Swiss statement in 2008 (Vernazza et al. 2008), but UK guidelines had yet to embrace Treatment as Prevention (TasP).[1] In a rapidly changing medical field, the central questions in this chapter examine the ways HIV affects gender relations and identities and the way they, in turn, intersect with decisions and socio-cultural meanings of intimate relationships, reproduction and parenthood. Drawing upon 18 in-depth interviews with four men and six women from diverse cultural backgrounds living in Northern Ireland, we explore how traditional ethno-gender scripts are negotiated

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[1] Treatment as Prevention (TasP) is a prevention intervention aimed at bringing forward the time when treatment is given to people with diagnosed HIV infection in order to prevent onward transmission of HIV to sexual partners and ultimately to reduce HIV within the population.

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and challenged as sero-different couples make decisions about their sexual relationships and, more specifically, reproductive decisions, including having unprotected sex in order to conceive “naturally”.

Background

Not surprisingly, research has shown that the desire to become a parent among heterosexual women, men and couples affected by HIV is no different from the general population (Nattabi et al. 2009; Barnes and Murphy 2009; Sherr 2010). However, the individual makeup of a couple, whether one or both are HIV positive, presents different needs in terms of prevention and reproductive counselling. Traditionally, for sero-different couples, added to concerns for their unborn child were concerns that the act of conception risked sexual transmission of HIV from one partner to the other. For many couples, options such as sperm washing, assisted conception, or self-insemination would all have been discussed with their clinicians. For HIV-positive men, sperm washing could be costly and not easily accessible, while donor insemination denied the opportunity for biologically fathering a child. For HIV-positive women, using a self-insemination technique, such as a syringe, eliminated the risk of HIV transmission to her negative partner, but it was also seen by some as too clinical and neither culturally or personally acceptable (Cibulka 2007; Mmeje et al. 2015).

However, even before the HIV landscape was changed by the celebrated TasP trials, scientists had cautiously welcomed the Swiss statement, but also harboured some doubt, leading them to guide HIV-positive people to continue using condoms (Moyer and Hardon 2014). However, qualitative studies of the experience of heterosexual sero-different couples had revealed a reality of inconsistent condom use, frequently linked to the negative symbolic significance of condoms within a monogamous relationship (Stevens and Galvao 2007; Milam et al. 2006; Van der Straten et al. 1998) and also the desire to conceive without interventions (Beyeza-Kashesya et al. 2009; Doyal et al. 2009). In addition, our own and other studies challenged a solely biomedical risk perspective, which failed to consider how personal priorities and broader social meanings and desires are central to the negotiation of risk in sero-different sexual relationships (Kelly et al. 2011; Persson 2010; Moatti and Souteyrand 2000; Ridge et al. 2007).

Theoretical Perspectives

Much of the strongest scholarship on reproduction and pregnancy arises through feminist approaches since its second wave in the 1970s when women’s control over their reproductive bodies became a central focus in understanding and achieving women’s liberation. However, despite the much greater understanding of the diversity of women's experiences in relation to "normal" reproduction as well as technology-assisted reproduction, contemporary feminist scholarship has been slow to integrate men's experiences into analyses on the gendered and social construction of reproduction among couples, including in the context of HIV (Sherr 2010). Whether heterosexual or homosexual, HIV-positive or HIV-negative, we know relatively little about men's reproductive concerns, reproductive decision-making and reproductive experiences, or indeed how men contribute to women's reproductive decisions and their reproductive health more broadly (Dudgeon and Inhorn 2004; Culley et al. 2013).

Critical studies of men and masculinity (CSM) offers an approach to empirically and critically explore men's involvement in reproduction, which can build on feminist understandings of the gendered nature of reproduction (Lohan 2015). Annandale and Clarke (1996:33) claim that such an approach provides a means of understanding reproduction in inter-relational terms rather than as women's difficulty. CSM arises from within feminist theory and queer studies (Hearn and Morgan 1990; Kimmel and Mahalik 2005) and serves to open up critical explorations of the social construction of gender in men's lives, as well as exploring relations between men and between men and women (Lohan 2009). According to Hearn and Morgan (1990), it is a way of exploring how men sustain as well as challenge patriarchy in daily relationships with women and it is a way of theorising men's lives which does not re-exclude women's. This feminist approach to understanding men and reproduction is important in terms of keeping a structural dimension of gender relations in society active as an analytical devise. CSM's critical contribution to understanding men and reproduction is its ability to hold multiple threads in productive tension. Specifically, it retains an analytical focus on how men's greater control of material and symbolic resources impacts on women's reproductive choices and on wider sexual and reproductive norms in society (Chant and Gutmann 2002; Dudgeon and Inhorn 2004, 2009), while also seeking to understand how men challenge gender norms and gender structures alongside women.

Theories of Intimacy in society offer another analytical framework for exploring the inter-relational context in which decisions about reproduction are made. Here the focus is less on gender dynamics and more on the social construction of contemporary romantic relationships. Essentially, the argument as represented in the writings of European theorists, such as Jamieson (1998), Giddens (1992), and Beck and Beck-Gernshein (1995, 2002), is that contemporary relationships are characterised by a new form of intimacy that gives heightened importance to love and equality in the emotional exchange, replacing the traditional bonds for relationships based on morality and the importance of the marital institution itself, and thus resulting in relationships that are more "democratic" but also inherently more unstable. They argue that the romantic bonds of the nineteenth and twentieth century were based on taken-for-granted patriarchal traditions of male privileges and power, whereas the new intimacy is based on self-conscious decision-making about relationships and how rights and responsibilities are to be shared between partners, regardless of sex.

In this chapter, we draw on feminist theory, including CSM, as well as theories of contemporary intimacy in society, to explore men and women's perspectives on reproduction in the specific context of an HIV sero-different relationship. We highlight both similarities and differences in the way men and women understand and manage reproduction in relation to their identities, their relationship, and any risks to their health. We are interested in how the condition of HIV as well as the biomedical strategies for preventing transmission are negotiated in sero-different relationships as men and women plan and pursue parenthood.

Methodology

Setting

The data presented in this chapter were drawn from a qualitative study conducted during 2007–2010 with heterosexuals living with HIV in Northern Ireland. Although HIV prevalence in Northern Ireland remains lower than in the other UK countries, the percentage increase (422 %) in annual new diagnoses in Northern Ireland between 2000 and 2013 is highest of the UK countries (Public Health Agency 2014). Heterosexual transmission has assumed increasing importance since 2003 and now accounts for 41 % (436/1062) of new diagnoses made to date. The majority of heterosexually-acquired infections were acquired outside the UK. Explanations for the general increase include earlier detection through increased testing and also an increased trend in migration to Northern Ireland as a result of the peace process and the accession of ten Eastern European countries into the European Union in 2004 and 2007.

Sampling Procedures

The study sample was purposeful: medical staff at the regional HIV clinic at the Royal Victoria Hospital in Belfast were asked to invite women and men who were actively trying to conceive, were pregnant, or were the HIV-positive partner of a woman who had recently given birth. In particular, three groups of women were sought for inclusion in the study and all three are reflected in the narratives presented in this chapter: those who were aware of their HIV diagnosis prior to pregnancy ($n = 2$), those who learned of their diagnosis in antenatal screening ($n = 3$) and HIV-negative women choosing to conceive with an HIV-positive partner ($n = 1$). The men's narratives presented are of HIV-positive men in sero-different relationships whose partner was pregnant ($n = 3$) or had recently given birth ($n = 1$) at the time of their inclusion in the study. Ethical approval for the study was granted by the Office of Research Ethics Committee for Northern Ireland (ORECNI/Ref: 07/NIRO1/68) and the School of Nursing & Midwifery at Queen's University Belfast.

Data Collection and Analysis

The majority (17/18) of interviews were conducted in participants' homes, during 2008 and 2009 and lasted between 60 and 90 min. In recognition of the multi-staged experience of the reproductive journey, a prospective repeat interview model was used, with interview schedules chosen to mirror the period of transition from reproductive decision-making through to parenthood (Miller 2000). The number of interviews with each participant was influenced by their stage of reproductive experience at the time of the first interview, but the endpoint was always in the postnatal period, approximately six to eight weeks after the birth of their baby. One woman was only interviewed once as she did not become pregnant during the study timeframe. Four women were interviewed twice and another woman took part in four interviews. Only one man was interviewed twice, with the other three men participating in one interview.

Data analysis was informed by the above theoretical frameworks, which acted as sensitizing constructs (Bowen 2006), as well as the methodological literature on narrative analysis, where the object of investigation is the story itself (Riessman 1993). The purpose of narrative analysis, as defined by Riessman (1993:2) "is to see how respondents in interviews impose order on the flow of experience to make sense of events and actions in their lives". Polkinghorne (1995:5) identified two types of narrative analysis. The first, which he described as the "analysis of narratives", produces paradigmatic typologies by identifying common themes and relationships between themes within the data. The second approach, "narrative analysis", transforms the data into an emplotted story that gives meaning to the data. A combination of both approaches was used to analyse the data from this study, involving horizontal and vertical reading of the data. Harvey et al. (2000) explain that reading vertically involves reading the whole narrative people give about their lives from start to finish, identifying major themes that seem to recur, while horizontal reading involves reading across the interviews so that relationships between themes are identified.

Participants

Four of the six women were born in the island of Ireland, one of whom was with a partner born in Africa. This woman, the only HIV-negative participant, was, at the time of interview, experiencing her second pregnancy with her HIV-positive partner. Another woman, born in Africa, was partnered with a Northern Irish man, and the sixth woman, born in Eastern Europe, was partnered with an African man. Both of these women learned of their HIV diagnosis through routine antenatal screening during their pregnancy. One of the Northern Irish women, interviewed during her third pregnancy, had also been diagnosed HIV-positive through antenatal screening four years previously, during her second pregnancy. The other two Northern Irish women were aware of their HIV status prior to pregnancy. All four men were African, three of whom had African-born partners and one who had an Irish-born partner. Three of these men had commenced antiretroviral therapy shortly after their diagnosis for their own health.

Findings

Negotiating Gender Identities and Emotional Intimacies in Sero-Different Relationships in Relation to Experiencing Pregnancy and Parenthood

The desire for children, the social importance of pregnancy and the desire to restore their own and their partners' sense of normality and well-being post HIV diagnosis, were evident in both the men and women's accounts of pursuing pregnancy and parenthood. Although four of the HIV-positive women had had children prior to their diagnosis, all of these were conceived in previous relationships. For these women, having a child for, and with, their current partner was a particularly strong motivating factor to conceive and continue with a pregnancy. There was a sense in which this was a gendered script of what women could do for their men through their pregnant body, to restore their relationship which for some had been fractured by the HIV diagnosis. Likewise, for the only HIV negative woman in the study, the significance of her and her partner's first-born was evident in her account; it was something she could give her partner to counterbalance the negative impact of his diagnosis on his health and self-esteem. The decision to have a child together signified their loving relationship and renewed faith in his health post-diagnosis.

> When [partner] was there with him [baby], just seeing him with him, you know, it was just like an amazing vision, you know. It was something that [partner] never thought was ever going to happen and the three months that he had gone through and was contemplating suicide and had planned it twice and came very, very close, thinking that he was never going to have a family and it was never going to happen. That was kind of a moment that I felt that I had given him something that he never ever thought he was going to have (Sophie, 30–34, HIV-negative woman).

The men's narratives also reinforced the notion that planning a pregnancy and being a father was central to the restoration of their sense of masculinity and their health post-diagnosis. Fatherhood, or the expectation of fatherhood, provided a sense of usefulness and responsibility. It provided an orientation towards the future for all of the men in this study and, even more profoundly for some who had entertained thoughts of suicide, quite simply a reason to live.

> It [HIV] makes me more [so] anxious that I want to die. But when I am here with my family I feel different. I feel as I want to live. To keep going. When I am with my kids and my wife I feel good. The things I told you about being useful, you know, when I am at the hospital talking about these things I feel less useful. I feel as if I don't want to live anymore.

> But when I am with these people who need my help, who need my support, who look for me as a husband, who look for me as a father, you know, I feel ok. I feel that even though I am living with a problem like death, you are still being alive (Henry, 40–45, HIV positive man).

Amongst this small group of African men living in the UK, there was a desire, comparable to the women, to pursue pregnancy and parenthood for the sake of "giving" to their partner and seeking to satisfy their need to be a parent. For example, in the following narrative Henry talks about his awareness of his need to give the opportunity of motherhood to his partner, to satisfy her. Implicitly in Henry's excerpt, however, there is a slightly different construction of gender. Below, motherhood is less described as a type of "usefulness" and more as an innate drive of women who are "in the condition to have another baby".

> Sometimes I feel it is better stopping this risk to have a baby. I have two babies, is ok. But she feel she is young. She is in the condition to have another baby. I have to satisfy her. Of course then I decide to have it … And the other thing is that I want to satisfy her. If you are living with your wife you have to be useful for her. It is not only the things you want to do, you have to do. You have to satisfy her like she satisfy you. If you can't do these things for your wife, she could refuse you. You start thinking that she could find another one who could do it with her (Henry, 40–45, HIV-positive man).

The women in this study also spoke about the restorative effects of pregnancy for themselves following their own HIV diagnosis. Pregnancy, it would seem for women who were HIV-positive in sero-different relationships, could, in many ways, become a route back to a positive gender identity and a positive relationship with their partners. The embodied stage of the pregnancy itself held the transformative power to restore some of the women's sense of womanhood, which had been challenged by internalised images of HIV-positive women. For example, Emma had only recently been diagnosed HIV-positive when first interviewed. She and her partner, who had tested negative, were actively pursuing conception through assisted fertility techniques. We start with an extract from her third interview, when she was in her third trimester of pregnancy. She talked about how she had regained her confidence and felt more "like her old self", which she attributed to her pregnant body and her partner's love of her shape.

> And I do think being pregnant is a big thing, you know, because I don't mind. [Partner] likes looking at me now, he thinks, 'god, you are gorgeous with the boobs', you know. And he is lovely because he is really loving the shape of me which is nice. He is loving it and I think the fact that he is loving it as much as he is makes me feel a hell of a lot better. He is just looking at it thinking it is amazing, you know (Emma, 35–39, HIV-positive woman).

The relevance of this extract is all the more poignant when juxtaposed with an extract from her first interview, conducted shortly after her HIV diagnosis when she was trying for a baby. It provides insight into the ways in which her diagnosis had created a "spoiled identity" (Goffman 1963), with the consequence of disrupting her relationship. In this extract, it is clear that the relationship between her body and her world was disturbed and her way of life traumatized. However, as the first extract illustrated, the pregnancy became an opportunity to *re-embody* an unspoiled identity; and it is her husband's attention to her changing body which allowed her to move from a very negative "dirty" body image to one that could be enjoyed by them both.

> And he [partner] keeps saying, 'but you haven't changed' and I say, 'well that is ok for you to say but I have'. You know, I have changed. Maybe not physically but I'm looking at myself and putting it into a physical context. But that is one thing I know, I don't look at myself the same way as I used to do. And that is one thing that [partner] has noticed. I will say, 'naw don't be taking that photograph of me' or if I see a photograph of me, 'it's like, god look at the shape of me in that'. Really critical, whereas I wouldn't have been like that … I think it's like a dirt, not a dirty feeling, but you know what I mean? It's that feeling that you just aren't alright in there, you know. That there is something in there that is bad, I don't know. I haven't analysed it too much but it is just that – I think it is just that dirty feeling, that is the only way I can put it, it is a dirty feeling that you know you are not clean, as such (Emma, 35–39, HIV-positive woman).

So far, we have argued that there were subtle gendered differences in the men's and women's narratives. For example, the women's descriptions centred on the embodied sense of pregnancy, while the men described how fatherhood provided a feeling of usefulness in life or how pregnancy gave purpose to their partner. Overall, however, there was a sense that both the women and men in this study experienced the planning of pregnancy with their partner, as well as pregnancy and parenthood, as a means to re-negotiate their emotional intimacy, to offer something positive to each other in their relationship and as a means of repairing their own or their partner's spoiled gender identity post-diagnosis.

Ethno-Gender Scripts and Power Relations

We turn now to what we regard as differences in the ethno-gender identities of men and women, as well as shifts of power in intimate relationships as described by the participants. There was some evidence that sero-difference can alter gender power relations and cause a shift in the power base of decision-making towards what Giddens might describe as a democratisation of intimacies (Giddens 1992). Traditional discourses of masculinity, particularly in African cultures, position men as the decision-makers in sexual and reproductive matters. Moreover, the African men in this study all described the cultural and gendered expectations for African men to procreate. For example, Robert, who had no previous children prior to his diagnosis, described the prospect of a marriage without children as "a shambles", explaining that "as an African, marriage means children", and as a Christian, "marriage and children is part of God's plan originally".

> If you are married today, in the morning, in the evening they want to know if you have children. That is an exaggeration but when you get married, they ask you, 'do you have children?'… They were asking all the time. So when my wife got pregnant, actually it was like a miracle (Robert, 40–45, HIV-positive man).

However, the narratives of these HIV-positive African men revealed how HIV could bring about a shift in ethno-gender power relations, from the man as the dominant decision maker towards negotiating reproduction not as a God-given obligation (as above), but rather as a woman's choice. For example, James admitted that his HIV-positive status made him feel powerless and insecure when it came to decision-making discussions.

> Because of my situation, I think I was letting it be her decision. And she said to me, 'it is our decision, it's what you want as well'. And to me, that was her being supportive. And it did help, you know. Because I think there were times when unfortunately the smallest things could trigger insecurities, you know. Sometimes, you wouldn't want to say that you think of yourself as less of a man [because of HIV], but you know, you feel you haven't as much power or right to some of the decisions, when it comes to things like that (James, 30–34, HIV-positive man).

James also described a period of uncertainty about his claim on the right to remain married to his wife, feeling instead that the power to decide the fate of their relationship should rest with her.

> I went through a time of being insecure, you know. I remember saying to [wife], 'listen I don't want you to feel trapped, you know. If you feel you can't deal with it, follow what your heart is telling you, and just be very open with me, you know'. But [wife] was like, 'we are in this together', and that has really helped (James, 30–34, HIV-positive man).

According to James' narrative, his African-born wife was clearly trying to bring a sense of equality into the emotional exchange by insisting that they were "in this together" and that any decision was "our decision". In this sense, his narrative suggests that both partners in the relationship were negotiating a new "democratized" intimacy particular to them and less with reference to the cultural gender norms in their countries of origin.

Wider gender differences emerged in relation to sexual risk-taking post-diagnosis in these sero-different relationships. At the time of this study, the participants were clearly aware that having condomless sex in the context of sero-difference posed a risk of HIV transmission, albeit small, and were cognisant of the advice of their healthcare teams. Back then, clinicians accepted that viral suppression through effective HIV treatment dramatically reduced the risk of infectiousness, but they still found it problematic to advise sero-different couples that the transmission risk was negligible, and would therefore have been advocating assisted conception rather than condomless sex. However, both the men and the women justified and rationalised condomless sex, not only with respect to their desire to conceive, but to conceive "naturally" without the further use of assisted reproductive technologies.

> You know, having unprotected sex with someone who is HIV-positive to become pregnant, to another person would be like, 'what, you have done what? Are you crazy?' you know, whereas to us now it's like, you know, yeah, if you want to have another one [child] (Sophie, 30–34, HIV-negative woman).

Nonetheless, both the HIV-positive women and the HIV-negative woman were likely to only take this risk in the context of trying to conceive, and condomless sex was described in their narratives as being carefully timed around planned conception, regardless of which partner was HIV-positive.

> We done a bit with the condom with the hole in it too, so that seems to be a better job [laughs]. The syringe thing is kind of an awkward auld thing. [Partner] would rather do it with nothing at all, but then you would have the worry after. Even though your woman [the doctor] said, like she did say you could try it with my viral load being undetectable so long, but you would be worried then after (Caroline, 35–39, HIV positive woman).

For some HIV-positive men however, condomless sex offered rewards beyond achieving the desired pregnancy. In addition to the physical pleasure, condomless sex was a symbol that implied commitment from their partners. Thus some of the men described having or longing for sex without a condom outside of the context of timed sex for conception. For example, for Henry, condoms were a constant reminder of his HIV status, which was imbued with negative representations of HIV as something dirty and contagious. In this narrative, we hear that Henry appreciates that he has to negotiate with his wife around this, but, at the same time, he tells us that sometimes he takes risks to enjoy the pleasure of condomless sex with his wife.

> Sometime I tried to use the condom, the condom broke and I go with her without the condom. I know it is totally different when you use the condom and when you are not using. It is totally different. To live your normal life, for me, it is going without a condom. To feel well when you do the sex … When the woman ask you, your wife ask you [to use a condom], things like that, you feel dirty, you know, you start to feel like you are not a man anymore (Henry, 40–45, HIV-positive man).

Discussion

The findings presented here are drawn from a small study in a part of the high-income world where reproduction in the context of HIV is becoming increasingly normalised and is supported through the publically available National Health Service (NHS). The findings are limited by the small number of men in this study, but are strengthened by the repeat interview methodology, which was able to follow men and women as they traversed one of the most momentous parts of their lives: through conception and pregnancy, into parenthood. In particular, the findings open up a traditionally unexplored area of HIV-positive men's lives and represent a renewed push from within feminist studies to understand men's lives alongside women's.

While feminist studies and feminist activism have done much to re-claim women's rights to control their reproductive bodies, such success has unwittingly re-constructed family planning and reproductive health as women's responsibility, as women's risks and as being synonymous with femininity. According to Sherr's review of 1122 studies of pregnancy intentions, 66 explored these intentions in the context of HIV, but only 14 studies reported on men's experiences (Sherr 2010). Reproduction, Sherr argued, almost always happens in couples, so missing men's perspectives is missing a critical dimension of reproductive choices for both partners in sero-different relationships. For scholars of critical studies of men and masculinities, it is an opportunity to understand how men and women challenge, as well as stabilise, gender dynamics in their intimate relationships, without losing sight of structural gender inequalities.

The findings tentatively reveal gender similarities and differences in the men's and women's reproductive decisions and the ways they made sense of their choices within the context of their sero-different relationships. In terms of gender similarities, the desire for children, the social importance of parenthood and the desire to "give" something life-affirming to one's partner post-diagnosis were evident in both men and women's accounts. Perhaps unsurprisingly, one of the most notable commonalities was that the HIV diagnosis had brought about a severe biographical disruption (Ciambrone 2001) for the participants, prompting suicidal thoughts for some and profound distress for all. Preparing and planning for pregnancy, on the other hand, was a journey of biographical and relationship repair for both fathers- and mothers-to-be. Yet the way participants spoke about themselves or their partners revealed subtle differences in the specific ways that planned parenthood repaired men and women's gender identities. For example, fatherhood or impregnation was described by the men as a means of demonstrating their usefulness, whereas women were more likely to describe their pregnant bodies as an affirmation of their femininity and beauty.

Moreover, the findings illustrated how traditional ethno-gender relations were challenged and new intimacies actively constructed in sero-different relationships in ways akin to the democratisation of emotional intimacy identified in the writings of Giddens (1992) and Beck and Beck-Gernshein (1995, 2002). The African men in this study were especially aware that their traditional heterosexual gender role within the relationship, as well as the perceived "normality" of having sex without condoms, were severely disrupted by their HIV status, which compromised their power within the relationship to make reproductive decisions as well as expect sex without condoms with their partners. New forms of emotional exchange emerged, as did a clear concern for a companionate relationship in ways not dissimilar to those found in Inhorn's (2012) study of infertile couples in the Middle East who were similarly facing reproductive disruptions. Clearly some men struggled with this change of power balance, with the concomitant perceived loss of respect and, for some, the loss of sexual pleasure. Nonetheless, these stories of sero-different couples seeking to become parents together were overwhelmingly stories of couples seeking renewed, shared and equitable love.

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Serodiscordance and Gender Dynamics in Indian Culture

Sangeeta Sharma Dhaor

Introduction and Background

Every society has ways of controlling and guiding the sexual conduct of its members. Indian culture is patriarchal, with strong gender norms and powerful ideals, such as *brahmacharya,* dating back to the Vedic scriptures.[1] Although *brahmacharya* originated in ancient spiritual traditions, its principles of celibacy and chastity are profoundly embedded in Indian culture more broadly, converging in complex ways with the colonial legacy of Victorian sexual morality and the history of Indian nationalism. Despite India's considerable sexual diversity, these ideals hold enormous sway in terms of prescribing and governing "proper" sexual conduct, such as sexual purity and chastity before marriage and sexual fidelity and virtuousness in marriage (Chakravarti 2011; Alter 2011; Nair and John 1998). These cultural restrictions on sexuality reinforce the notion that sexual life begins only after marriage, for the specific and sole purpose of begetting children, sons in particular (Nath and Leonetti 1998).

India's deeply patriarchal culture has created dichotomized gender roles and expectations for men and women. As in other patriarchal societies, these roles are inculcated through the process of socialization, making them resistant to challenge and change (Saraswathi 1999). In the words of Travers and Bennett (1996:64):

> Patriarchal social structures have historically and systematically excluded women from those aspects of society that are responsible for leadership, policy formation, resource

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[1] In Indian traditions, *brahmacharya* is the first of four age-related life stages *(ashrama);* the stage of learning and celibacy. In a spiritual context, the impetus behind *brahmacharya* is the salvation of the soul through the control of sexual energies and renunciation of worldly pleasures.

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> allocation and decision making. The power inequalities associated with such exclusions are reflected and maintained by the social conditioning of women and men where specific roles, attributes and behavior are considered not only gender appropriate but also gender-determined.

As Saraswathi (1999) and Ramasubban (1998) have shown in their work, Indian women's sexuality is especially circumscribed by cultural values and practices, with tremendous premium placed on virginity at marriage. Girls are groomed from childhood to accept and assume a subservient, modest role, and to be the carrier and guardian of family respect and honour, both within their birth family and, upon marriage, the conjugal one (see also Fruzzetti and Tenhunan 2006). Mehta and colleagues (2004:95–96) elaborate on the social status and conditions of young married women:

> Young women recognize that almost all marriages are arranged by parents and they will be marrying a stranger and moving into his household under the dominance of his parents … These young women hold the lowest social status in their new homes … They are expected to conceive within the first year of marriage and to keep getting pregnant until a son is delivered … These women realize that their duty is to be obedient to their husband and in-laws.

One implication of these cultural values is that sex education for young girls, as well as boys, is limited in India. As is the case in other cultural settings, there is a common fear among authorities, religious leaders and many parents that informing young adolescents about sex and teaching them how to protect themselves will encourage them to be sexually active. These social restrictions and the lack of comprehensive sex education is compensated and complicated by sexual literature, foreign films and information made available through peer groups and the internet (Tripathi and Sekher 2013; UNAIDS 1998).

As India becomes increasingly modernised and globalised, the schism between age-old proscriptions and contemporary social reality grows ever wider. To cite one example, in a study with low income college students in Mumbai conducted by Abraham and Kumar (1999), almost half of the surveyed (unmarried) male students had had some sexual experience, with a quarter having had intercourse (for a literature review, see Jejeebhoy 2000). Nonetheless, the social environment as a whole remains sexually conservative. India is a country where discussion about sex or issues related to sex is still taboo, which results in ignorance, shame and resultant neglect of sexual health (Ramasubban 1998; Tripathi and Sekher 2013).

Despite all the cultural measures to control sexuality—or more likely because of them— India now has the third highest number of people living with HIV in the world (UNAIDS 2014). In 2012, the National Institute of Medical Statistics and the National AIDS Control Organisation estimated that the number of people living with HIV in India was between 1.7 and 2.5 million. Of these, 39% are women (National Institute of Medical Statistics and National AIDS Control Organization [NIMS and NACO] 2012). Heterosexual sex among married couples is the most common mode of HIV transmission in India (Marfatia et al. 2013, 2015; Patel et al. 2014). In their review of available literature, statistics and census data, Saggurti and Malviya (2009) estimated that four out of every thousand married couples in India are serodiscordant, with more women than men having an HIV-positive partner, indicating a significant cohort of mixed-status couples considering the size of India's population (see also UNAIDS 2009).

HIV is highly stigmatised in India. As is the case in most parts of the world, the stigma surrounding HIV originates from its initial association with socially "deviant" practices and already stigmatised population groups. The stigma of HIV affects not only those who are infected, but the lived experiences of families and partners as well (Bharat 2001). When a married couple is serodiscordant, both partners share their lives with the virus. Yet, young people enter into marriages and sexual relationships without accurate information about sex and sexuality, or HIV. Their perceptions are coloured by traditional cultural concerns, which often do not reflect real world conditions. Marriages are considered a means of procreation and an undissolvable sacrament, and sexual behaviours within marriages are patterned by strong patriarchal norms internalized by both genders. Given this, it is important to better understand how these cultural gender dynamics affect serodiscordant relationships in India. It is against the background of these tensions between what is expected and what is real that serodiscordant living is explored in this chapter from a cultural gender perspective, with particular focus on HIV-negative wives, who are an invisible segment of people affected by HIV.

Methods

The Study Context

The data reported here are drawn from a larger, mixed-method research project aimed at exploring the lived experiences of people with HIV in the national capital territory of Delhi. The estimated adult HIV prevalence in the state of Delhi is similar to the national prevalence of 0.27%. Over the last decade, the state has seen an upward trend in the annual number of new HIV infections. The same period has seen a rapid scale-up of antiretroviral treatment coverage under the National AIDS Control Programme, with the aim to reach universal coverage by 2017 (NIMS and NACO 2012).

The project was carried out by the author in 2010–2012 in partial fulfilment of requirements for a doctoral degree at Lucknow University in India. The Delhi State AIDS Control Society in India provided considerable (non-monetary) support for the research. As is the case at many Indian universities, Lucknow University did not have a formalised research ethics committee with authority to grant ethics approval for the research project. However, many Indian university departments hold regular pre-submission meetings, where academics scrutinise research proposals, including postgraduate proposals. My research abided by standard international guidelines for ethical research involving human participants, including seeking informed consent from study participants (written or thumbprints) before collecting data.

The project featured in-depth, individual interviews with 105 HIV-positive people, as well as three group interviews. Over three quarters identified as Hindu. The group interviews were with participants who had a serodiscordant partner, in order to gain a deeper understanding of mixed-status relationships. Groups were stratified by gender, sexual orientation and serostatus, and included heterosexual HIV-positive men (10 participants); homosexual HIV-positive men (12 participants); and HIV-negative women who were partners of study participants and aware of their partner's HIV status (12 participants). The male participants in these groups were individual interviewees who felt comfortable speaking about such topics in the presence of others like themselves. In this chapter, I focus on the group interviews, as well as a sub-set of the individual interviews, reporting data from 41 HIV-positive people who had HIV-negative partners.

Recruitment

The study participants comprised what is a hidden, hard-to-reach population in India. Thus participants had to be recruited through a variety of avenues, including intervention projects and support groups run by non-governmental organizations, care homes catering to HIV-positive persons, and the snowballing method. Project managers at each location were informed about the research objective and asked to introduce the researcher to potential participants. Eligibility criteria included being an HIV-positive person above 18 years of age and willing to participate in research. Negative partners were not interviewed individually as this was not part of the original study design. The interviews were conducted at the locations where the participants were recruited. Informed written or thumbprint consent was obtained from all participants prior to both the individual and group interviews, which were all audio-recorded.

Data Collection Tools and Analysis

For the individual interviews, an interview schedule was developed in Hindi, the native language of the participants. The schedule, which included both a structured and semi-structured component, was pre-tested with a few participants to check for inadequacies. The final interview schedule was administered in Hindi by the researcher/author. Questions covered a range of issues, including demographics, diagnosis and stigma, sexual orientation, sexual behaviour, condom use, disclosure, and everyday living with HIV. Similar questions were covered in the group interviews, but with specific focus on the context of serodiscordant living. Information obtained in the individual interviews through structured questions was analysed using a statistical software package (SPSS) and chi square test to identify associations between different variables. The qualitative information obtained through semi-structured, in-depth questions in both the individual and group interviews was transcribed verbatim and analysed thematically.

Results and Discussions

Of the 41 HIV-positive participants who had an HIV-negative partner, 28 were men, nine were women and four were transgender women (known as *Hijras*[2]). Twenty-eight reported being heterosexual, 10 homosexual and three bisexual. Thirty-one were married, six were unmarried and four had been married in the past. Ten were illiterate, 19 had studied up to middle school level, and 12 above middle school. Nine of the participants had no income, while 19 had a monthly income of up to INR4000 (<$63USD) and 13 had incomes above this amount. The majority had a good understanding of the major routes of HIV transmission, with only three participants being unaware of any means of transmission. Twenty-three participants had disclosed their HIV status to their negative partner, while 18 had not disclosed. Twenty-eight were taking antiretroviral therapy (ART), in accordance with the national treatment guidelines recommending ART initiation when the CD4 count reaches 350 (NACO 2013). In summary, the sample had low levels of education, low incomes, good HIV awareness, and most were married.

In the larger study sample, HIV infection due to unsafe sex was commonly associated with particular vulnerabilities. A similar pattern was observed in the serodiscordant sub-group. Twenty men and one woman reported participation in commercial sex work, as client or service provider. In India, although sex work is not illegal, it is unregulated and largely hidden due to stigma and laws that criminalize public solicitation and brothels. As a consequence, sex workers have little access to health care, resources, or legal protection and are often not in a position to negotiate safe sex. Due to these factors, they are considered a group highly vulnerable to HIV infection, as are their clients (Buzdugan et al. 2012; Bharat et al. 2013). Thirteen of the men in the sub-sample were vulnerable to HIV infection due to sex with other men. Of the nine women currently in serodiscordant relationship, eight were infected by a previous husband. Three had been diagnosed with HIV during antenatal check-up, three were diagnosed due to the HIV diagnosis of their previous husband, another two were diagnosed due to illness, and one woman who worked as a sex workers had sought a test because she had perceived herself to be at risk.

Sexual Orientation and Marital Status

Table 1 shows the marital status of people with different sexual orientations. Three of the 10 homosexual men were married, six were unmarried and one was divorced. In India, as already mentioned, men and women alike come under significant social and parental pressure to marry and have children (Fruzzetti and Tenhunan 2006;

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[2] *Hijra* is recognized as a third gender by the Indian Government. The vast majority of *hijras* were born with male physiology.

Table 1 Sexual orientation and marital status

Sexual orientation	Married	Unmarried	Divorced	Total
Homosexual	3	6	1	**10**
Bisexual	3	0	0	**3**
Heterosexual	25	0	3	**28**
Total	**31**	**6**	**4**	**41**

Newmann et al. 2000). Because same-sex marriage and relationships are not sanctioned morally, socially or legally, some homosexual and bisexual men enter into a heterosexual marriage and become fathers. Hiding their sexual orientation behind a more socially acceptable role constitutes an attempt to protect themselves (Pandya et al. 2012; Solomon et al. 2010), though, as Asthana and Oostvogels (2001) point out, marriage and fatherhood are an important aspect of masculine identity for most men in India, regardless of sexual orientation.

Yet, it is alarming that HIV-positive men who identify as homosexual might feel obliged to marry, potentially putting their wives at risk, all because of social prejudices and the pressure to fulfill parents' wishes. This experience was shared with the researcher during one-to-one interviews with homosexually-identified men. To them, marriage and having a child was a compromise they had to make for the sake of their parents and to maintain the peace in the family. The group interview with the HIV-positive homosexual men revealed that a sense of guilt leached in when they found their child had been infected. Due to their marriage, they also felt dishonest towards their regular and secret male partner.

The group interview with HIV-negative partners revealed that these issues, challenging for homosexual men, have implications also for their wives. They become potential collateral damage of the entrenched homophobia and HIV-related stigma that compel men to keep their sexual orientation and HIV status hidden. Three of the HIV-negative wives spoke about feeling unwanted due to their husband's lack of attraction to them. One negative wife relayed how she felt betrayed by her husband and by her parents who had arranged her marriage, as is still customary in India:

> What is there to motivate me to live? He does not even look at me, nor does he sleep with me. I would have left him but now this baby is here. I do not know any skill to sustain me [financially]. Who is going to share the burden of two of us? My parents and brother are not going to support me. I am reduced to a nurse for him and the baby. I do not want to have sex with him because he is infected. I have to live like this until death (Negative wife of a homosexual man, 25 years).

For this woman, as for many in India, patriarchal culture dictates that she abides by her parents' decision in matters related to marriage. Her own needs are sacrificed for the sake of maintaining a marriage due to a socio-cultural environment that seriously constrains the life choices of both women and homosexual men.

Table 2 Disclosure and sexual orientation

Disclosure and sexual orientation	Disclosed	Not disclosed	Total
Heterosexual	19	9	**28**
Homosexual	3	7	**10**
Bisexual	1	2	**3**
Total	**23**	**18**	**41**

Disclosure, Stigma and Marriage

Disclosure of HIV status is an important step in the life of an HIV-positive person. How people disclose depends on their circumstances and what reactions they expect from family members and loved ones. As others have found, non-disclosure to a primary partner may be driven by fear of rejection, stigma and family breakdown (Patel et al. 2012). In the sub-group of HIV-positive participants in serodiscordant relationships, only slightly more than half had disclosed to their spouse or regular partner. Similar to other studies, men were found to be more reluctant to disclose than women (Marfatia et al. 2015). Table 2 shows that of 18 participants who had not disclosed; nine were heterosexual, including only one woman, seven were homosexual, and two were bisexual men.

It is likely that men with socially unacceptable sexual orientations were not disclosing their HIV status to their partner (married or otherwise) owing to external and internalized stigma. The stigma surrounding HIV, as Reidpath and Chan (2005) point out, lays not only in the infection but also in the mode of infection. As noted, homosexuality and bisexuality are condemned in Indian society. As such, these men faced multiple stigmas; the stigma of sexual orientation and that of HIV infection. One 25-year old man spoke of his previous homosexual partner: “He has been tested positive. He left for his village on the day after his HIV result. His parents have fixed his marriage to a girl. Poor girl she does not know [about his HIV status and sexuality]”.

During the individual interviews, 21 participants (20 men, one woman) reported being active in commercial sex, either as workers or clients, and explained that this was the reason they had had an HIV test. However, this information was not readily shared with their spouse. Instead, most had “partially” disclosed by giving some morally acceptable explanation for their HIV infection. The group interview with HIV-negative wives of both heterosexual and homosexual men indicated that many believed their husband had become infected through “innocent” means, as in the example below. However, cross-checking with the individual interviews revealed that the actual mode of infection was cited as sexual risk behaviour by the husbands. Partial disclosure tended to have a positive effect on the attitude of the wife towards the husband, as one 32-year old negative woman stated: “We have vowed to live together; now if he got infected how can I leave him? It was an accident; anybody can get a needle prick, it could’ve happened to me.” Believing the infection was due to an accidental needle stick injury, this wife expressed affection and commitment towards her husband in sickness and in health, enacting the Indian gender ideal of Savitri, who according to a famous legend brought her husband back from death.

In those instances where husbands had openly disclosed that their HIV infection was a consequence of "immoral" activities, such as sex with men or sex workers, the wives' acceptance towards their husband reduced significantly and was replaced by considerable anguish and resentment. In the words of one 32-year old HIV-negative woman:

> See what life I have … I was married off to an alcoholic philanderer man. All his life he was visiting those dirty women [sex workers], had all the enjoyment of life and now has brought the infection [into our home]. He has left his job too. I have to do everything from paying school fees to buying vegetables … Had these children not been here, I would have run away or committed suicide. No one is there to support me and my children if I leave him.

The exasperation of this wife, who worked as a domestic servant, is apparent. Irrespective of whether wives accept their husbands after disclosure or not, the lack of social, financial, emotional and legal support for women is a key factor in the decision to remain in a marriage. Leaving a husband is rarely an option for unskilled, poorly educated women with no or limited sources of income of their own. In such cases, it is not the cultural ideals of Savitri at play, but the stark economic realities for many women in India. Staying in the marriage under these circumstances is thus more of a duty or necessity than an expression of affection. It is also noteworthy that divorced women are not readily accepted in Hindu society. While the socio-legal framework does provide some provisions for a wife to leave her husband, such as on account of mental cruelty (Hindu Marriage Act 1955), this requires sufficient support from her natal family. Such support is not always forthcoming, due to the stigma attached to divorce for both the girl and her parents (among other reasons). As Mehta and colleagues (2004:96) explain: "Divorce within the Indian context carries extreme social repercussions even in abusive relationships. These repercussions include banishment from home without any support from the natal family." Hence, divorce is rarely exercised as an option, especially among women from lower socio-economic backgrounds.

Marital status seemed to affect disclosure in these serodiscordant relationships. Of the 31 participants who were married, 22 had disclosed their HIV status to their spouse and nine had not. Among the six unmarried participants, five had not disclosed their status to their current sexual partner, and none of the four divorced participants had disclosed to their partner (Table 3).

Due to the cultural values of *brahmacharya* and chastity, and the stigma of sexual activity before marriage in India, the unmarried men did not want their HIV status to be known by their partner, despite actually being in a sexually active non-marital relationship with that partner. In other words, the ideal and expectation of sexual "purity" pre-marriage not only contradicts real life, but can contribute to non-disclosure of HIV. Similarly, for the nine married participants who had not disclosed to their spouse, a major concern was that if they were to disclose, they might

Table 3 Disclosure and marital status

Disclosure and marital status	Disclosed	Not disclosed	Total
Married	22	9	**31**
Unmarried	1	5	**6**
Divorced	0	4	**4**
Total	**23**	**18**	**41**

also have to disclose their sexual behaviour. As one married 27-year old HIV-positive man put it:

> What to tell? Why to tell? If I tell one thing I may have to be ready to give other facts too. As they say, you should not try to revamp a working machine. Let it be. If something will happen we will see.

In this quote, non-disclosure is defended as a way to live a peaceful life; the participant does not want to disturb the status quo by disclosing, despite the cost of potential seroconversion of his female partner. Though non-disclosure puts a partner at risk of HIV, concern about the safety of wives or sexual partners was not an explicit theme among some positive men. This was echoed by the HIV-positive women in the study, who nearly all stated that their first husband engaged in unsafe behaviour and knew about his HIV status, but had only told them shortly before his death (Patel et al. 2014; Thomas et al. 2013). There was only one woman among the married HIV-positive participants who had not disclosed to their HIV-negative spouse. She had worked as a sex worker for many years. She explained that she had not disclosed to her husband because she did not want to break his image of her as an ideal, chaste wife. Beset by guilt, and unable to introduce condoms into a supposedly monogamous marriage, she avoided penetrative sex with her husband.

Condoms, Sex and Gender

Despite good HIV transmission knowledge among these participants, condom usage varied for various reasons. As in the case of the woman reported above, it was true of the sample more generally that non-disclosure of HIV made condom use much more challenging. Fourteen of the 23 participants who had disclosed used condoms consistently, while only four of the 18 who had not disclosed did so. Another factor affecting condom use was gender. Among the 18 HIV-positive participants who used condoms consistently, eight were women and 10 were men. None of the transgender women used condoms. Table 4 indicates that in couples where the woman was the HIV-positive partner, condom use was far more consistent than in couples where the man was positive.

Although non-disclosure among some men partly accounts for this pattern, the findings also suggest that, when women are the partner at risk of HIV infection, condomless sex is more likely, whereas when men are the vulnerable partner, risk tends to be averted by condom use. Similar patterns have been found in other cul-

Table 4 Condom usage by gender of positive partner

Condom usage	Males	Females	Transgender	Total
Consistent	10	8	–	**18**
Inconsistent	4	–	–	**4**
No condom	8	–	4	**12**
No sex	6	1	–	**7**
Total	**28**	**9**	**4**	**41**

tural settings (Sherr 1996, but see Patel et al. 2014). However, 34 of the 41 HIV-positive participants said they worried about transmission, either because they feared becoming responsible for infecting their partner or, if they had not disclosed, feared that their own HIV status would be exposed if their partner became infected. These fears caused some HIV-positive partners to withdraw sexually, which had an impact on the quality of relationships.

Sixteen men, two women and two transgender women reported a reduction in sexual activity after their diagnosis. Several explanations were provided during group interviews, including negative associations of HIV infection with the sexual act generally, erectile dysfunction, loss of desire and a decrease in libido resulting specifically from fear of transmission. One HIV-positive 45-year old man explained: “I do not feel like doing it and [I’m] not able to perform since I have been diagnosed with HIV. My heart sinks as soon as I get any [sexual] provocation [from my partner]”. The deterioration in couples’ sexual life was often a source of strain. A few HIV-negative women mentioned that they wanted to remain sexually active, but felt that using condoms was difficult, reduced intimacy and caused tensions in the relationship. Other HIV-negative women, however, minimised the importance of sex, owing to sociocultural values that frame sex as a negative activity unless it is for procreation. A slightly different theme revealed that some couples managed their serodiscordant status by accepting a sexless marriage for the sake of their children’s future and to avoid transmission. One 33-year old HIV-negative woman said:

> We have decided to fight with this together. So far as sex is concerned we can live without it because we already have three kids whom we have to bring up. There is no point telling other family members.

Conversely, six HIV-positive men revealed that their HIV-negative partners tried to avoid sexual relations, but would occasionally succumb to pressure to have sex. This suggests that, owing to patriarchal gender relations in India, HIV-negative women are not always able to exercise their choice in matters related to sex.

Reproduction and Care-Giving

Patel and colleagues (2014) have argued that the greatest risk factor for HIV infection among Indian women is marriage (see also Newmann et al. 2000; Kumarasamy et al. 2010). As noted, eight of the nine HIV-positive women in this study were infected by their previous husband. Gender power relations are one explanation for this. Another, as mentioned earlier, is the cultural emphasis on childbirth in India. Saggurti and Malviya (2009:26) argue that, “a monogamous married woman has little control over sexual negotiation and is faced with the dilemma of choosing between disease prevention and the fulfilment of her reproductive role”. There is tremendous pressure on married couple to have a son, since this ensures (patrilineal) family lineage and inheritance in India. It is also commonly believed that salvation of the soul is guaranteed if a son performs the last rites at death. In short, great value is attached to pregnancy and, because women’s role as mother is both paramount and idealised, women themselves are socialized to accept this role and derive great social status from motherhood. Those who are not able to conceive within a stipulated time tend to be shamed or ostracized (Fruzzetti and Tenhunan 2006; Saraswathi 1999).

Hence, reproductive choice is not easily exercised by women who are pressured to literally deliver the desires and cultural norms of the patriarchal society around them. In this study, these norms seem to have been internalized as appropriate and no efforts to contradict or challenge them were made. The desire and pressure to have a child, especially a son, was evident among the participants and tended to override any concerns about potential HIV transmission. The positive men emphasised the importance of sons for the reasons mentioned above. Many women believed that a child would make them complete, and that they would face negative repercussions if they remained childless. One woman who had been diagnosed during antenatal check-up said: “If we do not give birth in a year or two, we are deemed inauspicious. We are gradually shunned from family events. Marriage means procreation; a woman is incomplete without a baby in lap”.

Patriarchy is perpetuated not only by the powerful agenda of obligatory childbirth and the birth of sons, but also by gendered demands and expectations within the domestic domain. In the Indian gender system, women’s care-giving is of prime value. The perception of women as natural carers has deep roots that go as far back as the old Vedic scriptures: “In fact, wife is home” (Rig Veda III:53.4). “Give her ten sons and make her husband the eleventh son” (Rig Veda X:85), meaning the husband should be attended to with affection and care as if he was the youngest child (Vyas 1992:39), advice that makes an appearance even on modern-day online sites for marital guidance. This ideal rarely gets extended to women; there the need for care is largely ignored. All the HIV-negative women in this study focused on their role as care-giver to their husbands once they came to know of his HIV diagnosis, irrespective of their feelings about the marriage. Many had also taken up paid work to supplement the family income when their husband’s capacity to work diminished after his HIV diagnosis (in cases where he was not yet able to commence ART under India’s treatment guidelines). Some of the HIV-positive women stated that they did not need their husband to care for them as they felt that they were healthy, while others rejected the idea of their husband caring for them as they did not consider this to be a man’s role. Husbands were not found to be doing any domestic work. While these findings show how cultural gender roles can obscure women’s health and care needs, they also show great resilience on the part of these women.

Conclusion

The findings reported here showcase the influence of the gendered context of Indian society on serodiscordant relationships. Partners in mixed-status couples live amidst constraints that impose a conservative and heteronormative approach to sex, and define and limit the role of women to reproduction and the domestic sphere. Indian gender ideologies expect women to be sexually ignorant, yet accommodating of husbands' desires, and—most importantly—fertile, due to the cultural premium placed on motherhood. Asking for premarital HIV testing of a prospective groom is never an option for a "good" young woman, who is not expected to know anything about sex and related matters. Marriage constitutes the primary HIV risk for Indian women, who are less likely to become infected by any unsafe behaviour on their own part than by the behaviour of their husband. Marriage (and subsequent childbirth) is so important in this discussion because it is the normative and obligatory marker and outcome of attaining adulthood in Indian society for both men and women. In addition to the impact on women, this has special implications for homosexual men. Heterosexuality remains dominant in Indian society, while alternate sexualities are shunned legally, morally and socially. This study confirmed that homosexual men marry young women due to social pressure, but continue to have same-sex partners. The stigma associated with both homosexuality and HIV status, makes disclosure about such topics difficult, which potentially puts wives and children in a vulnerable position. In the context of serodiscordant relationships examined in this research, these dynamics can lead to anguish, unwanted marriages, and inconsistent condom use.

In India, the onus of sustaining a marriage is largely on women through their being generally submissive, and especially relinquishing their sexual and reproductive rights. The husband is considered the source of social and moral standing, so leaving him is rarely an option. Instead, as seen in this study, women who remain in marriages with HIV-positive men often serve as care-givers, and may also seek paid work. However, the HIV-positive women did not report receiving or expecting such support, which would have required role reversal, reflecting internalization of strong gender norms. This resilience on the part of women makes serodiscordant relationships possible and plausible in the Indian context. This is especially true among poorly educated, unskilled women from lower socioeconomic backgrounds where the presence of dependent children, a lack of parental support and financial means create the necessary conditions for her to stay in the marriage. In the spectrum of HIV care and support services, the negative wife is invisible, yet her presence is critically important due to her resilience, tolerance and self-denial.

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Part III

Love, Risk & Relationships: Negotiating Serodiscordance

Treatment as Prevention: A Love Story

Caroline Watson

I met my husband Deon in San Francisco before I turned 21, six years ago. I was dating his friend at the time, but we weren't right for each other, and we broke up pretty quickly. After a few months went by, I met Deon again, and we hit it off. He would come over to my place and we would talk about everything. Some things, however, were harder to talk about than others. Though I didn't know it initially, Deon was living with HIV. I found out when he took me to the place where he was staying. There was a sign on the door that announced it was HOPWA housing, which stands for Housing Opportunities for People with AIDS. When I saw it, I knew for sure that the rumors I'd heard about Deon were true.

I think disclosing his status was challenging for Deon because he felt very stigmatized. He didn't want anyone to know. But, living in San Francisco, I had friends who were living with HIV and on treatment. I knew that people living with HIV who are adherent to their medications can achieve an undetectable load and live long, healthy, productive lives. I wasn't afraid. I did some research and read about The Swiss Statement,[1] which said that if the partner living with HIV had an undetectable viral load, there was a next to zero chance that the negative partner would acquire HIV. I felt pretty good about that, and I encouraged Deon to go see his health care provider to get on treatment. He told me that his provider had recommended that he not start treatment until his CD4 count was below 200. I thought that sounded wrong, and did some more research, which confirmed that his provider's views were outdated. Deon ended up switching clinics. He started going to Ward 86

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[1] Vernazza P et al. (2008). Les personnes séropositives ne souffrant d'aucune autre MST et suivant un traitement antirétroviral efficace ne transmettent pas le VIH par voie sexuelle. *Bulletin des Médecins Suisses* 89(5), (English translation, including translator's affidavit, available at: http://tinyurl.com/cpyt5n, accessed 4 April 2016).

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at San Francisco General Hospital, where most of my friends went for their care. The doctor there advised starting treatment as soon as possible. After the social worker signed Deon up for ADAP (AIDS Drug Assistance Program), he was able to fill his prescription for Atripla. Thanks to this team effort and Deon's adherence, his viral load quickly became undetectable.

We had been having condomless sex before this, which we knew wasn't the best idea, but, being quite young, we were not in a very responsible time of our lives in general. On top of that, we were very much in love. We rationalized that Deon pulling out would minimize the risk of transmission. After he got on treatment, though, it made me think more about having to be on medication, too. Some time later, I started feeling really sick, and I was sure that I'd seroconverted. I asked Deon to come to the local clinic with me to find out, and he did. The results made us both think more seriously about our relationship—but not because of HIV (I was still negative). I was pregnant. Though I ended up having a miscarriage, Deon and I got through it together and it strengthened our bond.

When I became pregnant for the second time, it changed the way my mom felt about my relationship with Deon. At first, she'd been unenthusiastic about me dating someone who was living with HIV. After I sent her some educational materials, she'd begun to warm up to the idea, but it was when my mom learned she was going to become a grandma that she really overcame her reservations. By the time this second pregnancy occurred, Deon had been "undetectable" for about 2 years. I was excited to go for my first prenatal appointment with a midwife. She asked me the usual questions: Did I smoke? Drink? Do drugs? Have sex with someone with HIV? I answered "No" to the first three, and then I told her that the baby's father was living with HIV. She looked at me as if I'd grown two heads, and said that she'd "be right back." When she returned, she said that she couldn't be my provider anymore, and that she was referring me to the Bay Area Perinatal AIDS Center (BAPAC). I was happy about this, because I didn't like the way she was looking at me or her judgmental tone of voice.

BAPAC was wonderful. The providers were so amazing, competent, understanding, and helpful. Deon and I were treated as a couple; we got our care from the same provider. I was offered PrEP (pre-exposure prophylaxis), but I declined. I felt that there wasn't enough research on the effects on the fetus when the mother wasn't living with HIV. Also, I am bad at taking pills every day, and I didn't think that I could be adherent. The providers didn't pressure me about it; instead they had us come in more frequently for testing. Deon had his viral load checked and I was tested for HIV monthly.

Our frequent visits to BAPAC and the support we received there changed our lives even before our baby arrived. During my pregnancy, our social worker asked us if we'd consider being in a video targeted, in part, to couples like us. As I mentioned before, Deon never used to share his HIV status, so I was surprised when he agreed to think about it. As we talked it over, Deon said that, when he first got diagnosed, it would have been helpful to see someone like him speaking candidly about living with HIV. He wanted to do that for the people who would see the video, so we decided to say yes.

This was the beginning of a radical degree of openness about our mixed HIV status. Being in the video led to our picture appearing on the cover of the San Francisco Chronicle, as well as being on the radio and speaking at various conferences. It also brought me to my current job and future career—but that's getting ahead of the story.

My pregnancy was easy, but I developed cholestasis, a liver condition, a week before I was due. When I went to the hospital to be induced, the nurses made a fuss over us; they all knew who we were because we'd just been on the cover of the newspaper. More importantly, they also knew that they didn't need to do anything out of the ordinary for the delivery or to our baby (such as a C-section or giving any HIV medications to me or my baby). She was born after 3 days of induction attempts, and didn't cry when they put her in my arms.

These days, we don't think about our mixed status much; we've been together for almost six years and it's just part of our relationship. When we do think about it, it's largely because of my work. BAPAC, the clinic where I got my prenatal care, has since evolved into HIVE: a hub of positive sexual and reproductive health. I help produce most of the videos and blog posts on the website (HIVEonline.org). I'm also on the CDC's Expert Panel for Preconception Care and Reproductive Health, and a member of their Elimination of Perinatal Transmission Stakeholders Group. I think about HIV-related topics all the time, but I'm not personally worried about acquiring HIV. I feel safe in my relationship. I know even more about TasP (Treatment as Prevention) than I did before, because of the work that I do. I recently edited a video that my amazing boss, Shannon Weber, made with Pietro Vernazza, one of the authors of the original Swiss Statement. He talked about how TasP works, and gave his opinion that TasP plus PrEP is unnecessary and actually a waste of resources, when the partner who is living with HIV has been undetectable for over 6 months and is always adherent to the medication. More recently, in the PARTNER study, there were no cases of HIV transmission after couples had sex 58,000 times without condoms.[2]

Sometimes, as I write a blog post or edit a video, I am struck by how far we've come—both in our personal journey with HIV, and regarding the epidemic in general. Deon's father passed away from AIDS-related complications, so when Deon was first diagnosed, he thought his life was over. When his provider told him that he never had to develop AIDS, that he could live a long, relatively normal life and would likely die of something unrelated to his HIV status, he was extremely happy. Deon goes to his doctor appointments and takes his pill every day; he is very into being adherent.

Treatment actually plays an important dual role in our relationship. It keeps Deon healthy as we continue our love story and watch our daughter, who is now two-and-a-half, grow up. It also protects me. We still have condomless sex, and PrEP is still not right for me. In fact, between our daughter, my work with HIVE,

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[2] Collins, S. (2016). ZERO: No linked HIV transmissions in PARTNER study after couples had sex 58,000 times without condoms. *HIV i-Base*.http://i-base.info/htb/30108, Accessed 27 July 2016.

and being a full-time social work student, I feel it's even less likely I could remember to take a pill every day! I'm still not *afraid* of acquiring HIV, but now that I'm a mother, minimizing that possibility has assumed greater importance. So Deon is doing prevention for both of us.

Since the beginning of our relationship, we've thought about HIV and our mixed status as something we're in together. We make decisions that work for us. This joint approach is one reason why I don't use "HIV serodiscordant" to describe us. That term brings up ideas of disagreement, incongruity and a lack of harmony. My life with Deon isn't like that, and I'm sure that's true of many other mixed status couples as well. I'm big on language in general, especially non-stigmatizing language, so I use "mixed status" or "serodifferent" instead. Those words acknowledge difference without making it into something unpleasant—after all, it's OK to be different from your partner; opposites attract!

There are differences in serodifferent versus non-serodifferent relationships and, depending on the couple, they can be major or minor. For example, most of the other serodifferent couples that I know use condoms almost exclusively, even though the positive partner has an undetectable viral load. Some HIV-negative partners use PrEP as an extra layer of security while trying to get pregnant using timed intercourse. Others have used sperm washing when trying to conceive. Those are things that a couple without mixed HIV status wouldn't typically do, and accessing these services can be challenging in certain cases. Deon and I didn't feel these options were necessary—though we recognize that every couple is different and has different issues. For us, the differences that mixed status introduces are minor: my husband's doctor appointments and prescription, our being referred to a specific place for prenatal care. The biggest challenge related to our mixed status comes not from within our relationship, but from other people's reactions to it.

We find that misperceptions and stereotypes about mixed status and HIV in general are still common. For example, many people are shocked that we are open about our status at all, let alone that we star in educational videos and agree to be on the front page of the newspaper. Others express amazement that we were able to have a child together the old fashioned way, and that our daughter could be born HIV-negative (they often think that, even though I'm negative, our daughter must be positive because Deon is).[3] We know that many people have never been in a mixed status relationship, and also that lots of folks had their impressions of HIV formed during the early days of the epidemic; so Deon and I both like to help them understand more about the latest science when we have the opportunity. We tell them that people living with HIV can now live healthy, productive lives, have HIV-negative children, and be around to see them grow up. HIV is a chronic disease, like diabetes, that can be managed with appropriate care.

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[3] Fact check! This is incorrect. If the mom remains HIV-negative, the baby will always be negative, too.

Indeed, one could (almost?) say that I’ve been lucky HIV came into my life through Deon. Not only do I have a wonderful partner, and a precious daughter, but combatting stigma and outdated perceptions has become a mission that has shaped what I want to do with my life. In my case, the minor differences introduced by mixed HIV status have brought major blessings.

Relationships Between Serodiscordant Gay Male Couples in Lima, Peru: Sero-Disclosure and Living with Serodiscordance

Kelika A. Konda, Clara Sandoval, and Lizzete Najarro

Introduction

The availability of effective HIV treatment combined with effective HIV prevention has increased the possibility of living in long-term health as a serodiscordant couple. Most international research and public health programs focus either on HIV-negative people and prevention or on HIV-positive people and treatment, but less often on the intersection between these groups or on the complexities of serodiscordant relationships. The rise of treatment availability, including in low and middle income countries (LMICs), and decreased HIV-related mortality (UN General Assembly Special Sessions [UNGASS] 2014) influence how HIV is experienced by people living with HIV (Kerrigan et al. 2006; Bravo et al. 2010; Owen and Catalan 2012). However, the experience of this change remains relatively unexplored outside of the global north. In Latin America in particular, much research remains focused on clinical aspects of health or health services (Crabtree-Ramírez et al. 2014; Piñeirúa et al. 2015). HIV-related stigma and fear continue to influence societal perceptions of the virus (Neuman et al. 2013; Stangl et al. 2013).

The HIV epidemic's effects on key populations, including gay men, have been dramatic. Prior to HIV treatment, the mortality of gay men due to HIV/AIDS was substantial globally (Hogg et al. 1997). However, the loss of life, the pandemic

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nature of HIV, and the lack of treatment led to a lasting, intensely negative perception of HIV within and across societies. With the advent of effective antiretroviral treatment (ART), the medical community began to reframe HIV as a chronic disease (Deeks et al. 2013), though this remains more of a potentiality than a reality in many settings, given continuing challenges in providing adequate HIV-related services (Mugavero et al. 2013), especially in LMICs (Pineirua et al. 2015). Additionally, no clear or balanced message regarding HIV in the post-ART era has emerged to present HIV as something worthwhile to avoid due to possible complications from living with chronic disease, while simultaneously reducing the fear and stigma of HIV.

The onset of the HIV epidemic also affected gay men's intimate relationships. In addition to living in a homophobic society, the likelihood of having a healthy partner diminished. With no treatment available, a generation of gay men watched each other die, and the fear and visible struggles with the disease lead to the embedding of HIV into gay culture (Kramer 1985) and an evolving culture of safer sex, HIV testing and, in some settings, sero-sorting. Today, growing evidence that early treatment and good adherence are associated with decreased transmission risk to others (Cohen et al. 2012), as well as the repositioning of treatment as an effective form of HIV prevention at a community level (Montaner et al. 2010), are beginning to reshape how HIV is lived and perceived in many settings (Oguntibeju 2012). These developments are prompting a paradigm shift where having sex with someone of unknown HIV status, or someone who thinks they are HIV-negative but who has not tested recently, may be perceived as riskier than having condomless sex with an HIV-positive person with a controlled viral load (Goodreau et al. 2012; Caro-Vega et al. 2015; Skarbinski et al. 2015). As this shift is still evolving, the implications for how people with HIV establish and live in different kinds of serostatus relationships remain unclear.

The vast majority of information on HIV and gay men is from the global north where gay cultures are more widespread and accepted. In Peru, HIV is highly concentrated among men who have sex with men (MSM) and male-to-female transgender women, with an estimated HIV prevalence of 10–15 % and 20–25 % respectively compared to less than 1% in the general population (Baral et al. 2007). ART has been available in Peru since 2004, first funded by the Global Fund and now by the Ministry of Health (MoH) (UNGASS 2014). In theory, Peru offers treatment for HIV-positive individuals regardless of their stage of infection, if they have a serodiscordant partner (Benites 2015), but couples and health care professionals very often do not understand this part of the new guidelines and it has not yet been implemented (personal communication, L. Garcia). Also, the public health system relies on voluntary partner notification (Ministry of Health 2006), as the confidentiality of the HIV-infected individual is considered paramount. All HIV interventions, both prevention and treatment-focused, are for individuals; partners are addressed by the public health system only in the context of pregnant women (personal communication, A. Silva-Santiesteban).

Peru has a gay rights movement. Gay rights are very limited, and though many gay community and non-governmental organizations exist, they have little political influence. Currently neither gay marriages nor civil unions are sanctioned by law in Peru (Anonymous 2015). Most of the population is Catholic, although Evangelical Christianity is gaining adherents, and popular support for same-sex marriage is one of the lowest in South America at 26% (Pew Research Center 2014).

Very few studies have explored gay male couples in Latin America. Research with MSM in the region has been primarily epidemiologic and focused on this group's elevated risk of HIV and STI infection (Caceres 2002; Baral et al. 2007; Mimiaga et al. 2015). Recent work has explored the intersection of specific risk behaviors and sexual identities, including the relationship between identity and sexual role during anal sex (Clark et al. 2013) and condom use with different types of partners (Cambou et al. 2014). But no work has been done specifically on gay or serodiscordant relationships. We conducted the present study with gay men in Lima, Peru's capital, to better understand their relationships and to explore the influence of HIV serodiscordance on their relationships.

Methods

Semi-structured, in-depth interviews were conducted by the team of authors with 19 gay men in serodiscordant, stable relationships. Five couples (n = 10) were interviewed together and separately, while nine men participated in the study without their partner. Of these nine men, four were HIV-positive and five HIV-negative. Interviews were also conducted with gay men in sero-concordant couples (where both partners are HIV-positive or both are HIV-negative) and in couples of unknown HIV status, but data from these interviews are not included herein. Participants were recruited purposefully, to achieve balance within the sample in terms of individuals and couples, and positive and negative HIV status. Recruitment was conducted by five gay men from across Lima, each recruiting from his own social network.

The interviews were conducted by two Peruvian qualitative researchers (authors CS and LN), both with experience in sexual health research. During the couple interviews, the couple began the interview together in a room with both researchers. After a few initial questions, the partners were split up and interviewed separately, one participant with one researcher. Interviews with men who participated without their partner were conducted one-on-one. For both the individual and the couple interviews, questions covered relationship formation, their daily lives together, whether their families were aware of their relationships, and the influence of HIV on their relationship. The process of sero-disclosure within the current relationship was also addressed; sometimes information on past disclosure experiences was also discussed.

Interviews were digitally recorded and recordings were transcribed verbatim. Transcriptions were coded using a preliminary list of codes that the study team (the qualitative researchers and the lead investigator) discussed in detail prior to initiating coding. Codes were added as needed as the team discussed the interviews. The first two interviews were double-coded by the interviewers to assure coder agreement. All discrepancies in coding were discussed in the study team and resolved through consensus. During data collection and coding, which occurred simultaneously, the team met periodically to discuss emerging findings. These discussions assured that saturation was reached with regard to the main themes of interest.

The protocol was approved by the Ethics Committees of the University of California, Los Angeles and Universidad Peruana Cayetano Heredia in Lima, Peru. All participants provided informed verbal consent prior to initiating the study interview. Each participant was given a pseudonym to ensure confidentiality.

Results

Description of Study Participants

The average age of the participants was 36 (range: 21–50 years old). The gay couples we interviewed were mostly in long-term relationships, the average length of relationships was six years (range: four months to 20 years). Some lived together, though many did not. Although some had children from former heterosexual relationships, none lived with or were raising children. About half of the participants had come out to their families as gay, though fewer were aware of their relationship; often their partner remained a "friend" in the eyes of their families.

All HIV-positive participants had known about their HIV status for at least several months; most had been living with HIV for years. All were either receiving care that included ART, or linked to care but not receiving ART because they did not yet meet the Peruvian MoH treatment criteria.

Participants described condoms and lubricant as their primary HIV prevention strategy. Most HIV-negative partners reported getting a regular HIV test, but the majority did not understand the premise of treatment-as-prevention or TasP (maintaining a low viral load through ART adherence and thus reducing transmission risk). Treatment was seen as clinical management of HIV and important for the health of the HIV-positive partner, but not as a method of HIV prevention. In a notable exception to this trend, two couples mentioned that they had condomless sex because the HIV-positive partners' illness was "dormant", alluding to undetectable viral load. In both cases, one or both of the partners worked in healthcare. Very few participants mentioned sero-positioning. When asked about any other risk reduction strategy, like avoiding ejaculation, the response was generally that they had not considered this.

Disclosure Experiences: Fears, Reactions and Delays

Disclosure had occurred in all of the relationships included in our sample, except one, which was still forming. Most of the HIV-positive partners described their decisions to disclose as fraught; they assumed their HIV-positivity would threaten the relationship. As Jesus (27 years old, HIV-positive) stated, “I was scared, scared to tell him, scared that he would reject me.” However, once Jesus worked up the courage to disclose, the reaction was very supportive. His partner had hugged him, expressed his continued love, and commented that HIV transmission was not inevitable, saying, “It’s an issue of talking about it and managing it.”

Both HIV-positive and HIV-negative participants recognized the disclosure process was difficult for the HIV-positive partner. HIV-negative participants were often aware of their partner’s fear of abandonment or violence as a result of disclosure. Tomas (50 years old, HIV-negative), for example, described his partner’s disclosure-related fears: “He was scared, he thought I might say, ‘I’m going to kill you’ [laughs]. The thought never crossed my mind.”

Not all HIV-negative partners were so effortlessly sanguine in the face of disclosure, however. Renzo (27 years old, HIV-positive) had worried how to tell his partner about his HIV-positive status, and what the reaction to his disclosure might be. He ended up disclosing his serostatus to his partner one night when they had rented a motel room, a common practice for amorous encounters in Latin America. His partner left after the disclosure, seeming to confirm Renzo’s fears, but returned three hours later and said that he wanted to continue the relationship. Renzo was surprised that he was not abandoned after disclosure: “I thought he would disappear off the map, but no, we’re still together up to now.”

The stress of non-disclosure expressed by the HIV-positive participants stemmed from keeping an important secret from their partner, a secret that could affect their partner’s health. In the one partnership where the HIV-positive partner had not yet disclosed his status, he explained that he tried to protect his partner’s health, “I try to take care of him, right? I don’t want to hurt him.” His lack of disclosure weighed on him, and he thought that perhaps his partner suspected that he was positive due to his insistence on condom use. Although they had not discussed HIV, he expressed doubt that their relationship would continue if he were to disclose, “The day he finds out, he’ll leave me, no?” (Paulo, 30 years old, HIV-positive). However, his HIV-negative partner claimed in his individual interview that he would be supportive if his partner were hypothetically positive: “As a partner, yes, I would stay with him” (Francisco, 30 years old, HIV-negative). Since no disclosure had occurred at the time of the interview, the actual response is unclear.

Even when reactions to disclosure were not fully supportive, HIV-positive participants relayed how the act of disclosing tended to relieve their stress. One participant, after revealing his serostatus, felt: “More relieved, more relieved because it was a burden for me” (Sergio, 24 years old, HIV-positive). Though his HIV-negative partner was more distant afterwards, Sergio was nevertheless happy that he had told his partner. In this case, the disclosure had occurred only 2 months prior to the interview and his partner did not participate, so the longer term outcome of this disclosure is unknown.

Previous negative experiences with HIV could complicate ready acceptance of serodiscordance. For example, an HIV-negative participant who had lost a friend to HIV was terrified of infection. He described his state of mind after the sero-disclosure, imagining that he had already seroconverted: "I have this disease, I'm going to die very young, I cried, I hit my head, sometimes I wanted to tell my mom, but I held on. I didn't talk to him for two months" (Javier, 21 years old, HIV-negative). He returned to his partner only after receiving a negative HIV test. Despite his reaction, his partner Antonio (40 years old, HIV-positive), said that he thought the disclosure had occurred at the right time for the relationship to continue:

> I said [it] at the right time, because if I had done it at the beginning, perhaps I wouldn't be with him. Because the relationship was intense at the beginning and I was more intense than he was. Over time he started becoming fonder of me.

In serodiscordant relationships where the relationship had started prior to disclosure, the HIV-negative partner often assumed condom use would cease as trust developed in the relationship. This created pressure on the HIV-positive partner to disclose, as they did not want to put the negative partner at risk and, given the assumption that condoms are not used in stable relationships, their insistence on condom use led to distrust and questions. Antonio (40 years old, HIV-positive) described how he disclosed to his partner and how condoms played a key role:

> I have to tell you something serious, perhaps I'll lose the relationship, but I hope you understand,' I said. 'But I think it's time to tell you, I love you. I always made you use a condom, you never wanted to use a condom with me and you said I must be having sex with others and that's why I use condoms with you. But I have HIV.

In one of the couples, the HIV-negative partner described his reaction upon learning that his partner had not told him about his HIV infection for several months.

> At some point we had even discussed [HIV] because he had a health episode. And then … he had another episode and he told me … I didn't get mad because I didn't feel mad, but I felt disappointed … I felt that I deserved to know the truth before, no? I don't think I would have reacted differently, I mean, I don't think I would have gotten scared or anything. But I do think it would have been good to know (Alfonso, 37 years old, HIV-negative).

Disclosure Experiences: Education and Adaptation

As evident in the previous examples, HIV-negative partners' reactions to disclosure varied. Knowledge about HIV, especially regarding transmissibility, tended to mediate reactions and seemed a key facilitator of serodiscordant couplings. Several HIV-negative partners echoed the idea that their partner's HIV status was manageable and that HIV did not have to affect their relationship. One negative partner, who worked in the health field, asked about his partner's viral load and CD4 count when he disclosed. With less informed partners, HIV education was often part of the sero-disclosure process, with the positive partner telling their negative partner not only that they had the virus, but also about treatment, their treatment regimen, and how they live with HIV. Julio (41 years old, HIV-positive) explained that his negative partner had been afraid of beginning a serodiscordant relationship, but that he was able to educate the negative partner about HIV and alleviate his fears:

> I told him, 'I was in a relationship for a many years and I got infected with HIV', and I said, 'but I'm fine, I'm on treatment'. At first he was scared, he said, 'Damn, how many years do you have left?' [laughs] I told him, no, I explained to him, I began to educate him … and well, that's how we started.

Even in the one relationship were the sero-disclosure had not yet occurred, the HIV-positive partner said he had been trying to educate his partner about HIV to aid the disclosure process later on. Despite the importance of sero-disclosure in these relationships, the participants reflected that most gay men in Peru do not discuss HIV or HIV prevention and that, in this context, HIV status disclosure is very rare. As Claudio (43 years old, HIV-negative) explained: "It is a rare couple that talks about prevention or HIV. In [my] case, it was different because I met him when he already had his diagnosis, a friend of his told me about it." Several of the partners we interviewed had had this experience; they began their relationship knowing that the other person was HIV-positive. In these relationships, HIV was positioned as something to manage, not as a barrier to the relationship, because it was a given from the outset.

Once disclosure occurred, relationships adapted to serodiscordance; couples discussed the positive partner's treatment and HIV prevention for the negative partner. Participants expressed that, although HIV was present and had an influence on their lives; their relationships were similar to others. For example, when asked to reflect whether his relationship was affected by his partner's HIV, Javier (21 years old, HIV-negative) stated: "No, not at all, everything is exactly the same; it's as if he did not have [HIV]." Similarly, Alfonso (37 years old, HIV-negative) said in response to a question about if HIV had changed their relationship, "Believe it or not, in absolutely no way, no way, no way, no way." In summary, once disclosure had occurred and both partners were informed about HIV treatment and prevention, HIV was present, but not a constantly looming concern for these couples.

Fear of HIV Transmission Within Serodiscordant Relationships

All participants reported that they had discussed the possibility of HIV transmission to the negative partner, except in the partnership where disclosure had not occurred. HIV-positive participants often expressed fear of transmitting HIV to their negative partner; however, the HIV-negative partners were less concerned about transmission, which is consistent with other studies of serodiscordant couples (Persson et al. 2016). Thirty-six-year old Tito, one of the HIV-negative participants, responded philosophically when asked about fear of transmission:

> One does not go through life thinking that, oh, I'm going to get infected by something. No. Life must be lived and you have to cope with things that come, be it disease, an accident, a problem, or job loss.

For Tito, HIV was just another potential issue, but not one that he dwelled on. This is not to suggest that HIV-negative partners wanted to become positive. But the possibility of passing the infection to their partner weighed more heavily on the HIV-positive partners. In one interview, Jesus (27 years old, HIV-positive) shared an interaction with his HIV-negative partner that illustrated this dynamic:

> I said to him, 'What would happen if at some point the condom breaks?' And he told me, 'Look, I love you enough that when you told me you had HIV, I didn't care. If by chance at some point that happens, I'm sure we can handle it.' I told him, 'But … I would feel bad, I would feel guilty.' And he told me, 'You don't have to feel that way. Because if it happens, it happens.'

Several HIV-negative participants explained that if they were to become HIV positive, both partners would share the responsibility, because both know the risk involved due to the HIV-positive partners' status. As Tomas (50 years old, HIV-negative) said: "If at some point I get infected, well, I will deal with it in the best way. I am not the kind of person who would say 'You infected me.'" Alfonso (37 years old, HIV-negative) similarly reflected: "A few years ago it would have scared me, but now, well, I guess I'd regret it at first, but then I'd continue my journey, right? It might sound bad, but I really, it wouldn't bother me." Such responses are understandable when situated within their socio-medical context. That is, HIV-negative partners see that treatment is available, and that it works, leading to less fear of the virus. This context, in turn, influences what serodiscordance means to the men involved in such relationships. We argue that serodiscordance diminishes in importance vis-à-vis the other considerable challenges that same-sex Peruvian male couples face, as we explore below.

Secrets, Silences and Same-Sex Stigma

Among the participants, about half of their families knew about their sexual orientation, though less than half of those knew about their relationships. Several had been rejected by their families for this sexual orientation, though most had only revealed their orientation and or relationship to family members they perceived as safe, often mothers or other female relatives. Participants often reported limited familial support for being gay, irrespective of HIV status. Another participant succinctly encapsulated his family's approach to his sexual orientation this way: "My mom knows about my orientation, I know she knows, but she doesn't say anything to me" (Jorge, 38 years old, HIV-positive). Such tacit agreements could be less wrenching, however, than explicit discussions. Another participant, Matias (40 years old, HIV-positive), described his mother's discovery of his sexual orientation:

> It affected my mother horribly, she cried and hugged me and said, 'Son, if you are happy … I just want you to take care of yourself and I don't want any scandals, I don't want your choice to … have repercussions at home. Behave as you should behave.

Matias reported complying with his mother's wishes, noting, "I never come home very drunk, I don't do drugs, I'm not *scandalous*."[1] In other words, behavioral circumspection was the price for openness around sexual orientation. Many participants did not consider this a bad or unsupportive response, particularly in light of the stigma associated with male homosexuality in Peru (Cáceres and Rosasco 2000). How men managed their romantic relationships was partly influenced by traditional patterns of residence in Peru. Most Peruvians live with their parents until they get married (Epstein and Limage 2008), so there is less scope for living with a "roommate" than in other cultures. Some partners, nonetheless, were able to live together; this occurred more frequently among older participants and in more established relationships. Even in cases where the family was aware of the relationship, couples were still unable to be completely open. Jorge (38 years old, HIV-positive) and Tito (36 years old, HIV-negative), for example, described their relationship with their families this way:

> *Jorge:* My sister knows, but it's not something that can be brought up at breakfast, right? My whole family knows, everyone knows about our [sexual] orientation, no? But I don't [say anything]. I've introduced him as a friend, because it's not like I can say he's my partner.
>
> *Tito:* It's respect, you know?
>
> *Jorge:* They can accept, but you don't know how they will react in the moment, so it's better to avoid it.

The family tolerated the couple's relationship, and in return the couple showed "respect" by not really being out as a couple. Being respectful and avoiding scandal were common themes in the interviews with regard to families' reactions to and expectations around the participants' relationships with men. Limits on openness and on behaviors that would have been acceptable from heterosexuals structured these men's experiences. This was the case even without bringing another stigmatized element—HIV—into the social equation.

For the majority of participants, their partner and closest friends were the only ones who knew about their HIV infection. Only two HIV-positive participants had told their families about their HIV status, and they had only told one or two family members. This lack of disclosure was often due to fear that their family, especially mothers, would not be able to emotionally handle their HIV-positivity. In answer to a question about being discriminated against on the basis of his HIV status, 38-year old Jorge said: "No, because no one knows, outside of my friends … I'd like to tell my family … [but they would think] I'm going to die". Hence, for most participants, non-disclosure of HIV infection to family members, motivated by a desire to avoid causing them distress, is indicative of the level of HIV-related stigma and the lack of knowledge that persists in Peru.

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[1] In this context, "scandalous" (*escandaloso*) should be interpreted as immoral or indecent.

In summary, these gay male couples perceived that multiple elements of their romantic partnerships were potential sources of stigma within their natal families. This resulted in a general tendency toward secrecy or silence around these topics. While the couples' lived experiences of serodiscordance underscored the facility with which they came to manage and communicate with each other about HIV as a chronic disease, it can be argued that stigma around their sexual orientation was more persistently challenging.

Discussion

Although fear of HIV is still widespread in Peru, these participants demonstrated the lived experience of HIV as a manageable chronic disease. Although some HIV-positive participants mentioned medical issues related to HIV, most were healthy and on treatment. While the influence of the study design on our findings must be recognized, for HIV-negative partners in this research, the prospect of being in or starting a relationship with someone who is HIV-positive was not clouded by associations of severe illness, and they understood that it was possible to preserve their HIV-negative status. The discourse of both positive and negative partners constructed risk of infection as manageable, which resonates with other recent findings (Clark et al. 2015). This suggests that the availability of effective treatment reduces fear of HIV within intimate partnerships.

Despite the beneficial effect of treatment within serodiscordant couples, major gaps remain in their HIV knowledge. In our sample, condom use was the primary mechanism mentioned for preventing transmission to the HIV-negative partner. Only two participants understood that being on ART treatment and maintaining a low viral load could help prevent HIV transmission, which echoes a general lack of TasP knowledge among serodiscordant couples in other LMIC contexts (Bavinton et al. 2015). Most couples focused on HIV treatment as clinical care for the HIV-positive partner. This is unsurprising, as another, as-yet-unpublished study of ours found similar emphasis on the clinical benefits of treatment and the lack of knowledge of TasP among HIV counselors in Peru.

The public health system in Peru should devise interventions that inform about TasP and help to facilitate disclosure and communication within intimate relationships. As Johnson and colleagues (2012) have demonstrated, there is an association between having a primary relationship and maintaining good adherence to ART and achieving virologic control. Combination prevention approaches are needed for gay couples along with improved HIV education, which could help people living with HIV to be more open about their HIV status.

The image of living positively with HIV remains largely absent from Peru and other areas of Latin America whose HIV epidemics are highly concentrated in strongly stigmatized key populations (Valenzuela et al. 2015). Activists who are "out" as being HIV-positive do exist in Peru, but such openness is rare (Castillo et al. 2014). Magazines like *Plus, Poz,* and *Positive Living,* which are available online, do contain representations of HIV-positive people who know their status, receive treatment, become less infectious, and live a healthy life with a chronic illness, but these publication are from the global north and primarily target people already living with HIV. Even in the global north, the multiple benefits of ART have yet to penetrate society's understanding of HIV, as evidenced by the mainstream media's coverage of Charlie Sheen coming out as HIV-positive (Signorile 2015). Serodiscordant relationships are a microcosm where the benefits of treatment are intimately experienced. Notably, *the couples in our study were living positively with HIV, but they were doing so very quietly.*

Our study has a number of limitations. The couples included were most likely not representative of relationships between gay men in Peru. Our recruitment was purposeful with the goal of including partnerships with a range of HIV statuses, as described in the methods section. This most likely resulted in recruitment of more stable and long-term partnerships. Partnerships that are less stable might not have survived a disclosure process, although in our interviews only one person described past partnerships that had dissolved due to a revelation of their HIV-positive status. How HIV disclosure affects less stable and shorter term partnerships is something that requires additional research in Peru. Finally, the information that these couples are HIV serodiscordant is based on self-report. Therefore, it is possible that some of the participants who reported being HIV-negative might not have been. We did not include information from those who reported being of unknown HIV status in this analysis.

Conclusion

As HIV treatment improves, the quality of life for people with HIV and their intimate partners also improves. This has alleviated many challenges that HIV previously posed for serodiscordant relationships, allowing gay men in serodiscordant relationships to live with HIV, but without HIV dominating their lives. However, in Peru and more broadly, this change is not widely known or understood, because HIV remains a socially stigmatized and therefore hidden condition. In this study, very few participants had disclosed HIV to their families. While treatment provides huge gains for the lives of these couples, a lack of comprehensive HIV education perpetuates HIV as an invisible disease. Instead of replacing the fear of infection with the knowledge of effective treatment, the benefits of treatment remain hidden. A lot can be learned from serodiscordant gay couples, including how current HIV treatment can make it possible for both HIV-positive and HIV-negative people to live with HIV without fear.

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“HIV-Positivity and HIV-Negativity: Two Sides of the Same Coin”. Narratives of HIV-Positive and HIV-Negative Gay Men on HIV and Intimate Relationships in Greece

Chrysovalantis Papathanasiou

Introduction

“Serodiscordant”, “serodivergent”, “serodifferent”, “mixed-status”, “magnetic”, are some of the terms used to describe couples where one individual is HIV-positive and the other HIV-negative. During the last decades, mixed HIV status[1] couples have attracted the interest of both biomedical and social scientists. But why is the study of such couples important? How is this knowledge valuable for confronting the HIV epidemic? In biomedical research, mixed HIV status couples are seen as a clinical entity (e.g. through participation in clinical trials), providing insight into the conduct of the virus and the biological determinants which lead to vulnerability or resilience (e.g. Cohen et al. 2011; Hughes et al. 2012). In contrast, for social scientists, the study of mixed HIV status couples advances our knowledge about the couple as a component of society. The focus tends to be the interactions between constituent members (e.g. Palmer and Bor 2001; Beckerman 2002; Persson and Richards 2008), and between the couple and the community (e.g. Rispel et al. 2015), examining social and emotional factors that can either break or strengthen these relationships.

Mixed HIV status can be studied only in reference to aspects of time and place: these factors are significant for both biomedical and social research. Clinical

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[1] I prefer the term “mixed HIV status”, as it seems the most positive term. “Serodiscordant” suggests there is discord in the relationship; “sero-different” focuses on the distinction between two entities; “magnetic” refers to two opposite poles. In chemistry, a mixture is a physical system made up of two or more different substances which retain their identities. Respectively, in intimate relationships two human beings are joined, creating a new social form (the couple), while retaining their personal traits and their uniqueness. They can act both separately and together.

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research on HIV transmission, for example, is now quite different from what it was before the appearance of antiretroviral therapy (ART). ART had a similarly revolutionary impact on social scientists' concern with HIV-positive people's lives after diagnosis, since it opened possibilities of career, long-term intimate relationships and parenting (e.g. Beckerman et al. 2000). Globally, however, prospects for people living with HIV and the meanings attributed to the virus vary widely. In addition, within any given community, post-diagnosis opportunities are linked to socio-cultural factors such as gender, power relations, values, discrimination, and so forth. As such, it is important to situate this study in terms of *time-place*.

The data on which this chapter is based were collected in 2006, prior to groundbreaking discoveries around Treatment-as-Prevention (TasP) and Pre-Exposure Prophylaxis (PrEP). As such, it must be recognized that the advent of biomedical prevention strategies may have altered current attitudes and experiences among men in relationships of mixed HIV status in Greece. However, though HIV-positive people have access to free ART, and Post-Exposure Prophylaxis (PEP) is provided by Greek public hospitals, TasP has limited distribution (European Centre for Disease Prevention and Control [ECDC] 2013:9) and HIV-negative people have no access to PrEP yet (http://www.prepwatch.org). As this chapter focuses on male couples and mixed HIV status, it bears stating that, in many places – including Greece – significant differences exist in the way opposite-sex couples and same-sex couples are perceived socially (Bradbury and Karney 2014). Indisputably, dominant attitudes towards homosexuality influence all same-sex relationships, including those of mixed-status; hence I turn now to a more detailed consideration of such attitudes in the context where my study was conducted.

The Socio-Cultural Context

According to Lazos (2002), in Greece the dominant value system regarding sexuality is based on the dogmas of the Orthodox Christian Church. In this system, sexuality is organized around reproduction and is therefore synonymous with heterosexuality within the family. The family is a significant and powerful institution in Greek society (Maratou-Alipranti 1999), influential in the personal choices of its citizens, including issues of sexuality and marriage. As Ioannidi-Kapolou and Agrafiotis (2005) highlight, family honour regarding sexuality is a long-standing value. Marriage remains a priority for young people, as a duty to their family and to society.

Homosexuality, perceived as a threat to reproduction, is marked, stigmatized and rejected. It is considered shameful, not only for homosexuals, but for their entire family. In our study on political discourse on homosexuality in Greece (Papathanasiou and Apostolidis 2014), we showed that conventional morality required the concealment of homosexuality at the societal level, making it taboo. Greece was one of the last countries in the European Union (EU) to recognize same-sex unions, despite repeated condemnations by the European courts. The Greek Parliament finally approved a law allowing same-sex civil partnerships on 23 December 2015. Though the Greek LGBT movement has gained a political foothold in recent years (Papathanasiou 2011, 2013; Papathanasiou and Apostolidis 2014), this legislation still provoked strong opposition from the Church and conservative groups.

The taboo around homosexuality leads to social invisibility, with deleterious consequences, as can be observed in the country's HIV prevention policies. In Greece, although men who have sex with men (MSM) are, epidemiologically speaking, the group most vulnerable to HIV, few prevention efforts have targeted the LGBT community (Papathanasiou 2001, 2011, 2013).[2] The influence of the taboo might also explain why social research on the HIV epidemic is limited in Greece. Mixed HIV status couples in particular have not been adequately studied in terms of their experiences or their HIV prevention and support needs; my review of the literature found no studies conducted in Greece.

One of the main purposes of this chapter is to contribute some first reflections on these issues. Based on the epistemological tradition of the social construction of reality (Berger and Luckmann 1966), I explore psychosocial aspects of homosexuality and HIV, and relationship dynamics in male couples, focusing on mixed HIV status from the perspectives of both positive and negative gay men, to consider how HIV-positivity and HIV-negativity are constructed through socio-symbolic meanings.

Methods

This study was conducted in the Greek capital of Athens in March 2006; research procedures were approved by the Institute of Tropical Medicine (Antwerp) and the National School of Public Health (Athens). For this qualitative research, we modified focus group discussion techniques (Morgan and Krueger 1998) to inform data collection through group interviews. Two such interviews were conducted: the first consisted of eight gay men with a positive HIV diagnosis, and the second of seven gay men with a negative diagnosis. All participants had been part of a couple, though not necessarily one of mixed HIV status, either prior to or during the study. The goal was to understand the sexual health of HIV-positive and HIV-negative gay men in a particular social context, and explain how certain important factors come to have their influence.

Research participants were recruited by a local AIDS NGO. Information about the study was also distributed in the local gay press and by word of mouth through social networks of the NGO activists. Participation was voluntary and confidential; informed consent was obtained from all interviewees, who are identified by pseudonyms in this chapter. The group interviews were moderated by the author with a trained observer present, and lasted about two hours. The discussion, based

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[2] LGBT organizations strongly criticize current HIV prevention policies for men who have sex with men (MSM). As a representative of the LGBT group "Colour Youth" says: "We have not seen any activities. We have not seen anything good coming out for young gay men. We have seen a lot of negative things" (ECDC 2013: 13).

on a semi-structured interview guide, was audio-taped and transcribed verbatim. The observer's notes were also used as a data source. Data were analysed inductively, generating codes which were refined and sub-grouped as themes.

Findings

The findings presented in this chapter do not come from a study of mixed-status couples. However, secondary data analysis revealed interesting commonalities and differences in the discourses of HIV-positive and HIV-negative participants regarding the sexual and emotional life of gay men in Greece. These findings allow a deeper understanding of the establishment of gay relationships in general, including mixed-status couplings, by highlighting the meanings given by the participants themselves. Illustrative quotes were selected on the basis of relevance and representativeness of the sample.

Disclosure Dilemmas in the Relational Context

Despite significant advances in HIV medicine, anxiety is an emotion shared by a majority of newly diagnosed people (World Health Organization 2008). HIV-positive participants in this study were no different. "The stress is very intense at that moment", declared Dimosthenis, a recently diagnosed, HIV-positive gay man. Some of this anxiety stemmed from men's fears that their diagnosis might negatively impact personal relationships and expose them to stigma and prejudice. Thus, they confronted the question of whether or not to disclose. According to narratives of HIV-positive gay men in this study, however, this was actually a series of dilemmas: they wondered *if* they must announce their serostatus, *to whom*, *when*, and *how*. Their main fear was potential rejection by family members, sexual partners, close friends or colleagues. Different strategies were adopted: full disclosure, partial disclosure, and concealment. Given the focus of this chapter, I will present findings in this section that pertain directly to mixed-status couples.

If The majority of HIV-positive gay men in my study thought it desirable to disclose their HIV status to their partners. By disclosing, they were hoping for understanding, acceptance and support. In addition, they associated disclosure with *truth* as opposed to *lies* (associated with concealment). This binary seemed rooted in underlying values about relationships, which also manifested in other distinctions participants drew, between the *real* and the *unreal*, the *essential* and the *non-essential*, the *worthy* and the *worthless*. These distinctions were applied to all relationships, regardless of possible serostatus differences. As we see in the quote below, a real, essential and worthwhile relationship allows someone to be themselves without pretending, thus fulfilling a major need to be accepted as the person they are.

> We often wear a mask in our social relations, I don't want to [do that] … I need to be myself. Otherwise, what is the reason for being in a couple? I can't bear that my partner is

> indifferent about the person he shares his life with. Secrets are based on lies, and lies have no place in a real relationship (Loukas, HIV-positive).

To whom? The decision to reveal their HIV status seemed contingent upon the nature of the relationship between the would-be discloser and the potential recipient of the information. Inductive analysis revealed that HIV-positive gay men disclosed to the person they wanted an intimate relationship with, not to partners in the context of casual or short-term relationships. The binary *personal/impersonal* interaction seems to be an important factor in the disclosure process.

> There is no reason to disclose it to someone with whom you have impersonal [in Greek *aprosopo*, meaning "without face"] sex. Both of you are there for pleasure, pure sexual pleasure, not for confession and understanding (Nestoras, HIV-positive).

Also of interest is the finding that serostatus disclosure can serve as a *tool of assessment*, a kind of pre-testing of the *value* of the relationship. In this preliminary assessment, if the HIV-negative partner reacted positively, the relationship was experienced as promising. The reactions of the HIV-negative partner during post-disclosure everyday life (e.g. degree of fear of HIV and self-protection) constituted a second phase of assessment (post-testing), where HIV-positive partners evaluated the resilience and viability of the relationship. The goal of these assessments was to anticipate and thereby minimize the emotional trauma of subsequent relationship dissolution.

> Although he didn't react negatively at the beginning, his later behavior, his extreme fear of being contaminated, in everyday life activities, showed me that [the relationship] couldn't work (Loukas, HIV-positive).

When? Once HIV-positive gay men decided to reveal their serostatus to a partner, the next question confronting them was when to do so. Angelos and Kostas, participants in the group interview with HIV-positive men, used contradictory Greek proverbs in a debate on the appropriate timing of disclosure in a developing relationship: "Slowly, slowly, the sour grape becomes honey" (Angelos) versus "The sooner the better" (Kostas). Participants agreeing with Angelos thought that disclosing their HIV-positive status too soon risked terrifying the partner, which could result in abandonment (as also found by Derlega et al. 2002, 2004). Those agreeing with Kostas claimed that they preferred to confront this at the beginning of the relationship rather than later when they would be more attached to their partner, making potential abandonment more traumatic.

> I am afraid to tell it at the first date. I believe that I can't cope with it immediately. I need some time to know each other, to feel safe (Angelos, HIV-positive).

> I say it at the beginning. If he accepts it, ok. If he doesn't, it is ok too. It's better he leaves before I get attached to him (Kostas, HIV-positive).

How? The last challenge was to select a strategy that HIV-positive gay men felt would be effective. Disclosure is a relational act – both verbal and non-verbal – and, as such, requires specific communication skills. HIV-positive participants reported rehearsing the interaction, even thinking about the ideal place and the clothes they would wear. They constructed the moment of disclosure as a crucial one in the romantic story. As Angelos (HIV-positive) explained, it is like an academic examination; one must study hard, be prepared, and everything is judged in a moment – *success* or *failure*.

> I was feeling like I passed the exams to enter University. Like the result of this exam will influence my whole life … Before I disclosed my HIV-positive status, I rehearsed the words, I even tried to control any reflective reaction of my body, I was very anxious, like an actor before he goes on stage (Angelos, HIV-positive).

Disclosure appeared to be a significant relational factor for the HIV-positive and HIV-negative participants alike. Both the choice to disclose and a partner's reaction were interpreted as motivated by emotional considerations. For example, HIV-positive participants saw *acceptance* on the part of an HIV-negative partner as proof of his true feelings.

> Once when I disclosed that I'm HIV-positive to a person I was dating, who was very important to me, he ran away. After 2 years he came back and it was one of my longest relationships. This was a great recognition and satisfaction for me. HIV could play no role (Pavlos, HIV-positive).

Similarly, HIV-negative individuals perceived the disclosure of HIV-positive status from partners as an act of *trust*. They realized that the disclosure's purpose was for their protection.

> He could keep [his HIV-positive status] secret. The fact that he decided to share it with me means that he really loves me, he cares about me and he wants to protect me (Antonis, HIV-negative).

Thus, for male couples of mixed-status who stayed together after the revelation of one partner's HIV-positive status, the disclosure and its aftermath were interpreted as a significant emotional milestone in the relationship.

Male Homosexuality and HIV Infection: A Strong Symbolic Bond

While serostatus disclosure was portrayed as challenging by the HIV-positive gay men in my study, the experience was not altogether novel. The majority noted that they had faced similar disclosure dilemmas when dealing with another stigmatized characteristic: their homosexuality. Disclosing homosexuality and disclosing HIV-positive status follow the same psychological path, the so-called *coming out* process. Of course, one might argue that there is an essential difference between homosexuality and HIV: homosexuality is not contagious. Or – at a symbolic level – is it? As Giorgos (HIV-positive) put it, "I lost a lot of (straight) friends because of my homosexuality. For some of them, homosexuality is a disease, and even contagious!" Thus, the experience of disclosing homosexuality was used as a template for HIV-positive status disclosure. It helped HIV-positive gay men to avoid traps, to maneuver:

> The experience of coming out helped me to deal with the disclosure of my HIV-positive status. I have already known the risks and the consequences. Self-disclosure is not an easy process … you feel naked in front of the critical eyes of the others … It's less difficult if you have already been naked … [laughs] (Kostas, HIV-positive).

It was not only within the thinking of HIV-positive participants that HIV and homosexuality were tightly linked, however. For some of the HIV-negative participants, worry about becoming HIV-infected stemmed from a sense that this was inevitable, a destined moment in their lifespan as gay men. For them, HIV was central to their subjectivities as gay men. As Christos (HIV-negative) explained: "It's like a 'hide and seek' game; I am hidden and I am afraid that the virus will find my hiding place". One factor that influenced this perception of inevitability was the ban on gay men donating blood in Greece. The ban implies that all blood from gay men is potentially dangerous, *ergo* their individual HIV testing results have no validity.

> My blood is dangerous, even if I am HIV-negative. What is the difference [of being positive or negative] for society? There is no difference in fact. Being homosexual was always a sickness; the discovery of the virus was a proof of this point of view (Alexandros, HIV-negative).

For the HIV-negative group members, the tight association between homosexuality and HIV-positivity could work both as a deterrent or a facilitator for the formation of a mixed-status couple. For those whose discourse prominently featured binaries such as health/illness, safety/risk, and so forth, a relationship with an HIV-positive partner should be avoided. As Christos explained, "I couldn't be in such a relationship. I would feel like being at risk 24 hours a day." On the other hand, for HIV-negative participants whose discourse invoked notions such as stigma, prejudice, discrimination, and exclusion, being in a mixed-status couple could be seen as a political act. In the words of Alexandros, "Having an HIV-positive partner is a real proof of acceptance and solidarity."

Coupling and Serostatus Preferences

Analysis of participants' narratives in this study revealed three underlying gay sexual lifestyle models: (a) *abstinence*, (b) *hyperactivity*, and (c) *coupling*. Due to the focus of this volume on mixed-status couples, in this chapter I briefly outline factors that facilitate couple formation for HIV-positive and HIV-negative participants before moving on to discuss serostatus preferences.

HIV-Positives For some participants, casual sex, especially if considered the cause of the infection, ceased to provide satisfaction. They reoriented their sexual behavior from prioritizing casual pleasure, to a greater emphasis on the *emotional stability* and a *sense of security* offered by more enduring bonds, as explained by Markos (HIV-positive):

> After the infection, I stopped having sex with strangers. Promiscuous sex had nothing to offer me anymore. I needed the security and the warmth of a stable relationship. Casual and anonymous sex is harmful … I needed a safe haven … And I found it in his arms.

HIV-Negatives The majority of this group cited the need *to be with* (inclusion) and *to share with* (communication) someone as their primary motivation for wanting a long-term, stable relationship. Antonis (HIV-negative) said: "I want someone to have next to me … someone I will care for and he will care for me. Someone I can share things with!" In response to my question about which "things" he wanted to share, he explained:

> Daily life activities, you know … cooking, having lunch, shopping, watching a film on couch while eating popcorn (laughs), sleeping together … you know … simple things that make you feel like a human. Only with another person, we can be happy. No one is happy alone, not even in heaven, as my grandma says.

For Antonis, then, what we call "happiness" was a result of social interaction. Further, for him, being "a human" meant being social, with romantic relationships perhaps one of the most potent instantiators of our humanness. Of interest is the fact that when discussing "couple" relationships, participants in both the HIV-positive and HIV-negative group interviews were referring to monogamy. Open relationships were not acknowledged and no debate developed spontaneously regarding any sexual agreements couples might have (Crawford et al. 2001; Hoff and Beougher 2010).

One dilemma which surfaced for the participants who wanted to establish a long-term relationship was whether it was preferable to have an HIV-positive or HIV-negative partner. This often led to what Eaton et al. (2009) call "serosorting".

HIV-Positives The majority of the HIV-positive gay men in my study had had predominantly negative experiences with HIV-negative partners. Loukas (HIV-positive), for example, described one such relationship as: "Traumatic, I needed a lot of time to recover and to carry on with my life. So I avoid starting a relationship when the guy tells me that he is HIV-negative." Experiences of extreme fear, rejection, and abandonment oriented these participants towards other HIV-positive men. In addition, partnering with other seropositive men seemed safer because they would not have to fear rejection on the basis of their serostatus or worry about prevention. Indeed, some of them were more likely to report dispensing with condoms if their partner was HIV-positive too, ignoring HIV superinfection. Condomless sexual intercourse was seen as providing several benefits, as Markos (HIV-positive) made clear: "When my partner is seropositive as well, I feel more relieved, freer … I gain more sexual satisfaction … and intimacy of course."

On the other hand, a few HIV-positive gay men in my study preferred HIV-negative partners. They explained that mixed-status relationships lent a *sense of normality* to their everyday lives. For example, Pavlos (HIV-positive) stated:

> I don't want to date HIV-positive guys. I don't know why … Maybe because HIV is always there … it's a three-person relationship: him, me and the HIV. It spoils the mood. With a HIV-negative guy, I forget it. We don't talk about it. This allows me to live as a normal person, without concerns and fears.

Previous research has suggested too that HIV-negativity can act as a normalizing agent for HIV-positive people (Jarman et al. 2005; Keegan et al. 2005; Persson and Richards 2008). This normality was encouraged by what has been referred to as "sero-silence" (Persson 2008). As Remien and colleagues (2003:534) stated, it is "common for mixed-status couples to avoid talking about HIV-related topics" in order to protect each other from concerns, such as the fear of HIV transmission. The segment above illustrates these tendencies, and also exemplifies John Rolland's (1994) observation that "a chronic disorder can become a powerful third member in any dyadic family relationship", and that HIV-negativity is idealized ("without concerns and fears"), while HIV-positivity is devalued ("spoils the mood").

HIV-Negatives Of the seven participants in this group interview, two had experienced mixed-status relationships and one expressed that he would have no problem being in such a couple. The other four participants expressed a preference for partners who shared their serostatus. This was based on fear of transmission. With respect to HIV prevention, the participants who preferred a seroconcordant negative relationship invoked a rationality of self-protection. This rationality was grounded in their sense of personal responsibility to avoid becoming infected, while assuming HIV-negativity as the normative status (cf. Davis and Flowers 2011). HIV was described as introducing an unwelcome element of stress into what was supposed to be the carefree realm of sexual intimacy, as exemplified in this quote by Michalis (HIV-negative):

> A [mixed HIV status] relationship is *a priori* stressful. I mean you cannot feel entirely at ease. You have to be careful all the time and this is very stressful. When having sex, a moment when you should feel totally relaxed, HIV will be on your mind. You must think about not being infected, if you want to be responsible.

On the other hand, those who were currently part of a mixed-status couple, or who were open to being in such a relationship, pointed out the irrelevance of HIV in a romantic partnership. The discourse of these participants included several notable characteristics. First, for them, due to the prevalence of HIV within the gay community (Sheon and Crosby 2004), the normativity of an HIV-negative serostatus had become relative. As Alexandros, an HIV-negative gay man who was receptive to the possibility of a mixed-status relationship, explained: "There are so many positives in the [gay] community that HIV is not taboo anymore." Of note in the quote below, Stefanos, an HIV-negative gay man who was currently in a mixed-status couple, avoided the *medical discourse* of HIV serostatus and transmission, instead using a *discourse of love* that included the notions of *trust*, *care*, and *commitment*.

> It's the first time I feel so close to someone. I love him very deeply. Our relationship is based on mutual trust, care and commitment. We care about each other and each one supports the other. We feel like a team … the 'dream team' [laughs] (Stefanos, HIV-negative).

The kind of commitment Stefanos referred to manifested in these HIV-negative participants' discourse as a "we". Those who adopted this "we" orientation saw their union as a dyadic social alliance to cope with challenges of stigma, discrimination, exclusion. The Other was not only a partner for pleasure; he became what is known in Greece as a real *syzygos*.[3] As Antonis (HIV-negative in a mixed-status couple) put

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[3] An ancient Greek word meaning "consort", "comrade" and "yoked together", often used to describe the partners in a married couple.

it: “We are allies. With him I feel stronger. Together we can face any threat coming from society. Two are stronger than one.” Finally, with respect to risk management, these participants perceived HIV prevention as a mutual duty, a shared responsibility. Antonis made the importance of this clear:

> Prevention in such a couple [mixed-status] is a common worry, ok? I am as responsible as he is for the risk prevention. It’s not only his own business; it concerns both of us, as a couple. Based on my experience, it is of primary importance for the well-functioning of the couple.

Discussion

The term sero *discordant* suggests disharmony and tension (Persson 2008), and many studies raise questions about tensions in the context of managing transmission risk within mixed-status couples (cf. Remien et al. 2003; Eaton et al. 2009; Gamarel et al. 2014). However, few studies explore mixed HIV status from the point of view of such couples themselves. Likewise, this research was not designed to target mixed-status gay male couples; rather, it examined the narratives of both HIV-positive and HIV-negative gay men in Greece around sexual health issues in general. Some participants were, or had been, in mixed-status relationships; others had not. Nevertheless, partly due to the dynamics of group interviews, many participants shared experiences and feelings – whether personal or hypothetical – that shed light on the social construction of HIV and mixed-status couples in this milieu.

Regardless of serostatus, participants unanimously agreed on the connection in popular discourse between homosexuality and HIV-positivity. Both were perceived as problematic social situations because of stigma, prejudice and discriminatory practices. As is the case also in other settings, in Greece both homosexuality and HIV-positivity are shaped by normative cultural dynamics around health, gender, sexuality and kinship, which are framed in terms of binary oppositions: *normal/abnormal*, *moral/immoral*, *acceptable/unacceptable*. Banning gay men from blood donation exemplifies how legislation and public policies strengthen the association between being gay and being HIV-positive. This symbolic link exacerbates stigma and discriminations against gay men, increasing their vulnerability (Tucker et al. 2014). Indeed, participants’ discourse often emphasized their shared subject position within a macro-level cultural reality that transcends serostatus, namely living as a gay man in Greece. HIV-positivity and HIV-negativity are subtle variations in this experience, two sides of the same coin, as the title of the chapter indicates.

There were participants, both positive and negative, who eschewed mixed-status relationships. HIV-positive men who avoided negative partners tended to do so on the basis of stigmatizing or painful previous experiences; for negative men the primary deterrent was fear of transmission. Among those who were open to mixed-status partnerships, however, significant consensus existed with regards to certain components or interpretations that might facilitate the establishment of such a stable, intimate relationship. The first was the concept of disclosure as an emotionally meaningful act. For the HIV-positive participants, a supportive reaction to their disclosure meant acceptance, while HIV-negative participants perceived being disclosed to as an expression of trust. The second concept was protection of the self and the other as a mutual concern. The HIV-positive partner tried not to transmit the virus to his negative partner, but prevention was a shared responsibility. The third concept was commitment. The relationship was seen as an alliance against the difficulties of life and pressures from society, particularly as gay men. There was more variation among participants in terms of the degree to which their discourse reflected the biomedical and popular assumption of the normativity of being HIV-negative. For a few, HIV prevalence within the gay community appeared to have relativized this norm. It remains to be seen how increasing knowledge and availability of TasP and PrEP may impact these findings.

At this point, it is important to reiterate that the findings come from a study conducted in 2006. Although PrEP is not available yet in Greece, and treatment *qua* prevention is rare, attitudes and experiences may have shifted in the decade since these data were collected.[4] Other limitations include the fact that mixed-status couples were not the original target population for this study; hence, data are limited. Methodological alternatives, such as joint interviews, would provide a better understanding of the everyday social practice of mixed HIV status and should be conducted. Nonetheless, this secondary data analysis revealed robust and relevant patterns that begin to fill the acute gap in Greek literature on this issue.

In the near future, TasP and PrEP will likely engender new opportunities and complexities around HIV prevention for positive and negative gay men in Greece, making it more critical than ever to address the gap in research on HIV and gay men in this setting. With respect to future studies, it will be interesting to monitor whether attributions of responsibility for prevention of HIV transmission within mixed-status couples evolve as these biomedical prevention strategies become disseminated. In addition, gay men's representations of TasP and PrEP, and their impact on sexual practice and conceptualizations of mixed-status relationships will be crucial issues to explore. Another pressing need for future work in Greece is the investigation of health care providers' attitudes towards biomedical prevention, (homo-) sexuality, and mixed HIV status. For all of these endeavors, the findings reported here can serve as a foundational canvas. Further explorations of HIV and mixed-status relationships in Greece should begin from the country's socio-symbolic context and attend to research participants' own constructions of their lived realities.

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[4] Even so, it's notable that some participants invoked self-disclosure, mutual protection, and commitment (all culturally-constructed components of close relationships in Western societies, see Tang et al. 2013) as elements that make mixed-status relationships work – much as one might expect of relationships in general.

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“Because We’re So in Love”: The Experiences of HIV-Negative and HIV-Positive Partners in Serodiscordant Relationships in Vietnam

Khuat Thi Hai Oanh, Sally Cameron, and Lan Nguyen

Introduction

The official approach to HIV prevention in Vietnam has shifted over the last decade from a platform that blamed certain populations for the HIV epidemic to a stronger focus on public health. Emerging recognition that many women’s HIV infection risk occurs within intimate relationships has triggered a shift in Vietnam’s HIV prevention thinking. It is now accepted that HIV risk extends beyond the “social evils” (“tệ nạn xã hội”)[1] of injecting drugs, sex between men and sex work, and that risk can arise as a result of behaviors considered socially acceptable or even desirable, that is: sex between spouses and sex between monogamous heterosexual couples. There is growing understanding of the intersection between behaviors in different contexts and a realization that primary HIV prevention measures targeting key “higher risk” populations of people who inject drugs, men who have sex with men and female sex workers directly impact a secondary group: their intimate partners. Still, relatively little is known about the many contextual factors such as culture, intimacy and gender dynamics that influence HIV transmission risk among intimate partners in serodiscordant relationships in Vietnam and the way HIV infection informs their daily lives, including plans for the future.

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[1] A term institutionalised in government policy.

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Emergence of Serodiscordant Couples as a Priority for HIV Prevention

In 2014, an estimated 256,000 people were living with HIV in Vietnam (Vietnam Administration of HIV/AIDS Control 2013). The HIV epidemic is concentrated among key populations of people who inject drugs, men who have sex with men and female sex workers and their clients, with injecting drug use the primary mode of transmission. Most people living with HIV are men, however a steady increase in infections among women is being reported. In 2001, women comprised 15 % of people living with HIV (Ministry of Health data, cited in San et al. 2002). By 2013, women accounted for an estimated 32.5 % (Socialist Republic of Vietnam 2014).

While definitive surveillance data are not available, numerous studies suggest a primary source of HIV infection among women is their long term partners, and that increasing rates of infection among women likely reflect "slow but steady" transmission of HIV to women by men engaging in "highly risky behaviors" (Socialist Republic of Vietnam 2014). Intake data from voluntary counselling and HIV testing clinics between 2006 and 2010 showed 54 % of women diagnosed with HIV infection identified a husband or long-term male partner with high risk behaviors as their only possible exposure to HIV (UNAIDS and UN Women 2012). *Vietnam AIDS Response Progress Report 2014* states most women living with HIV report they were infected by a stable sexual partner who either injected drugs or visited sex workers (Socialist Republic of Vietnam 2014). The consequences of the "slow creep" of spousal transmission means that transmission from men engaging in high-risk activities to their long-term female sexual partners accounted for an estimated 28 % of *all* new infections in Vietnam in 2014 (Vietnam Administration of HIV/AIDS Control 2014). In this study (outlined below), 88 % of female participants reported they were HIV infected by their heterosexual partners.

Serodiscordant relationships are not unusual, particularly relationships involving an HIV-positive man and an HIV-negative woman or woman of unknown HIV status. In 2012, a UNAIDS and UN Women's data triangulation exercise examining intimate partner transmission found that between 53,000 and 160,000 women were potentially exposed to HIV by a high-risk long-term male partner between 2006 and 2010. Broken down by exposure category, this means up to 41,327 women living with an HIV-positive person who injects drugs; up to 11,017 women living with an HIV-positive man who have sex with men; and up to 107,652 women living with an HIV-positive client of sex workers. A recent study of HIV-positive married men registered at an HIV clinic in northern Vietnam also found a high proportion of HIV serodiscordance among HIV-affected married couples. Among the 163 HIV-positive men enrolled in the study, 63 % had wives who were HIV-negative (Sawada et al. 2015).

Limited progress in primary HIV prevention measures is placing serodiscordant sexual partners at significant risk, particularly when the HIV-positive partner is undiagnosed. HIV testing remains low among priority populations. In 2013, only 29 % of MSM and 24 % of people who inject drugs reported an HIV test in the previous 12 months (Socialist Republic of Vietnam 2014). Vietnam's national AIDS Law of 2006 provides that sexual partners of people who inject drugs and other key populations are entitled to access the condom promotion program (Socialist Republic of Vietnam 2006). There is recent official recognition of serodiscordant couples as a priority population for prevention (Ministry of Health 2014:15) and a growing understanding that additional measures are required to specifically address the HIV prevention needs of intimate partners of people with HIV. Prevention for serodiscordant couples is implemented through behavior change communication, HIV testing and counseling, and "treatment as prevention" (TasP). Even so, coverage of HIV testing and counseling services was very limited among female long-term partners of men at higher risk of HIV infection when this study was conducted in 2009; such remains the case in 2015.

The Study

This chapter is based on a 2009 multi-arm study documenting the sexual and reproductive health (SRH) needs of people with HIV (Oanh et al. 2011). The study was undertaken by the Institute for Social Development Studies in partnership with Vietnam Civil Society Partnership Platform on AIDS. The study was given ethics approval by the Institutional Review Board of the Institute for Social Development Studies.

The study's first arm comprised a survey of 2599 people living with HIV (PLHIV) associated with PLHIV groups in 22 provinces: 1300 women, 1297 men and two transgender people (referred to as "the core PLHIV study"). The self-administered questionnaire required Vietnamese literacy. The second arm involved 307 HIV-negative partners of some of those who participated in the first arm of the study (referred to as "the negative partners study"). The negative partners study grew out of feedback from the core PLHIV study, during which many participants suggested that sero-negative spouses should also be involved as they are an "integral part" of the sexual and reproductive health of people with HIV (Oanh et al. 2011). Negative partners of people with HIV were defined as those living with a positive person (regardless of marital status) and whose latest HIV test indicated they were HIV-negative. The majority of negative partners who participated in the study were women (87.6 %). Of those women, 58.2 % had been with their HIV-positive partner for five years or more and 29.4 % had been together for two to five years.

A qualitative arm was also conducted, spread evenly across seven geographic regions: Northwest, Northeast, Hanoi, Red River Delta, Central, Ho Chi Minh City and Mekong Delta. Efforts were made to ensure representation of men and women as well as representation across key populations. The qualitative arm included 21 focus group discussions (seven for men with HIV, seven for women with HIV, two for HIV-positive drug users, two for HIV-positive sex workers, and three specific to HIV-negative partners). It also included 72 in-depth interviews with people living with HIV and their regular (primary) sexual partners. "Regular (primary) partner" was defined as someone either living with the participant as husband or wife, or someone with whom the participant had sex on a regular basis and with whom the participant had had a strong emotional attachment for at least three months. Finally, 88 in-depth interviews with SRH service providers were conducted. This paper focuses on the qualitative interviews with HIV-negative partners and in-depth interviews with people living with HIV and their regular sexual partners.

Findings and Discussion

Marital or Partnership Status

Data from the core PLHIV study reveal a number of gendered differences among respondents living with HIV. Women tended to be younger, have fewer years of schooling, and were more likely to be responsible for providing economic support to at least one other person. Men were far more likely to have never been married/lived with anybody (Men 24.6 %: Women 3.0 %). Women were far more likely to have "ever lost a spouse to AIDS" (Men 6.9 %: Women 48.8 %). Women were also far less likely to have remarried following the death of a spouse, identifying current marital status as "widowed" (Men 1.3 %: Women 34.5 %). According to the participants, being known as the widow of someone who had HIV or was a drug user was considered a great disadvantage to women, undermining the likelihood of finding a new partner. Their experiences of personal loss also seemed likely to impact the nature of intimacy in future relationships.

The majority of HIV-positive participants (67.3 %) described themselves as having a regular partner (68.7 % of men and 63.2 % of women), however only a minority were formally married (46.0 % of men and 36.5 % of women). These rates were far lower than the general population, where 61 % of men and 77 % of women among those aged 25–29 years, and 84 % of men and 86 % of women among those aged 30–34 years are married (General Statistics Office of Vietnam 2005). This difference is notable, since formal marriage brings enhanced social standing and access to services. Unmarried partners also confront practical challenges, such as difficulties dealing with legal issues regarding children and inheritance outside of marriage. This finding suggests the importance of developing responsive interventions that recognize that the majority of people with HIV are in a relationship although many are not married.

Ninety-seven percent of respondents in relationships were in a heterosexual relationship. Of those people with HIV who had only one regular partner, 60.2 % (52.7 % men and 84.3 % women) had a partner who had tested positive for HIV, while 31.1 % (37.4 % men and 10.6 % women) had a partner who had tested HIV-negative, and 8.8 % (9.9 % men and 5.1 % women) had a partner whose status was unknown.

The research showed highly gendered patterns of serodiscordance. Almost half of all partners of men living with HIV were HIV-negative or of unknown serostatus. By comparison, only 15 % of partners of women living with HIV were HIV-negative or of unknown serostatus. Most serodiscordant respondents reported their relationships were either committed and/or loving, however many also struggled with fear of transmission and fear of losing their partner for a variety of reasons (outlined below).

Disclosure

HIV-negative partners came to be in a relationship with their HIV-positive spouse in a number of ways: they were unaware that their partner was HIV-positive when they first partnered; their partner was infected *after* they had formed a relationship; or they knew *beforehand* that their partner had HIV and made a commitment regardless. The majority of HIV-negative respondents had not been informed of their partner's HIV status before committing to the relationship. For a range of reasons, it not uncommon for people with HIV to have sex without disclosing their HIV status to their sexual partner. Although Vietnam's Law on AIDS stipulates that people with HIV must disclose their status to their spouse or fiancé (Socialist Republic of Vietnam 2006), in this study 26 % of men and 20 % of women who had had sex since being diagnosed HIV-positive had not disclosed to at least one partner before having sex.

Participants described multiple barriers to disclosure of HIV-positive status. Many people with HIV reported difficulties in disclosing although they wanted to disclose. The most common reasons for not disclosing were fear of being stigmatized or isolated (85.4 % men and 95.3 % women), fear of confidentiality being breached (86.2 % men and 86.9 % women) and fear that their partner would refuse to have sex with them (88.2 % men and 79.3 % women). Positive women were more fearful of being stigmatized or isolated than their male peers, which is perhaps not surprising given evidence many women become victims of abuse, violence or abandonment following disclosure (Eyakuze et al. 2008).

For some people, fear of the consequences of disclosure was so great that they chose to give up a relationship rather than disclose:

> That girl is really sweet. I like her a lot but I didn't know how to tell her [I have HIV]. If I had continued, I would have needed to let her know, but I didn't know how she would react. I am afraid that she would have looked at me with different eyes. Maybe she would tell other people … so I'm giving up (HIV-positive man).

One man had decided to stop three different relationships:

> It is like there is a wall, a wall in front. Every time I start dating someone I think, how can I say it … if I say I am diseased like this? So after some time, I give up.
>
> Interviewer: So why do you start dating these people?
>
> Well, at the beginning, because we are human, we have feelings. Having feelings, we want to date. After dating I feel … I feel if I am not going to tell her, I would of course feel

> guilty. I have to decide. Telling her is like killing; not telling her is also like killing. Then I think, it's better to withdraw myself (HIV-positive man).

Many HIV-negative respondents recognized their HIV-positive partners' decisions not to disclose or to delay disclosure were not straightforward and often involved considerable anxiety and guilt.

Staying Together

Clearly not all serodiscordant couples stay together. For example Sawada and colleagues' (2015) data show 4 % of men in their Northern Vietnam study sample had divorced since their HIV diagnosis. In this study, HIV-negative partners, including those who found out their partner's HIV positive status before or after getting together, gave a variety of reasons for staying with their HIV-positive partner (Fig. 1).

The importance of marital ties and/or romantic attachment frequently outweighed HIV-related concerns when deciding to continue the relationship. The majority of negative partners felt strong emotional attachment to and compassion for their positive spouses. When asked if they would like to have a new partner, 92 % of negative partners responded "no". Many of those who made a commitment to their partner after learning of their partner's HIV-positive status told stories of love and compassion.

> Because we were so in love … Well, when you are so in love, there is no fear anymore (HIV-negative, male).
>
> That day when I married him, many people said I am mad or that kind of thing. The day we decided we want to live together, I only thought 'if our love can protect and help each other, it is good' (HIV-negative, female).

In addition to love and commitment, both positive and negative partners in serodiscordant relationships often also experienced a range of different fears. For example, some positive partners spoke of their fear of losing their negative partner because of

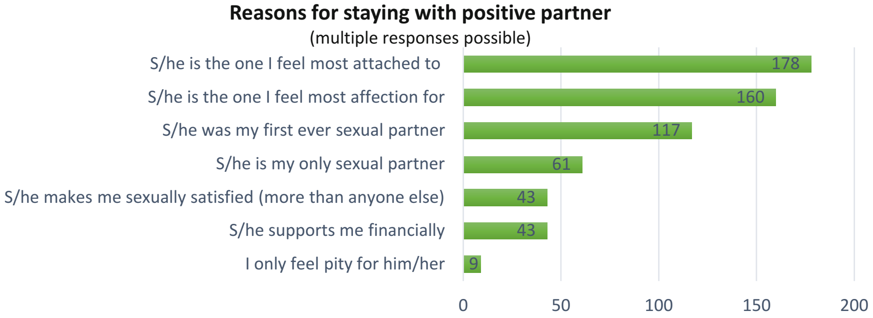

Fig. 1 Reasons given by (307) HIV-negative partners for staying with HIV-positive partner

the additional burden that living with a person with HIV may bring, or because partners and family members also experienced HIV-related stigma and discrimination. Indeed, the study uncovered cases where fear of a partner leaving the relationship may have contributed to cruel behavior, including gender-based violence:

> It is truly because of the pressure … Every time we start to have sex, my husband feels pressure so he becomes scornful. His personality has changed. Before he was 10 times sweet. Now he is 10 times cruel (HIV-negative, female).
>
> I know this guy. He is positive. His wife was not but he forced her to have sex without a condom. He kind of tried to infect her because he was afraid she would leave him. He even said to her that he would infect her so that when he dies she won't be able to go with another guy. She knelt in front of him asking him to save her so that she can take care of the children. Many people spoke to him but he insisted. Now she is positive (HIV-positive, female).

HIV-positive respondents also reported that their fear of transmitting HIV impacted their physical relationship:

> I am an infected person so our (sexual) relationship is not as enjoyable as it was at the beginning. I am always afraid and try to prevent transmission to my wife (HIV-positive, male).

Some negative partners also spoke of their fear of transmission:

> Sometimes while we are [having sex], I stop and check the condom. I am so afraid (HIV-negative, female).

In some cases, this fear was so severe that negative partners took extreme measures to avoid sex:

> We have our own beds. I have a 'security guard' so I am not afraid. The 'security guard' is my son [who sleeps with his father]. Going to sleep he uses a scarf to tie his wrist to his father's, and says to his father 'you should not go anywhere' (HIV-negative, female).

Fear of transmission, however, was not the only fear reported by negative partners. Some were also afraid their partner may leave them to look for an HIV-positive partner, to avoid concerns about transmission or to be able to have sex without condoms:

> I am afraid that he may look for a positive woman, for example, to have freedom [having sex] or he may think that she would understand him better (HIV-negative, female).

Sexual Activity

People with HIV were much less sexually active than their peers in the general population (National Sex Survey data in Hong et al. 2009, cited in Oanh et al. 2011:30). Positive people in a serodiscordant relationship were less likely to have had sex "recently" than those with HIV-positive partners. Fear of transmission was a key reason, but other reasons were also reported (Table 1).

Table 1 Last time had sex by relationship serostatus

	Serodiscordant relationship	Seroconcordant relationship
Previous 4 weeks	65.6 %	78.7 %
1 month to 1 year ago	20.6 %	15.7 %
More than 1 year ago	13.8 %	5.6 %

Some people with HIV and HIV-negative partners believed that having sex would badly affect the HIV-positive partner's health, so they tried to constrain their sexual activities.

> We are very normal. We have sex probably twice a month, because his work is hard and his health is that of a person infected with HIV, so I think if we have sex too much it will affect his health (HIV-negative, female).

After learning they had HIV, some HIV-positive people in serodiscordant relationships were not able to regain sexual desire. Not only their sexual lives, but their overall enjoyment of life appeared to have diminished.

> Since I discovered that I got it, I have not slept with my husband. I feel frightened. My limbs became weak. Lying next to my husband I have no feeling. I live only for my children. For the last two years I have not had [sexual] feelings and I don't want my husband to have [sexual] feelings. When I shower, I don't want him to see me. When he showers or changes he always closes the door. My life is not adequate. My life is so lacking in meaning (HIV-positive, female).

When people with HIV sought advice from health services, sex was mentioned almost exclusively in relation to risk and condom use. There was rarely any discussion about pleasure, intimacy or how to negotiate decreased sexual activity or desire in serodiscordant relationships.

> Since my husband died I no longer think about sex. Here there is a lot of education saying it is ok to have sex normally. There is also education about condoms and correct use of condoms. There was even a doctor who came from central level [rather than provincial level: suggesting the importance of the education session]. I understand quite well about these things but I'm finished, with no desire for sex. No feeling. No desire (HIV-negative, female).

The survey suggests that interventions to address the sexual well-being of people with HIV are urgently required, and that they should be integrated into HIV prevention education provided to serodiscordant couples.

Condoms

Condoms were found to be widely available, with 99 % of all people with HIV reporting no difficulty accessing condoms, and 90 % of those who were sexually active in the previous three months stating that condoms were always available. However, only 62 % of those who had sex with a positive partner and 82 % of those who had sex with a negative or status-unknown partner reported consistent condom use during the previous four weeks. Rates of condom use among *serodiscordant couples* varied by gender, with 16.6 % of positive men reporting consistent condom use with a female partner, compared to 33.9 % of positive women reporting consistent condom use with a male partner. Gendered rates of condom use among serodiscordant couples also varied by marital status. Approximately one third of HIV-positive women reported consistent condom use with their husband (37.1 %) or cohabiting, unmarried male partner (31.7 %). HIV-positive men were far less likely to report consistent condom use with their wife (11.6 %) than with a cohabiting, unmarried female partner (35.0 %).

Analysis of the qualitative data suggests condom use could be much lower, particularly among those in a non-marital cohabited relationship. The known serostatus of a partner also strongly influenced reported condom use, with condom use highest among people with HIV with a known negative partner, and lowest among those with a partner of unknown status: the latter being of considerable concern.

Regardless of their partner's HIV status, people receiving antiretroviral treatment (ART) were more likely to report consistent condom use than those who were not. Of those whose partner was known to be HIV-positive, 68 % of people on ART consistently used condoms compared to 56 % of those not on ART. Of those whose partner was known to be HIV-negative, 93 % of those on ART consistently used condoms compared to 83 % of those not on ART. Of those who did not know the HIV status of their sexual partner, 72 % of those on ART had consistently used condoms compared to 48 % of those not on ART. The reason for the greater use of condoms by people on ART is not known, however it may be related to increased access to information and counselling through HIV treatment and support services, greater awareness of sexual health, or exposure to biomedical discourses that would make reporting non-use more sensitive.

People with HIV reported being trapped between the pleasure of not using condoms and the fear of transmitting HIV. They also described a tension between the feeling of being protected by condoms and the cumbersome nature of their use.

> If I don't use condom, I am afraid that I may infect my wife. But I hate condoms. So does my wife. Sometimes after putting a condom on, I lose the excitement. Then I tried to avoid [sex] (HIV-positive, male).

Very often, people with HIV in serodiscordant relationships considered condom use an obligation. A positive man, who reported consistently using condom for 10 years with different HIV-negative partners confided:

> It is not really relaxing because using condoms is not very comfortable. I use them only because of a sense of responsibility (HIV-positive, male).

"Responsibility" may be understood as a desire to prevent HIV transmission but also unwanted pregnancy.

> I don't know if they [partners] are infected or not. I should prevent transmission. Also, I don't want [them] to get pregnant (HIV-positive, male).

In general, condoms were perceived by the majority of people with HIV in serodiscordant relationships as a pleasure inhibitor. In many cases, people considered not using condoms as a sign of trust. Others experienced fatigue using condoms and/or their reluctance to use condoms increased over time

> In general, [people] do not use condoms very much with sexual partners [they've] been with for a long time. [Me and my partner] have had sex for a long time so we are not afraid (HIV-positive, female).

One respondent articulated a perceived disconnection between knowledge and practice.

> To tell you the truth, many people who have knowledge from top-to-toe and preach about condom use, if you ask them, they don't use them (HIV-positive, female).

Some people reported not using condoms because of the difficulty of disclosing their status within the context of limited knowledge in the community and, specifically, limited knowledge of their HIV-negative partner.

> I didn't say anything yet. Every time we had sex I considered it normal, using no protection with my wife. Nothing. It is because [her] knowledge and understanding of [HIV and safe sex] was really zero. When I discovered I was infected, I came home and had sex normally. I didn't say that I was infected. I hid it. I didn't want my wife to know. If she knew, she would be shocked (HIV-positive, male).

Couples with children reported more consistent condom use across all categories: sero-concordant couples with children (69.8 %) compared to those without children (53.1 %); serodiscordant couples with children (91.7 %) compared to those without children (80.4 %); and couples with children where one partner was HIV-positive but the other's status was not known (60.6 %) compared to such couples without children (50.3 %).

It is important to recognise that condom use may be related to a desire to prevent HIV transmission or contraception, or a combination of both. Among negative partners in serodiscordant couples, 85 % reported using contraception, with 98 % of those reporting condom use. Yet notably, 17 % of HIV-negative women with an HIV-positive partner who had ever been pregnant reported that the last pregnancy was due to lack of access to contraceptives that suited them.

The differentiated use of condoms by couples with children is not fully understood, but may be partly explained by findings that condom use was associated with a sense of responsibility and desire to be alive and healthy, and to keep partners alive and healthy, for their children.

> We are thinking about the baby. Our wish has come true, so we no longer dare to take risks as before (HIV-positive, female).

The above findings suggest a need to design responsive HIV prevention strategies and programming that go beyond the rhetoric of 100 % condom use, recognizing the real reasons why people don't always use condoms and the interconnectedness of SRH services. These findings also suggest great potential for the use of treatment-as-prevention (TasP), which had yet to become a recognized prevention strategy at the time of this study, particularly if HIV testing and post-diagnosis counselling facilitates identification of serodiscordant couples. We note Sawada and colleagues' recent study in Northern Vietnam, which found no seroconversion during (a median 24.1 months) follow up of 61 serodiscordant couples in which HIV-infected male partners were taking antiretroviral treatment (Sawada et al. 2015).

Pregnancy and Child Bearing

It is a norm in Vietnamese society for adults to marry and have children. Culturally, a person's life is not considered complete until they have children.

> Many times, his old mother cries that as people die they have children and grandchildren, 'losing the rice but the broken rice remains' [the family line continues], but here everything will be gone, no broken rice, nothing left [there will be no children left to continue the family line] (HIV-negative, female).

In the core PLHIV survey, less than one-third of participants (21 %) stated they still wanted to have children (22.9 % men, 15.5 % women). For most people with HIV, their desire for children was overridden by fear of the child being HIV-infected, fear of economic hardship and fear of leaving the child orphaned. All HIV-positive people who wanted children stated that their dominant concern was having a child uninfected with HIV. Among people with HIV who had no children, the most common reason for wanting children was to continue the family line. Among HIV-positive people with children, the most common reason for wanting another child was wanting a child of a particular sex, usually (but not always) male.

Despite fears of infecting the HIV-negative partner or having an HIV-infected child, most serodiscordant couples wanted children, especially those who had not had a child. The main reasons given were to satisfy their desire to be parents, to strengthen the bond with their partner or to fulfill their responsibility with family.

> His family condition is like that – no grandchild. His father was desperate. I know [my partner] wants a child very much but he didn't dare ask me [because it would mean HIV infection risk through unprotected sex]. I was also afraid that he would go with a girl who is also infected to have children. So I decided to take the risk (HIV-negative, female).
>
> At the beginning we used condoms, then I heard his mum say, 'This family is so unfortunate. Every other family has grandchildren except this one.' So I stopped using condoms. I decided that on my own. I stopped for three months. Then I got pregnant (HIV-negative, female).

Serodiscordant couples wanting to conceive relied most frequently on condomless sex, as alternative conception options were unavailable or unknown.

> It's almost like we gamble. At the time my husband and I affirmed the saying 'Gamble with God'. If God cares, then there is no problem but if he doesn't, then we have to accept whatever happens. We were fearful. My husband was very worried for me as well (HIV-negative, female).

Serodiscordant couples came up with their own strategies, including "home remedies", to reduce infection risk while trying to conceive, such as cutting the tip off condoms, calculating days and not using condoms when ovulating, calculating days combined with the male partner masturbating and inserting his penis only when about to ejaculate, having sex without condoms and then the HIV-negative partner taking ART as post-exposure prophylaxis, and "having sex gently".

> I think if we were unlucky and the baby was born positive, we would be miserable. My wish is to have a child but I don't know where to go for counseling to know how to have a child without infection (HIV-positive, male).

Information and counseling services addressing the special needs of serodiscordant couples were not available when this study was conducted and remain largely unavailable in 2015.

Conclusion

The serodiscordant couples interviewed generally remained committed to each other, but many partners continued to experience fear that HIV would be transmitted. Many also described difficulty maintaining a satisfying sexual relationship and concern that the pressures of the relationship would cause one (HIV-positive or HIV-negative) partner to leave.

Limited knowledge of HIV risk reduction methods and contraception prompted use of a range of HIV prevention and family planning strategies, including unreliable "home remedies". Couples' strong desire for children, intensified by weighty cultural drivers to continue "the family line", remains unaddressed in Vietnam. The data suggested an urgent need for more comprehensive SRH services and their linkage to HIV services (including prevention of mother-to-child transmission services). It remains urgent 6 years later. That finding is supported by the 2011 *Vietnam: Rapid Assessment of Sexual and Reproductive Health and HIV Linkages* (World Health Organization et al. unpublished), which also argued for further exploration of the factors behind the high rates of abortion among women with HIV, including pressure from family, community or health services, fear of HIV transmission during pregnancy or delivery, and concern about supporting children in case of a parent's ill health. Prior poor experiences of health care may also play a role, given APN+'s (the Asian Pacific Network of People Living with HIV/AIDS) findings that during delivery and postpartum care, many HIV-positive women report extreme discrimination, including neglect during labour and healthcare professionals refusing to attend to them, touch them or bathe their newborn infant (APN+ 2012).

Social contexts, psychological drivers and gender dynamics of intimate partner relationships have tangible ramifications for service provision, particularly couple testing and counseling, prevention of mother-to-child transmission services, and TasP. Early evidence from pilot studies indicates that couples HIV testing and counseling, followed by immediate ART are feasible approaches to prevent transmission within serodiscordant couples in Vietnam (e.g. Kato et al. 2014). Similarly, Sawada and colleagues found that at-risk wives of HIV-positive men can be protected from

HIV transmission by proper use of ART (2015). Option B+ for prevention of mother-to-child transmission (i.e. provision of lifelong ART to all pregnant and breastfeeding women living with HIV regardless of CD4 count) has also been piloted in several provinces (Loc 2014).

Findings from this 2009 study have contributed to significant programmatic and policy reform within a brief period. It informed the ground-breaking 2011 workshop, Forgotten Voices: Issues of HIV Negative Spouses and Sero-Discordant Couples,[2] which raised awareness of HIV risk, care and support needs among serodiscordant couples, particularly the importance of spaces for HIV-negative partners to access support, network and advocate. Recent funding and capacity building for peer-support groups for negative spouses of people with HIV has enabled their representation on the Vietnam Civil Society Partnership Platform on AIDS, and the inclusion of serodiscordant couples and HIV-negative partners of people with HIV and other high risk populations as priority populations in formal national HIV response mechanisms such as the National Strategic Plan on HIV/AIDS. The 2009 study provides a resource for ongoing development of prevention policy as the Government of Vietnam and development partners seek to reorient prevention in the context of TasP (Kato et al. 2014). Importantly, care should be exercised in the development of increasingly biomedical prevention approaches to ensure people with HIV are not considered only in terms of "transmission risk" but are instead considered as whole human beings for whom sexuality, the quality of their intimate relationships, and their aspirations for their family lives are central issues.

Given the effects of cultural and contextual factors on critical behaviors, such as adherence to ART, condom use and the intersection of SRH and HIV prevention initiatives, a nuanced understanding of the dynamics and social circumstances of serodiscordant relationships in Vietnam is required to inform HIV program interventions.

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[2] This workshop was organised by the Community Advocacy Initiative (CAI), in collaboration with project partners, the Center for Supporting Community Development Initiatives (SCDI), Asia Pacific Council of AIDS Service Organisations and the Australian Federation of AIDS Organisations with funding from the Australian Government.

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Negotiating "Sero-Imbalances" Within HIV Serodiscordant Relationships in Canada: A Pilot Inquiry

Amrita Daftary, Joshua Mendelsohn, and Liviana Calzavara

Introduction

> A relationship means to me that it's a commitment between two individuals … it's not the HIV you love or the social stuff, it's the individual … If I love this person, I love this person … I'm not going to change if something should happen to that person. (HIV-positive pilot study participant, male)

What characterizes, shapes, and sustains HIV-serodiscordant relationships? This was the main question driving our pilot research into the dynamics of dyadic HIV-serodiscordant relationships in Canada. We sought to understand the course of these relationships, and the means each partner employed for navigating sero-difference, risk, health, and achieving relationship satisfaction.

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In most high-income countries, HIV has become a chronic and manageable disease (Deeks et al. 2013). Access to antiretroviral treatment (ART) has prolonged survival in people living with HIV. Education and awareness around safe sexual and drug-using practices have led to declines in new infections, and innovative interventions such as treatment-as-prevention (TasP) and pre-exposure prophylaxis (PrEP) are poised to extend these gains. Given this changing reality, there has been an expanded focus on enhancing the overall quality of life and wellbeing of people with HIV as they plan to lead longer, "normal" lives that include intimate sexual relationships with HIV-serodiscordant (henceforth, "serodiscordant") partners.

The literature is replete with insight on serodiscordant couples' sexual decision-making, risk perceptions, and risk-management practices within industrialized countries (Mendelsohn et al. 2015). However, relatively little has been written about the social, behavioural and structural issues that could enable or constrain intimacy and quality in serodiscordant relationships (Davis and Flowers 2011). Motivated by recent attempts to study serodiscordant relationships using critical social perspectives (El-Bassel et al. 2010; Persson 2008; Bourne et al. 2011), we aimed to understand the experiences of individuals living in these relationships in Canada.

The Canadian Context

Canada's experience with HIV is not unlike that of many other high-income nations. The first case was identified in 1982. Since then, over 24,000 persons have died from HIV-related illnesses, but mortality has steadily declined since the late 1990s (Public Health Agency of Canada 2012). Incidence has now stabilized with a little over 3,000 new cases diagnosed each year, but reduced mortality has led to an overall increase in prevalence. At the end of 2011, there were 71,300 people living with HIV in Canada. Although men who have sex with men (MSM) have historically been, and continue to be, the most affected population, HIV is increasingly prevalent among people who inject drugs, women, Aboriginal peoples, prison inmates, and people who immigrate from high-burden countries. In 2011, about 47 % of prevalent infections were attributed to MSM exposure, 33 % to heterosexual contact, 17 % to injection drug use (IDU), and 3 % to combined MSM and IDU exposure. About one-quarter of reported cases were among women, and 10 % were among Aboriginal peoples (Public Health Agency of Canada 2015).

The province of Ontario has consistently borne the highest burden of HIV, representing 44 % of national cases (Public Health Agency of Canada 2015). Data from the Ontario HIV Treatment Network (OHTN) Cohort Study, one of the largest clinic cohort studies in the country, found that 23 % of surveyed people with HIV reported being in a relationship with a "regular sex partner" who is serodiscordant; similar rates were found among MSM (22 %), women (23 %), and heterosexual men (27 %) (Ann Burchell, OHTN, personal communication, August 30, 2013). If we were to consider this as nationally representative, Canada may be home to over 16,000 primary serodiscordant relationships. With rapidly changing social environments and medical knowledge around HIV, AIDS service organizations (ASOs) are consistently challenged to address the growing needs facing people with HIV and their sero-negative partners.

Methods

This chapter describes a pilot inquiry into the experiences of individuals engaged in primary serodiscordant relationships in Canada, with the aim of informing a more extensive research program[1] and providing insights that could be used to develop new programming for such couples. Our initial efforts included consultations with Canadian ASOs to decipher key issues facing serodiscordant couples, and a scoping review of social and behavioural research in high-income countries that revealed major gaps in evidence regarding primary serodiscordant relationships in Canada and the linkages between HIV risk and relationship satisfaction, in particular (Mendelsohn et al. 2015).

Our many years of working with the HIV community, some of us since the time of HIV discovery, also provided an impetus for this research. Guided by early advocacy and research experiences, we hoped to normalize serodiscordant relationships as an extension of broader HIV acceptance. With the assistance of ASOs and word-of-mouth, in summer 2013, we interviewed four women and two men who had been involved in a serodiscordant relationship of six months or longer during the past year. Participants included four HIV-positive and two negative persons, aged 34–59 years, and both partners of two couples. They described having been in monogamous (n = 6), current (n = 5), same-sex (n = 2), heterosexual (n = 3), and both same-sex and heterosexual (n = 1) serodiscordant relationships of 0.5–15 years’ duration. HIV-positive participants had lived with HIV for 13–27 years. They were on ART, and reported being in stable physical health.

Each participant provided informed consent and was privately interviewed by the first author (AD).[2] Interviews were semi-structured, audio-recorded and lasted an average of 40 min. Questions were guided by our primary interest in capturing narratives about key enabling and constraining factors affecting relationship intimacy, quality, and wellbeing. Our interpretations are based on thematic analysis of these narratives. We share informative, but abridged excerpts in an effort to protect participants’ identities.

During data collection and analysis, we questioned our use of the label “serodiscordance”. Comparable terms such as “poz-negs”, “magnetic”, “mixed-status”, or

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[1] HIV serodiscordant couples in Canada: A mixed-methods study of risk management, health and wellbeing for people living with HIV and their partners (PI: Calzavara). Funded: CIHR (MOP-137009); SRC (Fund-487453/12).

[2] The study was approved by University of Toronto’s Research Ethics Board (SRC Fund-487453/8). Given the small sample, we do not link quotes to any potentially identifiable participant characteristics. We also refrain from using pseudonyms to prevent links between narratives.

“sero-different”, could similarly impose an implied polarity onto the nature of such relationships. While participants were largely accepting of the label – “it has to be something” – they contended that it could isolate people within the HIV community and mystify those outside of it: “It almost is like jargon. You know how people in different communities have their own language … I just think that language isolates communities, and ‘serodiscordant’ is one of those things”. We were conscious that our use of serodiscordance, albeit motivated by pragmatism, could obscure the diverse social realities and identities of such partnerships.

Navigating Disclosure

HIV disclosure is considered a crucial pathway to HIV ownership. Squire (2007:124) describes this process as coming to terms with one’s HIV status, believing it, and then accepting it; ownership “[takes] apart the stigma of HIV, unpicking its fatality and transgressiveness, taking it into one’s life”. However, disclosure is shown to create demonstrable shifts in relationship outcomes. Partner rejection and relationship dissolution are common consequences, as news of HIV positivity may engender feelings of mistrust, betrayal, stigma, and fear (Chaudoir et al. 2011; Smith et al. 2008). A range of individual and socio-structural circumstances have been found to contextualize such decisions including perceived partner support and communication, anticipated outcomes of disclosure, and the perceived quality of the existing relationship (Cusick and Rhodes 1999; Sullivan 2009).

In our study, three out of the four HIV-positive participants had suffered rejection by previous serodiscordant partners around the time of diagnosis. For one participant diagnosed in her early 20s, the trauma of that positive test result remained fresh more than a decade later. She had been distraught, destitute, even homeless, for several years before accessing supportive services and commencing treatment. In that time, she had been through several break-ups, which she described as her journey of “growing up” with HIV, the permanence of it, and learning to share it with others. Since then, she remained wary around disclosure. She reported sharing her status shortly before commencing engagement in sexual activities, which she would initiate only after establishing emotional closeness with her partner:

> It’s never easy. It’s the worst thing that you would ever have to do because everybody, basically most of the people that I’ve told are lovers and I don’t usually just get in ‘light’ relationships just to have sex. I only disclose when I really, really like the person, like a whole bunch, and it’s mutual ‘cause it’s still it’s totally terrifying … because they might just bail. And that’s happened, and it really, really sucks.

Having more time elapse since diagnosis, coupled with HIV ownership, appeared to facilitate the creation of a seropositive identity and mitigate participants’ fears around disclosure. Disclosure also became easier as positive participants passed through successive relationships. For example, two participants had lived with HIV for several decades. Though their journeys to ownership had not been linear and they remained cognizant of the potential for future struggles, they appeared to have overcome the initial emotional challenge of learning to live with HIV. They had become vocal about their serostatus, and described themselves as community advocates.[3] Overt disclosure was not something they thought much about, as most people in their lives already knew they were HIV-positive. The greater risk of going "public", as one participant described, mitigated the stress of disclosing to an individual within the confines of a private relationship:

> It doesn't have a huge impact on my relationship. The person that I was with previously knew that I was positive before we got into a relationship as well. So I've always been very open about it and I haven't let myself be in a situation where rejection was possible because of my status.

Early disclosure, prior to the establishment of emotional and sexual intimacy, minimized the negative impact of potential dissolution of the union for the HIV-positive individual. It also appeared to ease the pathway to intimacy for serodiscordant partners, as a major challenge to relationship viability was dealt with from the outset. Further, with HIV a known reality from the beginning, there was no need for subsequent 'redefinition' of the relationship, as might be prompted by disclosure later in a relationship. As one HIV-negative participant shared: "We were friends before we became a couple, so I went into the relationship with eyes wide open in the beginning".

Silencing HIV-Positivity

The (lingering) impact of HIV on the wellbeing of serodiscordant couples that remain together after HIV diagnosis and disclosure has been sparsely documented. Persson (2008:504) has pointed to "sero-sharing" and "sero-silencing" – mechanisms by which serodiscordant couples come to manage HIV in their relationship. In sero-sharing, partners may be considered to have a shared, coinciding experience around HIV; HIV becomes seminal to the identity of the relationship (Persson 2008). Squire (2007:145) has also highlighted the role of "HIV talk," or open discussions around HIV in enabling people to take ownership of their HIV-positive identity, not only via personal disclosure but additionally via impersonal conversations about HIV that do not necessarily lead back to one's own serostatus. In sero-silence, however, the positive partner is given exclusive custody of HIV, and deals with it in relative isolation from the negative partner. This may result in the absence of a shared experience, and among other things, a lack of open dialogue or shared decision-making around sexual safety (Persson 2008). Each partner's concerns get stifled to protect the other from any tensions around their sero-difference, and maintain a state of equilibrium. In some cases, however, silence may serve to restore

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[3] This process of coming out and adapting new roles of HIV educators, activists, and experts has been documented among people with HIV as a way to deflect and transcend the stigma associated with their disease (van der Straten et al. 1998).

intimacy and enable a sense of normalcy between partners, while in other cases it may result in the loss of a sense of HIV being a conjoined reality or mutual concern in the relationship (Persson 2008; van der Straten et al. 1998).

Participants constituting the two couples in our study reported engaging in overt discussions about HIV, and reached shared decisions about sexual practices early on in their relationships, reflecting a form of sero-sharing expressed through HIV talk. Both HIV-negative participants reported becoming more knowledgeable about HIV with time, feeling more comfortable in their relationships, and more frequently engaging in condomless sex, even despite a heightened awareness of HIV risk:

> It was awkward at first and then as time went on, it was just natural. It was a regular relationship once I learned more about viral loads and that kind of thing. Right now, as it is, we don't use protection. That's what it's come up to. I'm quite happy with the way things are and we've gotten over any issues around transmission and stuff like that.
>
> I would say if anything this safety, quote-unquote, of our sexual practices has diminished over time. It's arguably less safe than it was at the beginning of our relationship but I don't perceive myself as being any more at-risk than I was at any other time.

As relationships progressed, couples' discussions around safer sex dissolved. HIV appeared to take a backseat, reflecting some fluidity in their engagement with sero–silencing and HIV talk. With time, the impact of HIV was more frequently dismissed and eventually silenced in sexual decision-making, often to the greater discomfort of HIV-positive partners. Antiretroviral treatment and the absence of clinical symptoms appeared to facilitate these transitions:

> When you're on treatment and you're undetectable, the chances of giving it to somebody are so low that it makes sex totally way less stressful … [We] don't use protection … It just kind of started slowly happening and then it was like, okay, this is happening, I'm not sure if I'm comfortable with it. I was more uncomfortable with it than [my HIV-negative partner] for sure.

Still, a gradual transition from actively engaging in discussions about HIV to practicing a form of sero-silence was positively received by both partners of each couple, who appeared to welcome some reprieve from the seminal presence of HIV in their lives together. As one HIV-negative participant reflected:

> In the beginning, it wasn't as relaxed as it is now. I've just, over the years, learned so much and grown with [my partner] a lot … We discuss it, and become more comfortable with letting people know, and just incorporating it into life. Like, it's not an issue anymore.

On the other hand, if enacted soon after diagnosis, silencing could inhibit the positive partner's journey to HIV ownership. One participant had felt incapacitated by her perceived inability to talk about her concerns with her closest confidante, a serodiscordant ex-partner, when she was first diagnosed. She believed this early silencing had impeded her capacity to accept her diagnosis and access early medical care. At the time, she had been unwilling to lose a relationship that had survived the trauma of disclosure, and instead internalized her struggle for HIV ownership at great emotional cost. It took her more than 2 years to end the relationship, find her own pathway to acceptance, and respond to her clinical and emotional needs:

> [I was] probably in denial about the whole thing for a really long time … I was pretty miserable and didn’t really have anyone to talk to about it … That’s not good for a relationship because I wasn’t getting any support, and [my partner] wasn’t either … I didn’t seek out any sort of help or support for years … I used to think about [HIV] all the time … [but] you don’t want to freak people out … It took a long time to be able to talk about it without being self-conscious.

For this participant, the imbalance between her desire to share or talk, and her partner’s apparent preference to be silent, perpetuated feelings of marginalization. This contrasted with the experiences of participants who appeared to have reached mutual decisions with their partners, regardless of whether the decision was to foreground or dismiss the impact of HIV in their lives together. We return to these ideas of perceptual disparity between partners in later sections.

Silencing HIV-Negativity

There has been limited research around HIV-negative partners’ experiences within the context of their serodiscordant relationships. Persson (2011) has described the untold stories of HIV-negative partners who may feel as though they inhabit a liminal state as a result of their ambiguous social and clinical status in relation to HIV, and experience an invisibility resulting from a greater focus on their partners who are infected with HIV (Persson 2011). Indeed, several of our HIV-positive participants commented on the relative neglect of their partner’s needs and concerns. Considered the less-problematic identity, they were the least visible, with less access to support and resources than their HIV-positive partners:

> I think [my partner] didn’t want to worry me or stress me out with his worries and stresses, so I think he just kind of kept it to himself … just squish it down and make it go away … It’s a really unexplored issue and it’s an issue for every positive person … because there’s so many people who are in discordant relationships and I feel sorry for all the partners out there who are just, they’re kind of left out in the cold. We have all this community and support and they’re like, they don’t. We come home all happy after talking to a bunch of other poz people and they’re just kind of left out. They’re not allowed to come to the events, actually.

A perceived lack of control around HIV disclosure also isolated HIV-negative partners, and served to reinforce their invisibility. For example, one negative participant felt that his partner had exclusive control over disclosure decisions. He felt unable to discuss his partner’s condition, or their sero-difference, to anyone outside of his partner’s social network:

> She’s very particular about who she discloses to, so I’m comfortable talking with any of those people about her health or our relationship … I just don’t do it outside of that circle … they’re more her friends and acquaintances.

Thus, though verbal catharsis by way of disclosure helped HIV-positive participants to recover from the trauma of their diagnosis, and facilitated their pathway to HIV ownership, HIV-negative partners were not necessarily free to engage in similar strategies. It is possible that negative partners' invisibility within the broader HIV community could explain and, for some positive partners, justify their negative partner's disengagement from HIV talk. In other words, negative partners' relative marginalization may lead them to avoid participating in the process of sero-sharing, and effectively reinforce sero-silencing within their relationships.

We saw this portrayed in the narrative of one HIV-positive participant. For over a decade, he had dealt with his condition in isolation – his partner routinely switched topics when talk of HIV emerged – but silence was seen as a small price to pay for his partner's unwavering companionship: "When I [disclosed], [my partner] indicated that nothing will change, nothing absolutely, and that was a great deal for me, because that was one of the things that kept me going". Unlike some other participants' experiences with HIV-silencing, this relationship may have survived because the participant understood his HIV-negative partner's lack of verbal engagement to reflect a hidden and lonely struggle with an invisible identity:

> One of the disadvantages of some of these [support] groups, they take just one partner. And it's the most affected partner, or the infected partner … It's a huge stumbling block because a person who has been diagnosed don't want to talk about it, don't want to say it with their partner, because he's afraid that the partner will leave them, so the partner might not understand the issues so they don't know how to deal with it. It's a very complex thing, you know? And like I said before, there's not that support mechanism. There's the support mechanism for one person but not for the other … We always think of the one person that is the diagnosed person.

This sentiment resonated in the narratives of HIV-negative participants:

> Most of the functions and stuff that she's gone to have been [conditional on] the person having to be positive. Like the retreat she goes to, you have to be positive to go, that kind of thing. So I haven't had an opportunity to join her because of that.

Supportive mechanisms, analogous to the ones people with HIV had, were not built into negative partners' experiences with HIV; they lacked a clearly defined pathway to owning and managing a sero-negative identity in the context of serodiscordance. Recognizing this element in their HIV-negative partners' experiences with HIV, people with HIV may be able to understand a possible source of HIV-silencing within their relationships.

The Social Construction of "Sero-Imbalance"

HIV has been shown to provoke shifts in the balance of serodiscordant relationships (Davis and Flowers 2011; Palmer and Bor 2001). Findings from our study also point to the social construction of an imbalance, or what we conceptualize as "sero-imbalance", such that serodiscordant partners perceived each other's material and emotional needs, access to resources, and capacity to shape or control their relationship to exist on an unequal footing as a result of their sero-different status. We understood this imbalance to be dynamic and in flux, emerging in diverse ways and with variable intensities throughout the relationship lifecourse – depending on when and how HIV was disclosed, shared, or silenced – and with variable consequences, including continuous underlying disharmony, temporary moments of distress, or termination of the relationship.

For example, the perception that only one partner was dealing with a life-altering experience left some HIV-positive participants feeling as if they suffered from a disproportionate emotional (and physical) burden: "It can be a little unbalanced. I'm always dealing with this and [my HIV-negative partner] doesn't really have anything that's huge and fucked up to really deal with on a regular basis". That such sentiments co-occurred with a commensurate level of sympathy for the invisibility and neglect of HIV-negative partners, as described earlier, reflected the divergent dimensions of imbalance experienced by HIV-positive and negative partners when either of their sero-identities became de-emphasized or invisible.

At least two positive participants had suffered previous break-ups, which they considered to be a result of their ex-partners' different perceptions about sexual safety and clinical wellbeing. In the case of one relationship, the break-up was related to the negative partner's heightened risk perception:

> I was with somebody once [for] who [HIV] was a huge deal … He was always asking me questions and always really scared and really concerned and it was clear that he couldn't really handle it … It was too much for me … It's hard to be with someone who's scared.

In another case, the break-up was related to the positive participant's fear of HIV transmission, soon after diagnosis:

> In my previous relationship there was always a fear of passing it on. I always had a huge fear that my partner refused to wear a condom … And I was the only one who seemed to have that fear in the relationship, so that was a big issue actually, early on, even though he did know at the beginning that I was positive.

Imbalance within these relationships was driven by the partners' mismatched risk perceptions and related asymmetrical custody of sexual decision-making. In either case, the strain of differently perceived sexual risk resulted in a break-up, regardless of whether the risk burden was more closely held by the HIV-positive or negative partner.

One HIV-positive participant spoke about subtle changes in how he and his partner interacted with one another in their day-to-day activities (not just sexually), subsequent to disclosure. For him, these changes triggered an underlying sense of uneasiness about the relationship, though he could not trace this back to any particular act of rejection or disharmony. Rather, he simply was suspicious of an implicit disparity in the distribution of power or control within the relationship:

> Sometimes I will wonder, it might be he only stays with me because of this [i.e., my illness] … Just trying to worry about; does this person love me the way I do, or do I really love that person the way I should love him? … Sometimes it's just to wonder if there's a limitation in our relationship because of my HIV diagnosis … It's not that you don't trust the person but sometimes it [i.e., the way we interact] might not happen the way it should or used to and you're aware of questions there.

In several interviews, participants shared how specific events, such as the emergence of medication side effects or changes in treatment, could disrupt relationship dynamics that had otherwise reached a point of equilibrium, by re-opening previously settled issues of sero-difference:

> My medications usually work for two, three years at a time and then I have to change and she can see when things are starting to change because physically and mentally things start to happen. I start to get side effects, and she's very aware of that and notices them.

Disclosure to external networks was another point of temporary disruption that emerged at varying points in the life of relationships. While perceived to be in the hands of the positive partner, as we discussed earlier, the decision-making process tended to involve both partners, and could revive suppressed concerns around transmission, sexual safety, and prior negative reactions from disclosure:

> She did have some backlash from her friends about getting into a relationship with someone who's HIV positive … I told them to piss off … There was just the worry that she might contract it … that's the only place where it ever gets a bit touchy.

Sustaining Balance

The means by which serodiscordant partners learn to manage or resist disruptions in their relationship's balance have been seldom characterized in the literature. For example, in the pre-ART era, Palmer and Bor (2001) found that HIV-negative partners sometimes engaged in unsafe sex with persons outside of their primary serodiscordant relationship in an effort to acquire an HIV-positive identity, and in so doing, attempt to rectify the imbalance introduced by their primary partners' HIV-positive status (Palmer and Bor 2001). It is possible that the greater longevity and improved health of people with HIV in the ART era may have suppressed negative partners' engagement in such "balancing" activities; however, this remains unexplored.

In our study, serodiscordant partners were cognizant of challenges that could threaten the relationship equilibrium and resuscitate feelings of imbalance; they were understood to be "part of the journey" or an expected course of their relationship. Participants appeared to mitigate these threats by sero-sharing, or creating spaces in which HIV talk could be fostered, or by sero-silencing, as we touched upon earlier. We considered that for some people with HIV, the act of "going public" – that is, disclosing openly rather than in private, and before rather than during a relationship – was a pre-emptive (even if unconscious) strategy adopted to manage reactions to their positive status, and mitigate potential difficulties, including imbalance, within ensuing social interactions. We also considered that some negative partners' disengagement from HIV talk could be their way of re-establishing balance, given their relative suppression or invisibility in the broader HIV discourse. In partners' day-to-day interactions with one another, restorative strategies were fluid and adaptive to what participants believed was needed to sustain equilibrium within the context of their relationship history. For some, sero-sharing was seen as essential:

"The key to relationships is communication, and talking things out and just being really open with each other, so you're not having secret questions and not going around not knowing things". For others, it was more important to respect their partner's desire, even if it mean remaining silent: "If [my partner] doesn't want to talk about it [i.e., HIV], so I don't want to force the issue".

Participants also appeared to resist a sense of sero-imbalance by keeping things in perspective, not attributing all their problems to HIV, and emphasizing a sense of normalcy in their relationships. Positive participants attributed emerging distresses to things other than HIV: "It's interesting to me how we make HIV such a big deal around intimacy when there are so many other things that are much more complicated than HIV". One participant's partner suffered from a serious, although not life threatening, condition that required chronic treatment. That they both experienced "ups and downs" in health appeared to balance their relationship dynamic, and enabled them to move away from an over-emphasis on the supposed impact of HIV:

> It's just part of our life. It's not anything big anymore … This is what I have to do to make sure I keep healthy and my partner has things [my partner] needs to do to make sure [my partner] keeps healthy, just like in any other relationship.

Some spoke about the mental health problems of past partners as important reasons for disruption of those relationships. Others attributed disruptions to challenges likely to affect any relationship, e.g., their (HIV-negative) partner's sleep or work habits. While these may indeed have been the primary reasons, attributing relationship weaknesses to something other than HIV, to something controlled or "owned" by their HIV-negative partner, also allowed HIV-positive partners to remedy perceived relationship imbalances and resist self-blame.

Negative participants too appeared to shield themselves from feelings of imbalance by conceiving of their relationship as "normal": "As far as I'm concerned, it's just like being with a regular partner". They avoided attributing relationship tensions to their partners' HIV-positivity:

> In some ways it's not really there between us, but of course it's also something of potentially great significance in my partner's, well, in both of our lives. So it's maybe a bit like an elephant in the room … Not that it goes unaddressed, but … when we have challenges in our relationship, I can't think of a time when [my partner's] health status has become kind of embedded or somehow related to a challenge that we were experiencing.

Overall, the challenge of restoring balance was addressed through shared dialogue, respecting one another's need to de-emphasize HIV when needed, and independent rationalizations by each partner.

Conclusion

This was one of the first explorations of the dynamics underlying serodiscordant relationships in Canada. Our pilot sample was small and did not represent the vast breadth of serodiscordant relationships that may be comprised within the Canadian diaspora. We had a limited number of any one relationship group and, among other things, were unable to adequately explore gender differences or experiences within concurrent serodiscordant and/or seroconcordant partnerships. Nonetheless, the study findings substantiate prior conceptualizations of HIV disclosure, "HIV talk" (Squire 2007), "sero-sharing" and "sero-silencing" (Persson 2008), and the neglected experiences of HIV-negative partners engaged in serodiscordant relationships (Persson 2011).

The study also identified several new areas worthy of further inquiry. First, perceived imbalances within serodiscordant relationships appear to be shaped by the diverse ways in which HIV is disclosed, de-emphasized, or shared by partners engaged in such relationships. Positive and negative partners may distinctively resist these imbalances as a means to disentangle themselves from the seminal presence of HIV within their relationship in an effort to gain a sense of 'normalcy'. Second, gender norms and practices could shape how men and women experience and respond to constraints within the boundaries of a serodiscordant relationship. How particular aspects of gender may subvert or facilitate balance or harmony between serodiscordant partners should be explored in subsequent work. Finally, the chronology of events taking place within serodiscordant relationships, such as the timing of disclosure in relation to HIV diagnosis or the dismissal of HIV in relation to the formation of positive and negative identities, appeared to influence relationship outcomes. A lifecourse perspective may offer a compelling platform upon which to study the intersubjective experiences of serodiscordance and sero-imbalance.

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Pills, Providers and Partners: Exploring Trust Among Serodiscordant Couples in Australia

Christy E. Newman, Asha Persson, and Jeanne Ellard

Introduction

Couples with mixed HIV status have received increasing public health attention in recent years, much of which frames serodiscordance as a site of risk, rather than as part of a complex set of relational dynamics between two people in intimate partnership (Persson 2013a). *YouMe&HIV*, a qualitative study conducted in New South Wales, Australia, recorded interviews with couples and individuals in order to better understand the lived experiences of serodiscordance. The interviews produced rich accounts of the challenges and joys of these relationships; these are described elsewhere along with methodological details (Persson 2015; Persson et al. 2015). "Trust" stood out as a theme across the diversity of relationships described in the study: gay and straight couples, long-term and new relationships, urban and regional settings, and couples who met before and after diagnosis. This led us to ask how concepts of trust figured in these accounts of HIV serodiscordance in a high income setting, where access to medicine can be largely assumed, and where strategies to reduce HIV transmission among couples with mixed HIV status are receiving increasing attention, in an era of treatment-as-prevention (Newman et al. 2015a; Persson 2013b).

The concept of trust has received considerable attention in the social sciences, with particular focus in recent decades on how trust dynamics shape and are shaped by contemporary discourses and practices in the medical field (Gilson 2003;

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Sztompka 1999). Trust is recognised as essential to social relations, as the “glue that holds society together” (Ward et al. 2014:1); trust makes it possible for us to go about our daily lives, rather than living in constant uncertainty about how to act (Luhmann 1979). And yet, “trust is not faith; we need not trust blindly” (Govier 1998:7). On the contrary, what is seen again and again, including but not only in health and medical contexts, is that trust “can no longer be assumed, it is conditional and has to be earned” (Calnan and Rowe 2008:101). Indeed, a decline in public trust in social institutions and knowledge systems has been described as “the cultural logic of modernity” (Aupers 2012: 22), with science increasingly the object of some of the most contentious expressions of doubt, fear and scepticism among diverse communities (Hobson and Niemeyer 2013).

While trust clearly figures across many areas of social relations, the particular context and circumstances in which couples of mixed HIV status enact trust has the potential to illuminate these dynamics in important ways, particularly given the “leap of faith” (Möllering 2001) in the practice and promise of science many serodiscordant couples are now asked to make in preventing the sexual transmission of HIV to the negative partner (Newman et al. 2015a). To consider this potential in more depth, this chapter explores three sub-themes within a broader theme of “trust ”observed in these interviews.

Method

The *YouMe&HIV* study was conducted in New South Wales (NSW), Australia, between 2013 and 2015. The study included interviews with 20 service providers working in public health settings, to capture “expert” perspectives on key issues for couples, and those results have been reported elsewhere (Persson 2014). Semi-structured interviews were then conducted with 38 people in serodiscordant relationships; these are the focus of this chapter. Eighteen interviewees were HIV-positive and 20 HIV-negative. Twenty-four participants identified as gay men (10 HIV-positive), six as heterosexual women (four HIV-positive), five as heterosexual men (two HIV-positive), one as a bisexual man (HIV-positive) and two as transgendered (one HIV-positive transwoman and one HIV-negative transman). Ages ranged from 25 to 70 years. Fourteen participants resided in Sydney, and the rest throughout regional NSW. Twenty-seven participants were born in Australia, (two to parents born elsewhere), and 11 were born overseas. The cultural backgrounds of study participants included South America, East and West Africa, Southern Europe, the Middle East, Asia, the USA, the UK, and New Zealand Pakeha and Maori.

In all, 25 relationships were represented in the study,[1] with either one or both partners taking part. Of these relationships, 16 were between gay men, seven between heterosexual women/men, one between a transman/gay man and one between a transwoman/straight man. Where possible, quotes from interviews

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[1] This number included one “throuple” (a relationship involving three partners).

reproduced in this chapter are linked to key information about both (or all) partners, rather than only describing the person speaking. This is a deliberate strategy, aiming to focus attention on the relationships described in the study, rather than the individual participants (Treloar et al. 2016).

Relationship length ranged from 2 months to 20 years. Half (n = 12) of the relationships had commenced with knowledge of serodiscordance, while the other half (n = 13) had received the diagnosis during the relationship. Of the latter group, in four couples the diagnosis was received shortly after the relationship had started, and in another three couples infection was attributed to sex outside the relationship. Just over half (n = 14) of the couples were monogamous, including all but one of the heterosexual couples. Nine of the couples always used condoms during sex, all of them gay men, 11 couples practised condomless sex only, three used a combination of both, and two did not engage in penetrative sex.

In 20 of the 25 relationships represented, the HIV-positive partner was using antiretroviral therapy (ART), and an additional three were planning to commence. Nearly all (n = 19) of those using ART had an undetectable viral load. Regular (every 2–6 months) viral load testing in the positive partner was reported in 24 couples, and regular (every 3–6 months) HIV testing in the negative partner was reported in 17 couples. These couples were clearly highly engaged with the field of HIV medicine, through regular use of treatment and associated service use for monitoring and testing. Regular (every 6–12 months) testing for sexually transmissible infections (STIs) was however less common in either partner, reported by the positive partner in 12 couples, and the negative partner in 13 couples. Monogamy was cited as the main reason for not testing for STIs.

All de-identified interview transcripts underwent detailed coding in NVivo 10 (Bazeley 2007), with a particular focus on data relating to treatments, health services, health providers, and other aspects of the medical field. When an overarching theme of “trust” was identified in this material, a more detailed analysis was then conducted of data that engaged with this concept. This deductive approach to thematic analysis (Braun and Clarke 2006) permits an open-ended exploration of the range of views and experiences associated with a central concept, along with an appraisal of any variations or outliers from the main patterns. Three main subthemes were identified through this analysis, organising the broader theme into a focus on trust in “pills”, “providers” and “partners”. The following sections will describe the most important aspects of each of these, as well as some minor areas of variation or divergence, to consider what these themes reveal about the enactment of serodiscordant relationships today.

Trust in Pills: Investing in a Shared Future

We know a minority of people with HIV in Australia hold concerns about the use of ART (Newman et al. 2015a, b), particularly if their general health is good. However, in the interviews conducted for this study, almost all participants expressed a very high degree of trust in HIV medicine in general, and HIV medications in particular. As Leo [*positive gay man, 40s, born Australia; partnered for one year with Jack, negative gay man, 40s, born Australia*], stated: “I think that they’re fundamental to staying healthy and alive.” In many instances, this trust was described as having been earned as a result of direct experiences of ART use as both tolerable and effective. Jasmine [*positive heterosexual woman, 20s, born non-English speaking overseas country; partnered for seven years with Adam, heterosexual man, 30s, born Australia*], claimed that: “It’s 100% good. People should [use ART]. Even those who think ‘Oh, my CD4s are high’ … This virus still eating your inside. So you need to take medicine.”

For others, even knowing there might be some negative effects of the treatments did not reduce the level of investment in what HIV medicine can promise regarding a longer, healthier life. As Luke [*positive gay man, 30s, born English-speaking overseas country, partnered for 18 months with negative gay man, 30s, born Australia*], put it: “I am a bit nervous about starting them and getting the side effects, [but] I’m all for medication, really! I don’t see the point in suffering if you can take a tablet.”

Given that taking ART requires a daily practice – or sometimes more than once a day – complemented by regular visits to doctors for monitoring, the “leap of faith” or “suspension of the unknown” (Möllering 2001:736) that trust involves, is necessarily repeated and negotiated, day in day out, particularly by the HIV-positive partner, but also by the HIV-negative partner. Contradicting research which has argued that mistrust has become a *defining feature* of life in late modernity (Ward and Coates 2006), HIV pills were described by couples largely as a technology in which they were willing to entrust the health of their bodies and relationships. Trusting in the effectiveness of HIV medicine was viewed as a far safer bet than the risks involved in *not* using treatments.

Importantly, this trust in pills was commonly articulated as a shared, collaborative social value, and as a relational investment, an intervention anticipated to keep both the positive and negative partner healthy and happy into the future. Borrowing from Meyer and colleagues’ (2008:181) discussion of trust in the health system, these couples welcomed medicine into their lives and homes, expressing considerable enthusiasm for “the perceived legitimacy, technical competence, and the ability of the ‘expert system’”. For example, Emma [*negative heterosexual woman, 20s, born Australia; partnered for eight years with Dawit, positive heterosexual man, 30s, born non-English speaking overseas country*] explained how much she had come to rely on HIV medications to provide reassurance of a shared future with her partner:

> I hate that it has any kind of effect on him and his body, and how he feels, but I just think that it’s obviously working … If you’re given the ability to take this medication, for a longer life … you’re so lucky. Other people aren’t that lucky … It’s kind of like somebody with diabetes has to always take the medication. And that’s how to live your life as healthy as you can, you *have* to take your medication. That’s how we see it.

Some HIV-negative partners positioned themselves as critical contributors to partnerships in which trust in medications was negotiated over time. These partners were personally invested in the idea of the treatments working, but represented this investment as a social value: in this community, in this relationship, we believe that HIV medicines work, and we encourage their appropriate use. This could lead to conflict if the positive partner was less sure about whether or not he or she could indeed trust the medicines. Damien [*negative gay man, 20s, born Australia; partnered for five years with a positive gay man, not in study*] told us:

> The earlier you start, generally, the better long-term outcomes you have, the less damage the virus can do to your body. And, in spite of me saying that for the last ten months, he's only just starting it now. [That's] bad.

Damien clearly viewed HIV medications as both necessary and reliable, but there was also a deliberateness to the way he described the trust he placed – and wanted his partner to place – in these medications. Indeed, in these interviews, negative partners commonly described feeling very reliant on HIV medications being used by their partner strictly as recommended by clinicians in order to fulfil a narrative of a shared life and future.

Even though both positive and negative partners noted some of the potentially more difficult elements of medications – side effects in particular, but also some fears about long term impacts on health, and the challenges of maintaining adherence over time – this was only a minor theme in the data. Participants largely emphasised the benefits of using medications and saw these as far outweighing their risks and challenges, particularly because of the prevention benefits for sexually active couples. One evocative example was provided by Justin [*positive gay man, 40s, born Australia; partnered for four years with Marcus, negative gay man, 50s, born Australia*] who stood out in the study as the only participant to really resent taking medications, but who nonetheless viewed them as a non-negotiable requirement of his serodiscordant relationship:

> [Treatments are] not as nice as what they say they are! They're not, they're fucking horrible … [Doctor X] is very good at treating, and he's very pleasant [but] there's a hell of a lot of side effects … [The doctors] see you and, 'Oh look, you're doing great guns! Your T cells are…' [Yet] I can't hold down a job because I'm using a bathroom 27 times a day … If I didn't have to take the fucking medications due to the side effects, I wouldn't take them but in order to keep my viral load down, to keep others around me safe, my partner safe, well then therefore that's every motivation in the world for me to take these shitty tablets … It's not a lot to ask if it means you allowing yourself or to live a sort of a normal life, you know?

For Justin, being able to keep his partner Marcus safe and live a "normal" life together made all the challenges of medication use worth it. Indeed, one of the great motivating factors among the positive partners in the study for taking medication (including overcoming appreciable barriers to adherence) was their investment in their relationship. Based on these findings, we can posit that placing trust in pills in the context of serodiscordance is not only about investing in the health of the positive partner, but also about creating the conditions of possibility for the health and the future of the relationship itself.

Trust in Providers: Engaging Couples in Care

Sociologists have argued that there are two distinctive forms of trust: trust in abstract or “faceless” systems, and trust that is negotiated through interpersonal or “facework” processes (Giddens 1991, 1994; Luhmann 1979). Research has shown that even in contexts where trust in medicine as an institution is declining (although we did not see that in our study), trust in clinicians largely continues to be high (Calnan and Rowe 2008; Calnan and Sanford 2004). Indeed, most HIV-positive participants in this study described strong and trusting relationships with their care providers: “I’m in awe of their abilities to understand how the body works and how to protect people … I think we’re special and lucky” [*Georgia: positive heterosexual woman, 40s, born Australia; partnered for six years with negative heterosexual man, born English-speaking overseas country, not in study*]. In general though, trust in providers was not a default position, but a deliberate, negotiated process:

> I have a good [specialist] doctor … She’s very attentive. She’s really great. And, if I have a problem that, you know, I don’t think the GP’s quite understanding, then I go see her about it. And then what she doesn’t know she, you know, communicates with her colleagues … I respect her because she’s an intellect who knows enough to say, ‘I don’t know’, okay? … She cares about what she does. [*Dennis: positive bisexual man, 50s, born English-speaking overseas country; partnered for 13 years with negative man, born English-speaking overseas country, not in study*]

Health care providers were largely described as having *earned* the trust of both positive and negative partners through their actions and advice. Calnan and Rowe call this “earned trust”, describing it as “conditional” (2008:101) and based on “the quality of the patient-clinician interaction [and] the competence and empathy that is displayed” (2008:102). For Dennis, trust was earned through the experience of feeling fully attended to by his care providers, and witnessing evidence that these providers were willing to acknowledge when the limits of their own expertise had been reached. Key here is the sense among the participants that HIV medicine is a field that providers care about: they are engaged and invested, and thus, people with HIV and their partners feel they can invest their trust safely.

However, trust relations with providers were represented as more tenuous in relation to negative partners. While providers were seen to support and facilitate serodiscordant relationships by providing advice on safer sex, HIV treatment-as-prevention (TasP) and reproductive possibilities, negative partners sometimes felt they were positioned as outside of the model of care for the person with HIV, and thus less of a priority or partner in the process. For example, Marcus [*negative partner of Justin, previously quoted*] described feeling a step outside of the relationship his partner had with HIV care providers:

> I leave [treatment decisions to] him and his [doctors]… You’ll sit there and you might say, ‘Oh yeah, well, [partner] has been falling over lately and hitting the wall. What’s causing this?’ And then they might change the meds, do something like that, but … you can only be a part as much as what they’ll let you.

Marcus' comments provide insight into the sometimes awkward role that negative partners can play in relation to care provision: they may feel welcomed to contribute only when it is considered appropriate and desired by the positive partner. This was represented as problematic by some who emphasised the important role that negative partners can play in conveying information to the provider, as well as ensuring the advice of providers is taken up in everyday life. As illustrated in the following quote from Flynn [*negative gay man, 30s, born non-English speaking overseas country; partnered for 15 years with positive gay man, born Australia, not in study]*, some negative partners may view themselves as also "living with HIV" by virtue of their intimate involvement with HIV treatment and prevention activities (Mahoney et al. 2015; Van der Straten et al. 1998; Persson 2011):

> I will be the support person if something [goes] wrong … So we [need to] choose the better time for us [to initiate treatment] – 'We are ready to be on treatment' … So that's why we made the decision together.

Couples may therefore expect that both partners be engaged with and involved in clinical appointments and decision-making relating to the management of HIV, and be disappointed when they are not encouraged by services to contribute in that way.

Other negative partners felt there was a missed opportunity in HIV medicine for providers to deliberately engage them as the other half of a serodiscordant duo:

> It's just a funny, one-sided thing that goes on. I mean, I'd be quite amenable to more attention than what I get … not even for my own sake … [The doctors could] say, 'Well, just in case, and for her health, would you get tested [for STIs]?' And I'd be like, 'Well, for her, sure!' … It seems somewhat disingenuous … if the services don't pay much attention to both sides of the relationship … If you wanna stay in that sort of dialogue or [recognise] that there's always some degree of risk … [It seems] in serodiscordant couples, [doctors] aren't actually paying a great deal of attention to the negative partner … It is a real hole in services at the moment. [*Adam: negative partner of Jasmine, previously quoted*]

This is one of the few places in the data where a participant explicitly articulated a desire for a rethinking of the service model for people with HIV who live in serodiscordant relationships to encompass their negative partner. Apart from reproductive services, where both partners are more directly engaged (depending on their circumstances), most other forms of clinical care direct attention largely to the positive partner, with only secondary support provided to the negative partner (Mahoney et al. 2015). The introduction of accessible pre-exposure prophylaxis (PrEP) programmes for negative partners is likely to shift those dynamics a little, albeit not necessarily by challenging the individualist model of care that dominates the medical field. But in terms of thinking about how trust in HIV medicine is achieved, it is important to consider whether and how services can better engage serodiscordant couples in ways that genuinely extend beyond the individual, to embrace a more relational understanding of HIV management (El-Bassel et al. 2010; Goldenberg et al. 2013; Pereira et al. 2011; Persson 2011).

Trust in Partners: Health as a Relational Project

Implicated in and intersecting across the forms of trust we saw expressed regarding pills and providers, was trust in partners. Trust in partners was also described as critical to successful serodiscordant relationships. While likely also applying to other intimate relationships, trust in serodiscordant partners appears to comprise some distinctive relational practices specific to the context of serodiscordance. This firstly involved viewing and practicing health as "a shared thing". As Dawit [*positive partner of Emma, previously quoted*] explained, his wife reassured him when he received his diagnosis: "Basically my wife was next to me, you know, [saying] 'We can get through it together. We can go through with it'. So it [gave] me a lot of courage". Rather than prioritising trust in the medical system, this theme reveals a commitment to share the experience of living with HIV together, whatever challenges it may bring. Charlie [*negative gay man, 40s, born English-speaking overseas country; partnered with Blake, positive gay man, 40s, born Australia*) explained that from his perspective:

> It's as much your issue as it is their issue. And, if you just treat it as their issue, you're gonna fail. It's a shared thing. It's not just about someone having a disease and you not having a disease. It's actually about sharing the problems that that [brings].

This sharing was described by many couples as encompassing the needs of the negative partner, particularly, but not only, among couples in which the negative partner was managing his or her own chronic health conditions. In these couples, the practice of health comprised a range of activities extending well beyond the realm of HIV medicine, and permitting a sense of shared endeavour regarding taking pills and visiting doctors. As Elliott [*negative gay man, 60s, born Australia; partnered for nine years with Hugo, positive gay man, 70s, born Australia*] recounted:

> He manages [HIV], sees his doctor regularly … we just talk it through and … remind each other. I'm on blood pressure medication and all sorts of, the joys of things getting old! [laughs] … So each night I go, 'Have you taken your medication tonight?' He goes, 'Yeah, yeah, I've taken it'. So just sort of looking after each other that way, I suppose.

In addition to demonstrating the normalisation of HIV medicine in this domestic environment, Elliott's account also reveals how routines of medicine-taking underpin a sense of mutual trust in the relationship. It speaks to a practice of "witnessing" within the relationship, in which both parties feel recognised in the work they do in engaging with medical recommendations and therapies.

HIV treatment practices were not always viewed as a shared endeavour: some negative partners were very hands off, and some positive partners were not at all open to sharing decisions or even discussions about treatment. But those who did approach HIV as a joint practice saw this as instrumental to negotiating serodiscordance, to achieving a trusting partnership more generally, and to maintaining an overall trust in HIV medicine. For example, Troy [*negative gay man, 50s, born Australia, in a "throuple" relationship; partnered for 11 years with negative gay man, born English speaking overseas country; and eight months with positive gay man, born non-English speaking overseas country, neither partner in study*], explained that:

> What works for us is trust. The ability to discuss anything, be it health, viral load, 'What did the doctor say? Have you taken your pills?'… There's constant communication and constant follow-up, but not like in a nagging kind of way … If there's no trust, it's just not gonna work.

Importantly, as suggested in Troy's quote, trust in partners involved an explicit expectation that the positive partner would achieve very high levels of adherence with their treatment regime, and that they would share honestly the results of tests monitoring the level of viral infection in the blood. For many, trust in partners also included an expectation that both partners keep agreements related to sex outside the relationship. These expectations mattered particularly for couples who engaged in condomless sex, and for whom HIV transmission, as well as any STIs acquired from outside the relationship, posed a particular risk.

Trust in partners also involved viewing the prevention of HIV transmission within the relationship as a shared project. The following extract includes quotes from both partners in one of the couples interviewed [*Merlin, positive gay man, 30s, born Australia; partnered for three years with Daniel, negative gay transman, 30s, born Australia*), providing important insights into what is at stake in achieving trust in your partner in the context of serodiscordance:

Daniel: I could sit there and go, 'These are the facts. If he has his medication every day, which, by evidence, he's doing … I'm willing to take the risk [of engaging in condomless sex with my HIV-positive partner]'. Because I know he's doing everything he possibly can to keep me safe … I said to [him] … 'If you were just going at [treatment] half-half … that would be a totally different situation'. There would be no relationship because he's not taking responsibility for his health as well.

Merlin: Yeah. It's like the responsibility has to be on me and once we decided that [it was up to] me, taking my drugs every day without fail. And I've only failed to take my drugs probably like four or five days ever in the whole time I've been on them … I'm very, I'm very strict about it.

There were high stakes for this couple in maintaining trust. Merlin was particularly worried about risking transmission as Daniel had underlying heart and liver issues, partly due to the hormones he used to maintain his gender transition. This meant that, for this couple, the emphasis was very firmly on Merlin maintaining an undetectable status. Nevertheless, the sense of this being a shared project is evident: Merlin was not "on trial" in relation to his behaviour; they simply had a clear agreement that required him to take medications as a relationship practice, as well as a responsible health-promoting habit.

The couple's agreement, in addition to providing a concrete example of how trust in one's partner makes mixed-status relationships possible, crystallises something important about the nature of trust more generally. As illustrated above, serodiscordant couples accept certain behaviours– the taking of pills, the setting off for clinical appointments and the sharing of blood test results – as evidence of positive partners holding up their end of the bargain, to minimise risk of HIV transmission. And yet uncertainty remains. Is adherence as good as it appears? Are there other complicating factors – other infections, for example, or sex outside the relationship – which may compromise how “safe” it is to have condomless sex together? While some might argue that these forms of vulnerability threaten trust, a more incisive analysis reveals them as the very conditions that make trust possible. As Sztompka (1999:25) defines it, trust always involves “a bet about the future contingent action of others”. Trust, therefore, according to Meyer and colleagues (2008:180), is “only required where there is ignorance; there is no need to trust in a situation of complete knowledge”. Perhaps then, while the relational practices involved in establishing and maintaining trust within any intimate partnership likely involve a “leap of faith”, for couples of mixed HIV status, the specific circumstances in which trust must be maintained reveals these dynamics more starkly and routinely, requiring a repeated and explicit reaffirmation of these trust relations.

Conclusions

This analysis has explored how trust figures in the everyday lives of couples with mixed HIV status. We have argued that trust was enacted relationally across multiple and intersecting domains. Guided by a persistent faith in the potential for medicine to make new things possible, placing trust in pills, providers and partners was described as essential to securing health, intimacy and the sense of a shared future. We focused on examples of trust achieved through dialogue by these couples, but there were some counter-examples important to also recognise here. A few negative partners had little understanding of what their positive partners engaged in with regard to treatments, service attendance and testing, and some positive partners did not want their partners involved in these aspects of their lives. But even those participants were invested in the idea of trust, albeit one that involved permitting the partner to manage their life and health independently, without a need for collaboration or oversight. This reminds us that serodiscordant partnerships can be negotiated and lived in many different ways, partly reflecting the diversity of ways in which trust can be achieved. Despite this variation, relationally investing trust in pills, providers and partners remained core dimensions of the “doing” of serodiscordance.

As medical advances in HIV permit a narrative of “negligible risk” to expand into ever new territories, further work is needed to understand how serodiscordance is lived in different contexts and relationships, including among extended families and communities. As wisely put by Lucy Gilson, “health systems are inherently relational and so many of the most critical challenges for health systems are relationship problems” (2003:1453). Indeed, while trust may be described as flourishing among our study participants, the challenges of achieving and maintaining an undetectable viral load, and negotiating relationship agreements in this context, and over time, deserve dedicated support and understanding. Fotaki has argued for an *a*ffective understanding of trust dynamics, which recognises that “Relationality fosters trust by binding us to each other through our shared vulnerability”

(2014:1288). Conducting research with and paying close attention to the stories and experiences of serodiscordant couples are likely to provide us with the most useful insights regarding how trust can be forged from the shared vulnerabilities of both positive and negative people.

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