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Alean Al-Krenawi *Editors*

Culture, Diversity and Mental Health - Enhancing Clinical Practice

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Culture, Diversity and Mental Health - Enhancing Clinical Practice

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Preface

If we have learned one thing from the many momentous events of the first two decades of the twenty-first century, it is that our well-worn assumptions about people and the cultures in which we live our lives are due for a fresh look.

Culture, Diversity and Mental Health - Enhancing Clinical Practice is designed to help clinicians meet the complex needs of their clients at this time of critical reflection. Seventeen chapters, each of which offers a fascinating discussion in its own right, are assembled into a single volume of indispensable reading for today's practitioners. With its wide scope of important topics for clinical practice, *Culture, Diversity and Mental Health - Enhancing Clinical Practice* covers issues ranging from intersectionality to perceptions of disability, and from immigrant to Indigenous populations.

Part I, *Intersectionality and Disability*, begins on a broad note with Bramesfeld, Platt, and Bal's chapter, "Mental Health, Multicultural Competence, and Cultural Humility from an Intersectionality Framework." Here, the reader is introduced to the vital notion of going beyond individual categories of identity to understand how identities intersect, affecting each other to produce experiences that critically mold mental health outcomes. This idea of intersectionality is central to the second chapter, "Archetypes of Black Womanhood: Implications for Mental Health, Coping and Help-Seeking," by Waldron. Setting forth stereotypical societal images of Black women, the author demonstrates how these representations have harmed Black women and contributed to the formation of a Black feminist consciousness that emblematizes Black women's position at the nexus of various social identities. The chapter further discusses how this consciousness affects Black women's experiences with mental illness.

Laying the groundwork for wider treatment of mental and physical challenges, Buettgen and Gorman's chapter, "Disability Culture," treats disability from a critical disability studies perspective. The authors explore and explode the myth of any essential "disability" that exists outside of its historical, cultural, and social context. In the final chapter of Part I, "Deaf Mental Health: Enhancing Linguistically and Culturally Appropriate Clinical Practice," Bone examines the health inequities of a specific "disabled" community, namely the Deaf community. She reports on a range of barriers that Deaf people experience in accessing mental health services, including audism and clinicians' inadequate understanding of Deaf culture and language.

Moving to Part II, *Immigrant and Indigenous Mental Health*, in "Best Practices and Research Perspectives Working with Immigrant Groups," Mercado, Venta, and Irizarry propose considering both cultural and psychological variables in an integrative model of health for different immigrant groups, including Latino immigration to the USA and global Middle Eastern and North African migrations. Following in these footsteps, Khanlou, Khan, and Mill offer, in the next chapter, "A Health Promotion Framework for Women with Precarious Immigration Status in Canada." The authors propose a tripartite "Health Promotion Framework for Women with Precarious Immigration Status." Next, in his examination of an extreme case of immigrant mental health, in "Living in a Refugee Camp: The Syrian Case in Jordan" Al-Krenawi tackles the searing context confronting Syrian refugee children in both camp and non-camp settings, including child marriage, child labor, and gender-based abuse. Concluding the immigrant section of Part II and narrowing the focus to Syrian refugee women, in "Exploring an Islamically Integrated Peer Support Model for Muslim Syrian Refugees," Qasim and Hynie propose using the existing social support found at mosques to provide this population with Islamically integrated peer support groups as an alternative to traditional therapy.

Bridging the immigrant and Indigenous worlds, in "The Impact of Cultural Beliefs on Mental Health Diagnosis and Treatment," Al-Krenawi shows how quality mental health care for migrant and Indigenous communities alike requires, first and foremost, culturally sensitive training for general health care workers.

Turning to Indigenous populations, Le Grande, Jackson, Ski, Thompson, and Brown inform us in their chapter, "Depression, Cardiovascular Disease and Indigenous Australians," of mounting evidence on causal relationships between psychological distress, depression, and cardiovascular disease in Indigenous Australian communities. They specifically note intergenerational trauma and discrimination as crucial determinants of well-being. In their own contribution, "Culture Through a Clinical Lens," Wesley-Esquimaux and Koptie engage with the lived experiences of Indigenous people, presenting a model that uses a "medicine wheel" developed by Wesley-Esquimaux to facilitate the identification of the impact of trauma and the move towards healing. Continuing the exploration of Indigenous mental health in "Trauma and Its Impacts," Sutherland provides a lucid discussion on Indigenous individuals' and communities' negativity towards governments and authorities, which is an enduring and pervasive response to traumatic events such as enslavement, being forced off land, and the policies and practices of assimilation.

Part III of the volume, *Culture and Mental Health*, opens with Srivastava and Srivastava's chapter "Supporting Post-Secondary Youth Mental Health through Inclusive Practices Attuned to Culture." The authors argue convincingly that cultural competence and inclusivity constitute the primary keys to supporting the mental health of post-secondary youth. Moving forward with the theme of mental health and culture, in "A Cross-Cultural Study on Dimensions of Experiences of Shame and Guilt between Mainland Chinese and Euro-Canadians" Hynie and Su present their work on Chinese and European Canadian perceptions of shame and guilt. In

"Social Capital and the Quality of Life of Parents of Children with Autism Spectrum Disorders: A Comparison between Bedouin Fathers and Mothers," Manor-Binyamini and Ka'abeya make a compelling case for increasing the "Quality of Life" among Bedouin mothers of children with ASD—a population that lacks "bridging and linking social capital," compared to Bedouin fathers of children with ASD. Part III—and the volume as a whole—ends with "Culture and Psychopathology: Contributions of the Philosophical and Clinic Phenomenologies," Moreira, Bloc, Castelo, and Telles' intriguing chapter on the relationship between psychopathology and culture as seen through the prism of philosophical phenomenology (Maurice Merleau-Ponty) and clinical phenomenology (Arthur Tatossian).

Toronto, ON, Canada — Masood Zangeneh
Be'er Sheva, Israel — Alean Al-Krenawi

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Part I
Intersectionality and Disability

Chapter 1
Mental Health, Multicultural Competence, and Cultural Humility from an Intersectionality Framework

Kosha D. Bramesfeld, Lisa F. Platt, and Jaspreet K. Bal

Multiculturalism encompasses identities that include, but are not limited to, "race, ethnicity, language, sexual orientation, gender, disability, class status, education, religious/spiritual orientation, and other cultural dimensions" (American Psychological Association, 2003, p. 380). These cultural group memberships help to shape the collective identities of individuals and impact how people experience privilege and oppression within systems of structural inequality (Bowleg, 2012; Dhamoon, 2011). A focus on multiculturalism may be particularly important within a mental health context, as collective identities can have a positive impact on mental health and well-being (see, for example, Kosciw, Palmer, & Kull, 2015; Smith & Silva, 2011; Yoon et al., 2013). But the discrimination associated with marginalized collective identities can also place people at higher risk for both physical and mental health problems (see, for example, Kosciw et al., 2015; Mak, Poon, Pun, & Cheung, 2007; Pascoe & Smart Richman, 2009).

An intersectionality framework for mental health care urges practitioners to go beyond the examination of single categories of collective identity to recognize how various identities converge, intersect, and mutually influence one another to create unique subjective experiences that help to shape, inform, and explain mental health

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outcomes (Bostwick et al., 2014; Cairney et al., 2014; Calabrese, Meyer, Overstreet, Haile, & Hansen, 2015; Seng, Lopez, Sperlich, Hamama, & Meldrum, 2012). In this chapter, we introduce the concept of intersectionality and discuss how it applies within two models of mental health practice: (1) multicultural competence in counseling and therapy, and (2) cultural humility in social and community services.

Intersectionality in a Mental Health Context

Intersectionality, which was inspired by Black feminist scholars, can be broadly defined as the "critical insight that race, class, gender, sexuality, ethnicity, nation, ability, and age operate not as unitary, mutually exclusive entities, but as reciprocally constructing phenomenon that in turn shape complex social inequalities" (Collins, 2015, p. 5). Intersectionality frameworks focus on multiple collective identities and how they mutually impact and change one another *and* on how those identities coexist and interact within systems of privilege and oppression (e.g., racism, classism, sexism, heterosexism, ethnocentrism, colonialism, ableism, and ageism) (Bowleg, 2012; Dhamoon, 2011). Intersectionality is not just about identifying specific marginalized groups (e.g., Blacks and women) within specific categories (e.g., race and gender), but rather on identifying the *processes* by which people come to experience their collective identities within the broader social, historical, and political landscape (Dhamoon, 2011). As an illustration, Ferree (2009) discusses the intersection of gender and race:

> The 'intersection of gender and race' is not any number of specific *locations* occupied by individuals or groups (such as black women) but a *process* through which 'race' takes on multiple 'gendered' meanings for particular women and men (and for those not neatly located in either of those categories) depending on whether, how and by whom race-gender is seen as relevant for their sexuality, reproduction, political authority, employment or housing. … In such a complex system, gender is not a dimension limited to the organization or reproduction of family, class is not a dimension equated with the economy, and race is not a category reduced to the primacy of ethnicities, nations and borders, but all the processes that systematically organize families, economies and nations are co-constructed along with the meanings of gender, race and class that are presented in and reinforced by these institutions separately and together. (p. 87)

Within a context of a focus on process, rather than categories, an intersectionality framework avoids the temptation to make sweeping generalizations about "race," "gender," "class," "sexual orientation," or any other collective identity. Instead there is a recognition that, within any given category, there will be individuals who are simultaneously experiencing that category of identity with other identities of oppression and privilege. Thus, a Black, middle-class, cisgendered, heterosexual man without a disability is likely to experience racism very differently than a Black, lesbian woman with a disability who is living in poverty. Both of these individuals coexist in a racist society, but their individual experiences of racism could be fundamentally different from one another due to the convergence of their other identities.

Understanding how people come to experience privilege and oppression may be particularly important within a mental health context, as collective identities can have a positive impact on mental health and well-being (see, for example, Kosciw et al., 2015; Smith & Silva, 2011; Yoon et al., 2013). But the discrimination associated with marginalized social statuses can also place people at higher risk for mental health problems (Kosciw et al., 2015; Mak et al., 2007). One of the possible consequences of the convergence of multiple oppressed identities is that intersections of oppression could result in "multiple jeopardy" for individuals belonging to two or more socially oppressed groups (King, 1988). In support of this idea, several studies have found that individuals who are multiply oppressed experience more discrimination and worse mental health outcomes than individuals who experience fewer sources of oppression (Calabrese et al., 2015; Gayman & Barragan, 2013; Grollman, 2012).

Still, the interpretation of these experiences matter (Purdie-Vaughns & Eibach, 2008). Indeed, even though many research studies show that groups who experience multiple forms of oppression are the most likely to experience discrimination, other studies have found that, in some contexts, individuals with single oppressed identities may actually experience more discrimination than individuals with multiple oppressed identities (Griffith, 2015; Purdie-Vaughns & Eibach, 2008). It may seem contradictory that holding multiple oppressed identities can lead to both more and less discrimination, but this contradiction makes sense when considered from an intersectionality framework. Purdie-Vaughns and Eibach (2008) note that systems of privilege and oppression are designed to support hegemony, which describes how social norms are determined within a society. If being "male" is considered the norm, then being female represents the alternative or "other" experience. If North America has been colonized by White, European settlers who now hold political power, White is the norm by which all other racial/ethnic categories are compared. If cisgendered, heterosexual, able-bodied, and middle-class or wealthy individuals are the standard by what is considered "normal," then anything outside of these norms will be considered deviant (Purdie-Vaughns & Eibach, 2008).

Within any cross-section of these categories, the dominant discourse dictates the assumed default comparison group (Purdie-Vaughns & Eibach, 2008). For example, discussions of "sexism" will center on comparisons of White, cisgendered, heterosexual males versus White, cisgendered, heterosexual females. Considerations of "racism" will focus on White, cisgendered, heterosexual males versus Black, cisgendered, heterosexual males, and so on. This means any group that exists outside of the dominant social group and/or the default comparison group (e.g., women of color, sexual minorities of color, and sexual minorities with a disability) is likely to be rendered invisible in the dominant discourse (Purdie-Vaughns & Eibach, 2008). Purdie-Vaughns and Eibach (2008) note that this "intersectional invisibility" is associated with both protective and risk factors. On the one hand, invisibility may protect multiply oppressed individuals from the direct wrath of dominant groups, resulting in less direct forms of prejudice and oppression. On the other hand, invisibility can leave multiply oppressed groups feeling disempowered and underrepresented in public discourse. This can result in fewer leadership positions, less power, and reduced access to resources (Purdie-Vaughns & Eibach, 2008).

When researchers focus on process, rather than on categories, it becomes apparent that the convergence of multiple identities can exert an influence on mental health which is similar to a single source of oppression (unitary), equal to the combined effects of independent categories of oppression (additive), equal to more than the sum of its individual parts (multiplicative), or transformative in reducing the effects of oppression (protective) (Bostwick et al., 2014; Bowleg, 2012; Cole, 2009; Hankivsky & Christoffersen, 2008; Purdie-Vaughns & Eibach, 2008; Seng et al., 2012). As such, an intersectionality framework for mental health moves away from a cultural worldview that is static and predictable to one that is dynamic and process oriented. It also promotes a cultural worldview that is inclusive of everyone. As Dadlani, Overtree, and Perry-Jenkins (2012) observe, "culture is often considered only when a patient is a member of a marginalized group. However, all patient social identities emerge from and operate as a result of unique cultural experiences…clinicians must remain cognizant of how experiences of privilege and oppression affect every patient" (p. 177).

Along with this recognition that (1) cultural viewpoints affect everyone and that (2) multiple identities are experienced simultaneously, Dadlani et al. (2012) additionally identify two other cultural principles that should be recognized when applying an intersectionality framework to mental health practice: (3) "All clinicians have privileged and marginalized identities that influence diagnosis and treatment" (p. 178) and (4) "The therapeutic relationship is a cultural context that is informed by the social identities of both patient and therapist" (p. 179). In the next two sections, these principles are put in to practice as we examine the implications of an intersectionality framework within the context of (1) multicultural competence in counseling and therapy and (2) cultural humility in social and community services.

Multicultural Competence in Counseling and Therapy

When considering the delivery of mental health treatment, the intersection of social identities has important implications for multicultural competence in service provision. As defined by Sue and Sue (2016), multicultural competence encompasses three domains: (1) personal awareness, (2) cultural knowledge, and (3) appropriate multicultural clinical skills. These three domains are often cited as the necessary components of multicultural competence for mental health care providers. Embedded within this model of multicultural competence is the assumption that a clinician does not necessarily reach an endpoint in training and knowledge acquisition, but instead continually explores and addresses all three domains.

This three domain framework presented by Sue and Sue (2016) has historically emphasized a categorical approach to understanding client and therapist cultural identities. Demographic categories such as race, gender, and sexual orientation were often implicitly or explicitly discussed as separate, non-related social identities

(Reimers & Stabb, 2015; Seedall, Holtrop, & Parra-Cardona, 2014). For example, in early research on multicultural competence in mental health treatment, much of the focus was on the experience of racial minority clients (Constantine & Sue, 2006; Sue, 2004). This research consistently demonstrated that racial minorities are disproportionately impacted by macro-level systemic risk factors which have detrimental effects on mental health and functioning (Constantine & Sue, 2006). Also, racial identity development and its relationship to the therapy variables has been researched extensively (Helms, 1995; Kwan, 2001). While this body of research has been quite valuable in advancing awareness of the importance of multicultural competence, this categorical approach to understanding social identities is only one, usually simplified, lens to understanding client experiences.

An intersectionality framework suggests that a simple categorical approach to building one's multicultural competence is insufficient (Robinson, 1999). Standalone categories are only one part of a more complex system of social identities that every person possesses. Within this system, every identity interacts and intersects with every other identity to create a multifaceted system of relative power, privilege, and oppression in daily life. Using Sue and Sue's (2016) three domain model, intersectionality theory offers a new way to approach multicultural competence in mental health treatment. The following sections address the importance of intersectionality in multicultural competence across the three domains of personal awareness, cultural knowledge, and appropriate multicultural skills. To further illustrate each of these domains, a fictional case example is presented, created by the second author L. Platt, based on her experiences as a counseling psychologist.

Case Example

Anthony is a 24-year-old, cisgender man who called a local counselor in private practice to seek help for anxiety problems and panic attacks. Anthony is biracial, with his mother being of European-German descent and his father being African-American. Both of his parents have college degrees and now work in the business sector. Anthony was raised in an upper socioeconomic environment. He was raised with both parents and identifies with both ethnic and cultural backgrounds that make up his biracial identity. However, from a visual perspective, most people who encounter Anthony view him as a light-complexed Black man. Anthony identifies as heterosexual, currently single. He also regularly attends a Christian Bible church and states that his faith is important to him. Anthony is in his first year of a Master's of Business Administration (MBA) degree at his local university. He is the only minority student in his cohort of 12, and is attending on a scholarship designed to increase diversity in his graduate program. He is having increasing difficulty attending classes due to anxiety and panic attacks once he enters the classroom. He describes how he had some anxiety as an undergraduate student, but he was able to manage it without impacting his grades. However, now that he is in graduate school, the anxiety has become much worse. He has a documented learning disability as well, which he has not disclosed to his current professors, but which makes reading comprehension difficult and reading time slower than average. In his classes there is a large volume of reading, which he is having difficulty keeping pace with.

The counselor Anthony is working with is a White, cisgender woman who is 35, named Amy. Amy has a master's degree in counseling from the same university Anthony is attending and is a licensed professional counselor. She has been in private practice for 6 years. She comes from an upper socioeconomic background and is able bodied. Amy is heterosexual and has been married to a man for 7 years. She is not religious and identifies as atheist.

Domain 1: Personal Awareness for the Provider

Sue and Sue (2016) suggest that the first domain of multicultural competence lies with the provider. Mental health providers must have awareness of their own cultural values, beliefs, and assumptions. Training, clinical supervision, and practice opportunities are often the settings where providers are challenged to consider their own cultural worldview as a critical element in multicultural competence. The emotions associated with examining the intersection of social identities are often a difficult topic for clinicians because in many cases one must consider the intersectional impact of both privilege and oppression in his or her daily experience (Watts-Jones, 2010). The overlapping layers and interrelated contexts of all of one's social identities are complex in most cases, creating a need for more critical analysis and a tolerance for ambiguity (Robinson, 1999).

When a provider is able to more holistically come to understand his or her cultural worldview as a unique, complex intersection of many social identities, there can be benefits for the clients being served. This level of awareness in a provider can reduce the chance of unintentional biases or overlooked cultural assumptions which could negatively impact the clinical work (Ramsay, 2014). A critique of the categorical approach to multicultural competence is that by only focusing on one social category at a time, a clinician overlooks the larger context of his or her social identities and can miss hidden assumptions and values within that context. An intersectionality approach challenges individuals to consider social identities on multiple levels.

Also, as intersectionality work is marked by its complexity and need for cognitive flexibility, this work can build skills that also help improve the therapist's ability to manage multilayered, difficult client situations (Cole, 2009). Learning about one's intersectionality builds critical thinking skills and helps a clinician develop a greater ability to complexly consider life experiences and worldviews. Intersectionality awareness requires an ability to tolerate ambiguity, flexibility to consider multiple points of view, and humility to accept the reality of privilege as well as oppression. These are also important skills for a clinician to have when working with clients (Sue & Sue, 2016).

In the provided case example, Amy, as a counselor, must take into account her own intersectional identities as she works toward multicultural competence in her practice. As a White, upper SES, heterosexual, able-bodied individual, Amy has a number of privileges afforded her, as this combination of identities are not marginalized (McIntosh, 1989). However, Amy is also a woman, who changes the intersectional view on privilege and oppression. White, heterosexual women face many societal oppressions about body image, career aspiration, and family expectations. As Amy considers her intersectional identities, she must take into account how her relative power, privilege, and oppressions shape her cultural values, beliefs, and assumptions. For example, how does her gender and other identities factor into her decision to enter into the helping profession? How does being a White, otherwise visibly privileged individual, make her daily experiences easier and different from non-White individuals? There could be many different intersectional viewpoints to examine in Amy's cultural matrix, all of which likely influence her counseling style and work with clients.

Domain 2: Cultural Knowledge of Others

The second domain in Sue and Sue's (2016) model of multicultural competence is the importance of understanding the worldview of culturally diverse clients. This domain has historically been dominated by a categorical, group membership approach. Early cultural training would involve looking at generalized information about each group (i.e., Asians tend to be more communal) with less attention on intragroup differences or intersectionality across groups (Mio, Barker, & Santos-Tumambing, 2012). The focus of clinical training is currently shifting to a more complex understanding of client worldviews. An intersectional framework emphasizes that every encounter with a new client is a multicultural experience, requiring an understanding of the unique combination of identities for each person, no matter how similar or different a client may seem in comparison to the provider. A provider needs to recognize how the overlay of relative power, privilege, and oppression within each visible and non-visible identity intersects and influences the client's lived experiences (Robinson, 1999). This social identity matrix is complex and requires critical analysis at multiple layers and levels.

Within the case example, as Amy approaches her work with Anthony, it will be important for her to consider his constellation of identities and how they intersect across privilege and oppression, and to consider how this is likely different than Amy's own life experiences. There are a number of intersectional viewpoints to look at in Anthony's matrix of identities. Anthony is a biracial man, whom most people visually attribute to be a Black man. While being male can carry certain societal privileges (McIntosh, 1989), being seen as a Black man is often fraught with many daily oppressions, such as being assumed to be a criminal, stereotyped as non-intelligent, and facing daily microaggressions (Sue, 2010). In Anthony's case, although he carries European heritage, he is not in a position to benefit from

White privilege, making that aspect of his identity invisible. Yet, as is often the case for biracial individuals, because of his light skin he may not be totally accepted into the African-American community either, further marginalizing his identity. As a man from an upper SES background, with two successful parents, he may be facing pressure to succeed in college. This pressure may be further increased because he is the only racial/ethnic minority in his cohort in graduate school, on an explicit diversity advancement scholarship. He may be facing extra scrutiny and pressure to perhaps represent all of his minority group as he advances educationally. This pressure may be even more salient due to his learning disability, which as a minority male he may not feel comfortable disclosing or seeking help for, but which is impacting his current performance. As a minority student, he may also face disproportionate dispositional attribution to his poor academic performance, with professors possibly attributing his problems to factors such as lack of intelligence, lack of motivation, or racist beliefs about his ethnic group.

Anthony is also a heterosexual religious man, from a denomination that values male-led families. He could be facing pressure to find a spouse and start a family, while being able to be a good financial provider. As Amy approaches her work with Anthony, it will also be important for her to be flexible and open to assimilating new cultural knowledge that is specific to Anthony's situation, as often there is considerable within-group difference of how cultural identities are experienced.

Domain 3: Appropriate Multicultural Clinical Skills

The third domain in Sue and Sue's (2016) model stresses the importance of culturally appropriate interventions, strategies, and techniques in providing multiculturally competent care. Within this domain, an intersectional viewpoint is critical to providing the best, most relevant care to clients. This domain covers the technical skills needed in the provision of mental health care. Included are such skills as developing culturally appropriate case conceptualization, implementing interventions, creating treatment plans, and determining an appropriate diagnosis (Sue & Sue, 2016).

Accurate and complete case conceptualization of clients is a basic skill for all mental health providers (Gelso, Williams, & Fretz, 2014). It is important for a clinician to be able to take information gained from a clinical interview, assessment materials, and other sources, and accurately form a conceptualization of the client's case and symptoms. Typically, it is the case conceptualization that informs the diagnosis, clinical interviewing, and treatment plan for clients. Intersectional understanding of the client's experience with stereotyping, prejudice, discrimination, and relative power and privilege must inform case conceptualization in order to have multiculturally competent care for the remainder of treatment (Sue & Sue, 2016).

The information often used in a case conceptualization includes the client's history, current presenting concerns, and all other relevant factors to explain the client's behavior, experiences, and choices (McLeod, 2013). An intersectional approach to case conceptualization would consist of considering all the client's social identities as one, holistic package, understanding that each identity intersects and influences all other identities. These intersecting cultural factors should be considered when helping to conceptualize the client's symptoms, daily life experiences, social supports, family dynamics, and obstacles that may be faced in the community.

In the provided case example, Amy's work with Anthony should start with an appropriate multiculturally informed case conceptualization. Anthony's intersection of identities likely means that he faces numerous daily challenges and oppressions, while he is currently trying to navigate considerable cultural, social, and personal pressure to succeed in his graduate program. This pressure is likely compounded by his learning disability, which is invisible to others but makes school work more difficult. In this academic environment, lack of success could carry more weight and meaning, given Anthony's intersecting identities. Since Anthony was already facing low-grade anxiety disorder symptoms in prior years, it is highly likely that this combination of intersecting societal and academic pressure is a contributing factor in his current increase in symptoms. As Amy works to develop this case conceptualization, she should find explicit ways to ask about Anthony's intersecting identities and his beliefs about their impact on his current symptoms. This clinical knowledge could be useful insight and validation for Anthony, but also help guide a more accurate case conceptualization.

Case conceptualization, the theoretical and practical explanation of a client's presenting features, is the foundation for intervention and treatment planning (Gelso et al., 2014). Treatment planning typically includes identifying treatment goals and identifying which interventions to use in order to reach treatment goals. When deciding upon intervention and treatment plans, a provider must consider the complete matrix of intersecting identities of the client to make culturally informed decisions about the appropriate course of treatment. The intervention plan must also take into account the cumulative negative impact of oppression, particularly if the intersection of identities places the individual in a further marginalized social position (Sue & Sue, 2016). Intersectionality must be a focus throughout this process, otherwise a clinician risks missing important cultural implications as he or she progresses in providing care.

In the provided case example, treatment and intervention for Anthony could involve a number of approaches to reducing his symptoms. However, as Amy considers helpful interventions, she must acknowledge and help Anthony cope with the multicultural, intersecting factors he is facing. This must be explicit and carried out in a manner that validates and affirms Anthony's lived experiences. Treatment should work to reduce Anthony's anxiety symptoms while also helping Anthony cope with the real cultural, systemic pressures he is going to have as he continues in school. Also, Amy should be aware of and avoid perpetrating microaggressions as she discusses cultural issues. Often, microaggressions are well intentioned statements that reflect internalized stereotypes or prejudice, perpetrated from a position of privilege (Sue, 2010). In this light, it would likely be beneficial to address how Amy's cultural identities differ from Anthony and how their work together will be shaped by these multicultural forces.

Intersectional awareness must also be taken into account when considering an appropriate diagnosis. The Diagnostic and Statistical Manual (American Psychiatric Association, 2013), put out by the American Psychiatric Association, is written from an atheoretical, categorical framework. The DSM is meant to be a straightforward manual where a clinician can use established diagnostic criteria to confirm a diagnosis. While the DSM provides many benefits to the professional fields it serves, there are some drawbacks. One criticism of the DSM is the possibility of misdiagnosis of culturally diverse or marginalized populations, typically in the form of pathologizing what are actually culturally relevant behaviors or reactions (Guthrie, 1997). Psychology has a long history of misdiagnosing under-privileged clients based on cultural misinterpretation or bias (Guthrie, 1997; Snowdon & Cheung, 1990). It is worthwhile to consider how the client's symptoms are related to his or her cultural experience, broadly defined, from an intersectional viewpoint. It is important to also consider how the matrix of identities, and the power, privilege, and oppression therein, explains or contributes to the diagnosable symptoms the client is displaying (Dadlani et al., 2012).

In the case example, as Amy decides on a final diagnosis, treatment plan, and case conceptualization, it is important that she utilizes skills that validate, incorporate, and address the intersection of Anthony's cultural and social identities. This intersectional approach should be the focus in every aspect of the treatment planning and implementation. The intersectional approach should also be considered in regard to the therapeutic relationship and addressing the cultural similarities and differences between Amy and Anthony.

In conclusion, the holistic and complex nature of an intersectional lens offers hope that clinicians can avoid the pitfalls of the past in regard to misdiagnosis and over-pathologizing marginalized populations. The case example provided is designed to highlight the complexity and necessity of an intersectional awareness to multicultural competence within the Sue and Sue (2016) three domain framework. It is highly likely that without an intersectional awareness, important cultural and social factors will be overlooked or invalidated in understanding the viewpoint and experiences of the client. Providers must consider this intersectionality approach in understanding themselves, their clients, treatment planning, and the multicultural experience of a counseling or therapy relationship.

Cultural Humility in Social and Community Services

Working in communities, and specifically with children and young people, challenges practitioners to apply theories of intersectionality. This section focuses on how community workers and social service providers can use the framework of intersectional cultural humility in their practice, by focusing on examples from work with children and young people.

The root of the struggle with cultural competency is the desire to be able to work with those who do not occupy the same social positions as the practitioner. Griffith

(1998), in her review of the insider/outside debate in research, asks "Does the biography of the researcher-their race, class gender, sexual identity and history-privilege or disqualify their knowledge claims?" (p. 361). After exploring the insider/outsider debate, Griffith contends that social boundaries are not as static as the debate assumes, and that epistemic privilege alone is not a qualifier for research. The same dilemma can be extended to work in the community. Does the biography of a practitioner, or their epistemic privilege from the many social categories they occupy, privilege or disqualify them from working with others of similar or different categories? Also, in the fields of social and community work, where services are not fueled by matching positions of clients and practitioners, how do workers prepare themselves to interact with diverse groups? Most often, practitioners find themselves working with many individuals with whom they share little or no social positions. It is in these situations that having guidelines to structure interactions is useful. Practitioners must be able to incorporate nuance into their work on the basis of the lived experiences of their clients. In the absence of the ability to completely master knowledge of another's social situation, cultural humility offers some guiding principles.

Cultural humility, as Tervalon and Murray-Garcia (1998) explain, has a history in medical practice. Necessitated by a growing need to address the lack of multicultural education of physicians, and the inadequacy of the cultural competency model, cultural humility was developed with the following pillars. First, there is a commitment to self-reflection and being a lifelong learner; practitioners must be able to position their own cultural backgrounds and influences and commit to a never-ending journey of learning about their patient's or client's realities. The lifelong component of this is essential, in that it acknowledges that culture is not static and, since each person holds multiple, intersecting, ever-changing social positions that converge to form their identity, mastery is useless and becomes void in the moment it is attained. Second, there is a stress on being patient focused. This means shifting from a controlling authoritative practice to valuing the patient's perspectives and needs. There is a push for community-based care and advocacy and moving away from homogenous university or medical center training grounds. Finally, and with sharp contrast to a model of cultural competence, there is the search for institutional consistency. Questions and critiques must be welcome at the institutional level, looking to see if the institution is as diverse as the population they seek to serve. The emphasis is not only on the differences between the physician and the patient but also on the institutions reproducing the differences (Tervalon & Murray-Garcia, 1998). Combined, these elements seek to re-examine the power imbalance between physicians and patients, and to develop more equitable relationships with individuals and communities.

There has been a recent shift to using this framework in social and community work as well. Echoing the concern of mismatched social positions between physicians and patients, social and community workers are able to easily incorporate the tools of cultural humility into their practice. Fisher-Borne, Cain, and Martin (2015) further conceptualize the core elements of cultural humility as follows: institutional and individual accountability, lifelong learning and critical reflection, and mitigating power imbalances. The focus here is on individual accountability and away from mastery, as cultural competency inherently implies. Cultural humility moves away from solely looking to understand the client's culture as a means of addressing inequality, and toward looking at the structures that produce the inequality in the first place. Thus, cultural humility allows for practitioners to have a transformative agenda, as it looks at the systems which create intersecting identities and challenges them (Fisher-Borne et al., 2015).

Moving specifically into working with children and young people, Ortega and Coulbourn Faller (2011) discuss the implications of cultural humility as a training tool. As the practitioner gives up the position of expert, they remove themselves from the center of the child's care and stand beside the child and family in a supportive role. The family, and the child in the context of the family, become the experts of their own experience. Professionals, while experts in their respective fields, are not required to be perfectly versed in every experience of culture, race, sexuality, gender, etc. They are required to look at the larger structures of child and youth care services and question them. The injustices against Aboriginal children in Canada and the role of residential schools and the child welfare system serve as an example. Practitioners working with Aboriginal children in Canada do not do so in a vacuum; they do so while situated in a profession that is deeply tied with a problematic history of colonization and genocide (Jones, 2010). Cultural humility, rooted in an intersectionality framework, would demand that a non-Aboriginal practitioner working with an Aboriginal child acknowledges his/her own status as settler, acknowledges the child and their community as experts on their culture, and continually questions the institutions and structures that affect the lives of young Aboriginal people.

Case Examples

So what might this look like in practice? To illustrate the implications of intersectionality theory, I (Jaspreet Bal) share my experiences working with children to highlight how an intersectionality approach to cultural humility might work in the field. As a young intern with the Canadian International Development Agency (CIDA), I was working on a human rights project in Punjab in India around the dissemination of the Convention on the Rights of the Child in the public school system. I was staying alone at my grandparent's old house in our village which quickly became an interesting space for young girls to hang out as it was away from the eyes of much of the village. Girls would stop by on their walks home from school or in the evening on long and hot days and we would sit and share stories. I distinctly recall one young girl talking about how she had not studied for a test at school one day. Her teacher, in turn, had beaten her hands with a stick until they were numb. She laughed as she told this story and the other girls from the village laughed alongside her; the unmistakable laughter of finding yourself in someone else's story. My reaction, however, was more subdued. I was born and raised in Ontario and the product of a public school system in which teachers' behavior was largely regulated by policy. No teacher, from my specific perspective, had so much as raised their voice at me, much less wielded a stick. In this specific circumstance, I was present as a researcher, and so the extent of my intervention was to listen and take note; I was not required to report or modify behavior.

Framing this experience with an intersectionality and cultural humility lens, a few things were important. First, being in that moment required me to have a critical reflexivity. I was immediately aware that I had a different reaction to the story than the girls did. Then, allowing the expertise of the girls to prevail, I listened and did not express my different reaction to the story. I also had to be critical of the larger structures at play. Everything from the global development industry that fueled my being there as a CIDA representative, to the neo-liberal reform that had public schools in India failing their students in the face of being underfunded and deregulated (Johnson & Bowles, 2010). Without this larger critical understanding of intersectionality, and a cultural humility framework in which to address it, I could easily fall into the traps of trying to "save" the girls, or not be moved to social action on a larger level.

More recently, I was leading a workshop with children, aged 3–10, in the Toronto area, around the construction of space. Age serves as its own category of social position as children are constructed with minority group status (James, Jenks, & Prout, 1998). Children seldom contribute to the construction of their own spaces, including schools, homes, playgrounds, and community spaces. This workshop was designed to help them imagine what their space would look like and express it through play and art. Again, intersectionality and the cultural humility framework was in play. With respect to some of the children, I shared the same language, culture, and/or gender; with others, I did not. In the category of age, however, we were distinct; they were all children, and I was outside of this minority group status as a privileged adult. Knowing this about myself, I had to acknowledge the power I had and defer to them for their expertise. We were inescapably products of our institutions; I had more power and I had picked the time and structured the workshop. I then challenged the power structure and asked them to lead with their ideas. I asked a question about how they might design their own spaces, provided art materials, and got out of their way. I listened as they came forward and shared their ideas. Cultural humility also demanded that I examine the institutions and social structures that framed this interaction. To that end, I actively listened and incorporated their ideas into my understanding and planning of spaces. As an ally and a culturally humble practitioner, I try to bring the voices of children into the construction of spaces where they have so far been left out. I have to acknowledge the history of childhood in the Toronto area, the specifics of the children's lives, and where I stand in all of those.

Working in communities is always an exercise of balancing best interests with participation. Social and community work is an art and a science. There is no one universal equation that can quantify the process of cultural humility and make it easy to carry out. On the contrary, it necessarily complicates the simple and taken for granted basis of our interactions with clients. Working in social and community services is in equal parts about the practitioner and the client. As Garfat (2004) points out, each brings to an exchange their respective history and walks away changed. The process of meaning-making depends on the value given to the intervention by virtue of the many social positions each occupies. He states,

> The culture of the young person and family, the culture of the dominant society, the culture of the program and organization, and the culture of the worker all impinge on the intervention process. It is only when the worker attends to how meaning is construed in all of these that she can being to understand the young person and his or her behaviour. (p. 9)

There is a difference in perspectives when the social positions of practitioner and client do not match, and being able to constructively work with that difference is the responsibility of the practitioner. Neither complete mastery nor feigned neutrality on the subject of culture is a realistic option in the field. A practitioner can reflexively acknowledge their ethnocentricity and work on decentering their perspective to bring their client's expertise to the center of an intervention. It is neither a simple work nor ever truly finished. It is a lifelong commitment to always be in process. Whether cultural humility is envisioned as an alternative to cultural competence (Fisher-Borne et al., 2015) or as a complimentary model (Ortega & Coulbourn Faller, 2011), it is a useful conceptual framework for all practitioners who find themselves in social positions that do not align with their clients. In the absence of strictly defined boundaries of social positions that allow for insider and outsider status, all practitioners must constantly engage in a reflexive model that accounts for intersectionality.

Summary of Recommendations

In summary, an intersectionality framework for mental health urges practitioners to go beyond the examination of single categories of collective identity to recognize how various identities converge, intersect, and mutually influence one another to create unique subjective experiences that help to shape, inform, and explain mental health outcomes (Bostwick et al., 2014; Calabrese et al., 2015; Cairney et al., 2014; Seng et al., 2012). Our discussion of the applications of an intersectionality framework within the context of mental health, multicultural competence, and cultural humility reveals a common set of recommendations for practitioners:

1. In an increasingly diverse world, practitioners must be prepared to work with individuals who occupy different social locations than the practitioner (Griffith, 1998).
2. A simple categorical approach to building one's multicultural competence is insufficient. Practitioners must consider how multiple identities converge to influence personal experience, interpersonal relationships, and social-political influence (Seng et al., 2012).
3. Practitioners must become self-aware of their own social locations, including sources of marginalization and privilege within their own lives (Ortega &

Coulbourn Faller, 2011; Sue & Sue, 2016). The focus is on cultural humility and individual accountability, not mastery, so self-reflection must be a lifelong, continuous process (Fisher-Borne et al., 2015).

4. Practitioners must understand that every client, even those with relative privilege, is influenced by culture (Dadlani et al., 2012). As such, practitioners should seek to understand the cultural worldview of each of their clients (Sue & Sue, 2016). This worldview will be shaped by all of the client's multiple and intersecting identities (Bostwick et al., 2014; Calabrese et al., 2015; Cairney et al., 2014; Seng et al., 2012).
5. The practitioner must recognize that every encounter with a client is a multicultural experience. Within that multicultural experience, the practitioner should work to identify, acknowledge, and mitigate any power dynamics that exist between the practitioner and the client due to the multiple and intersecting identities of both the client and the practitioner (Dadlani et al., 2012; Tervalon & Murray-Garcia, 1998).
6. The practitioner must continuously adopt culturally responsive skills when completing case conceptualizations, implementing interventions, creating treatment plans, and determining appropriate diagnosis (Sue & Sue, 2016). Experiencing multiple marginalized identities may place individuals at even higher risk for stigmatization, stress, and mental health problems (Calabrese et al., 2015; Gayman & Barragan, 2013; Grollman, 2012). To best understand these risk factors, practitioners should focus on the processes by which collective identities shape, inform, and explain mental health (Dhamoon, 2011; Purdie-Vaughns & Eibach, 2008).
7. Practitioners must work to adopt transformative agendas in order to identify, understand, and change systems that create inequality (Fisher-Borne et al., 2015). In this process, one must be aware of how dominant discourses define who is recognized and included in these agendas, and how multiple intersecting identities might serve to render people invisible within these discourses, stripping them of their power and representation (Purdie-Vaughns & Eibach, 2008). Public and mental health agendas must be transformative and incorporate a reflexive model that accounts for intersectionality.

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Chapter 2
Archetypes of Black Womanhood: Implications for Mental Health, Coping, and Help-Seeking

Ingrid R. G. Waldron

The bodies of Black women have long been sites of trauma that carry the weight of the past and present stereotypes that dehumanize them. They continue to embody the traumatizing effects of multiple forms of structural violence, historically and in the present day. Structural violence refers to the systematic ways in which government and social institutions disadvantage, oppress, and harm Black and other racialized communities through dehumanizing societal representations and media images, inequitable treatment by the criminal justice system, discrimination in labor and employment, and many other gendered and racial injustices. Myths about Black imperviousness to pain have endured since slavery (Washington, 2007) and have informed perceptions of Black women as strong, invulnerable, and non-human, leading to the "othering" of Black women in healthcare settings.

The experiences of Black women can be characterized in terms of their structural location at the intersection of race, gender, class, sexual orientation, and other social oppressions, as Mirza (1997) observes:

> Black women inhabit a space which, because it overlaps the margins of race, gender, and class discourse and occupies the empty spaces in between, exists in a vacuum of erasure and contradiction. It is a space maintained by the polarization of the world into Blacks on one side and women on the other (p. 4).

Essed (1991) coined the concept "everyday racism" to refer to experiences of discrimination that Black women face. She recognizes the circuitous, contextual, and multidimensional nature of everyday racism that characterizes the connection between the macro-structural forces of racism that often occur within societal institutions and structures, and the micro-situational events that are characterized by racism and that may occur between individuals. She also coined the term "gendered racism" to describe the many ways in which Black women are subjected to biased

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gender roles, as well as their experiences of racial oppression. She argues the impossibility of disentangling gender from race when examining the discriminatory encounters faced by Black women.

Black women's structural location has shaped their identities, resulting in a Black feminist consciousness that combines both a feminist and an ethnic or racial consciousness (Reid & Comas-Diaz, 1990). Alice Walker (1983) coined the term "womanism" to characterize the feminist consciousness of Black, Chicana, and Asian women who stand at the crossroads of race and gender simultaneously. McClintock (1995) and Stoler (1991) articulate the ways in which race provided the lens through which class and gender were understood in the construction of metropolitan identities. Through a scientific process that was set up to formalize boundaries between metropolitan dwellers, a hierarchy was constructed that used race and gender to allocate power and resources to white middle-class men and to exclude women and racialized peoples. This hierarchy ultimately placed Black women at the bottom of the heap because they were racialized both by their physical appearance and by their gender. Race, gender, class, and other social constructs have informed societal representations of Black women, resulting in six main stereotypes that emerged during the slave era and continue to resonate today: Mammy, Matriarch, Welfare Mother, Jezebel, Angry Black Woman, and Black Superwoman (Abdullah, 1998; Ashley, 2014; Bing & Reid, 1996; Hill Collins, 1990; Pleck, 1990; Waldron, 2002). Black women's internalization of these stereotypes, as well as their efforts to invert, subvert, and resist them, have led to the development of a Black feminist consciousness that provides insight into the corrosive health and mental health effects of structural violence on Black women, as well as the ways in which Black women cope with, manage, and seek help for mental health issues.

This paper begins with a discussion on some of the most pervasive and long-standing controlling societal representations and images of Black women that have served to harm them in every aspect of their lives—from relationships with their families and partners to their experiences in employment, the labor market, and health care. Next, I argue that these representations contribute to the development of a Black feminist consciousness that embodies Black women's unique location at the crossroads of race, gender, class, and other social identities. The paper concludes with a discussion on how a Black feminist consciousness not only influences Black women's experiences with mental illness but also provides a reservoir from which Black women learn to cope, manage, and seek help for these issues.

Black Female Archetypes: Mammy, Matriarch, Welfare Mother, Jezebel, Sapphire, and Black Superwoman

Much has been written over the years about how Black women's location at the intersection of race, gender, and class has resulted in socially constructed images and stereotypes of Black womanhood (Bing & Reid, 1996; Carrington, 1980;

Hill Collins, 1990; Copeland, 1982; McClintock, 1995; Moynihan, 1965; Mullings, 1992; Pleck, 1990; Stasiulis, 1990; Steady, 1987; Stoler, 1991; Waldron, 2002). These studies have identified six main controlling images of Black women that emerged during and since slavery, and continue to influence how Black women are perceived in every sector of society: Mammy, Matriarch, Welfare Mother, Jezebel, Sapphire, and Black Superwoman (Ashley, 2014; Carrington, 1980; Copeland, 1982; Moynihan, 1965). These controlling images were created outside of the Black community to not only denigrate Black women and the Black family but also legitimize and justify their oppression (Jewel, 1988; Waldron, 2002).

The two most enduring images of Black women—the Mammy and the Matriarch—take on new meaning among many depressed African American women who express strong needs to nurture and take care of others in their lives, oftentimes at their own expense. The Mammy image characterizes African American women as loyal, submissive, religious, asexual, and nurturing. Furthermore, images of Black women as caretakers for their own and others' families, along with the legacy of their participation in "manly" forms of labor outside of the home since slavery, have led to perceptions of Black women as aggressive, domineering, and emasculating (Carrington, 1980; Waldron, 2002).

In slight contrast to the Mammy image is the image of the Matriarch. The "Black Matriarchy theory" was created to explain the problems in Black America and blamed African American women for African American men's oppression and their continued absence from the home (Bing & Reid, 1996; Copeland, 1982; Moynihan, 1965). Moynihan (1965) describes the African American family as a "tangle of pathology" and blamed the matriarchal structure of the African American family for the social ills that disproportionately impact African Americans, such as crime and educational underachievement. The Black Matriarch is perceived as a "bad mother" because her single-parent status and participation in the labor force were said to prevent her from fulfilling her "motherly duties" inside the home. Although still perceived as the caretaker, these women are characterized as aggressive, domineering, and emasculating because they have taken on the breadwinner role in their families. The Black Matriarchy theory masculinized and sub-humanized African American women because their breadwinner role and their single-parent status challenged the existing social order in which men were supposed to hold power.

Challenging these stereotypes, other scholars (Bing & Reid, 1996; Steady, 1987; Waldron, 2002) have argued that the Black Matriarchy theory negates the role that economic, political, and social injustices play in limiting opportunities for African Americans, including the very real problem of Black male peripherality. Black male peripherality in the USA, the Caribbean, and African societies undergoing industrialization is the inevitable consequence of the economic marginalization and imposed poverty in these communities and societies. Since Black men have high rates of unemployment in the USA, Black women, most of whom are poor, are forced to take on the breadwinner role. Therefore, the Black Matriarchy theory fails to fully capture the experiences of many African American women who are located at the bottom of the socioeconomic hierarchy (Bing & Reid, 1996; Steady, 1987; Waldron, 2002).

The Welfare Mother—the third ideological representation of Black women—is an image that was associated with Black women's increasing dependence on the post-World War II welfare state, and that evolved out of the "breeder woman" image that was pervasive during slavery. The breeder woman image likened Black women to animals because it characterized them as being more able and suited for producing and caring for children than white women. Slave owners encouraged slave women to breed because slave children symbolized profit (Hill Collins, 1990).

Conceptualizations of Black women as Jezebels—the fourth archetype—are most pervasive in media, where they are presented as promiscuous, hyper-sexual, unchaste, and immoral. Efforts to control Black women's sexuality lie at the heart of Black women's oppression. Pleck (1990) observes that ideologies about race and sexuality were rooted in European religious beliefs that equated African peoples and their practices with non-Christian religions. In the early fifteenth century, before the commencement of the African slave trade, the sexual practices of Africans were denigrated by Christian missionaries who visited the African continent. Upon seeing semi-nude African women dancing in, what was to them, a vulgar and sexually explicit manner, Europeans decided that they were sexually promiscuous and immoral.

Gilman (1992) discussed how the Black female was constructed within that representational system through a linkage between two images—the Hottentot female and the prostitute. The social construction of "Black femininity" was based on both the female Hottentot, who came to represent the Black female in the nineteenth century, and the prostitute, who represented the sexualized woman. These categorizations helped create a class system which represented specific qualities of human behavior and Black sexuality, in particular deviant sexuality. Similarly, Mullings (1992) and Stasiulis (1990) observe that the sexualities of Black and White women became polarized during slavery, as they were based on a romanticized image of the ideal woman as pure, passive, and moral. It is an ideology that located Black and White women at opposite ends of a hierarchy, casting White women as fragile, modest, and sexually repressed and Black women as aggressive, resilient, and sexually immoral.

The fifth archetype of Black women is that of the Sapphire or Angry Black woman—hostile, aggressive, bitter, and irate. It is an archetype that fails to consider how Black women's anger is rooted in historical, cultural, social, economic, and political processes. Moreover, mental health clinicians who lack an understanding of the sense of disempowerment that many Black women experience will misinterpret their emotional experiences, emotional expressions, and responses to stress, and, consequently, fail to appropriately assess symptoms as well as diagnose and provide treatment to Black women. Many Black women who distance themselves from the Sapphire stereotype may suppress disclosures of anger, depression, and stress, and minimize their health and mental health impacts (Ashley, 2014).

These five stereotypes combine in unique ways to characterize Black women as nurturing, strong, invulnerable, and resilient "superwomen"—the sixth archetype of Black womanhood. More than any other archetype, the Black Superwoman image undermines the racialized physical and mental trauma that Black women have long had to endure, often leading Black women to internalize these damaging stereotypes, as well as to minimize, ignore, and deny the many challenges they face. The origins of the strong Black woman archetype, which has its roots in slavery, were created to justify the maltreatment, abuse, and sexual violence of Black women by slave owners. It was a stereotype that characterized Black women as having superior physical and psychological strength compared to white women, and suggested that they could more easily withstand pain and harsh conditions (Stanton, Jerald, Ward, & Avery, 2017).

The Black Superwoman myth has persisted over generations in unfair expectations from Black family members and society at large that Black women be the pillars of the Black family by providing physical, emotional, and economic support, even when that support is rarely returned. Black women are the by-products of a culture that teaches them to minimize the gravity of their problems. Mays, Caldwell, and Jackson (1996) point out that African American culture stresses early in life the ability to "do it," which emphasizes the importance of actively managing difficult situations without showing stress. Therefore, Black women often internalize the myth of the Black Superwoman by taking on the role of a strong, self-reliant, and independent amazon and minimizing their stress and emotional problems, fearing that others will perceive them as weak (Carrington, 1980; Hooks, 1993; Mays et al., 1996; Schreiber, Noerager Stern, & Wilson, 1998, 2000).

Stanton et al. (2017) recognize the paradox of the strong Black woman stereotype that on the one hand may be detrimental to their self-care behaviors but on the other hand may help facilitate their survival and self-efficacy. However, while the stereotype has historically been perceived as a positive alternative to the Mammy and Jezebel, research conducted over the past 30 years suggests that internalization of the strong Black woman stereotype is limiting because it encourages them to perceive themselves as superhuman and to undermine or dismiss their emotions, needs, vulnerability, and humanity. Negative physical and mental health outcomes are also associated with embracing this stereotype.

In their study, Donovan and West (2015) examined whether endorsement by Black female college students of the strong Black woman stereotype worsens the deleterious relationship between stress and mental health among Black female college students. They found that endorsement of this stereotype moderated the relationship between stress and depressive symptoms. Both moderate and high levels of endorsement of the stereotype increased the positive relationship between stress and depressive symptoms, whereas low levels of endorsement of the stereotype did not. These data support the studies mentioned earlier (Carrington, 1980; Hooks, 1993; Mays et al., 1996; Schreiber et al., 1998, 2000) which show that internalization of the strong Black woman stereotype as a central component of Black womanhood can be harmful to Black women because it promotes a conception of Black women as having excessive strength, caretaking abilities, and emotional restraint and, consequently, may be detrimental to their self-care behaviors.

Thomas, Witherspoon, and Speight (2004) examined how the internalization of these stereotypic roles shaped racial identity and self-esteem in Black women. They used three scales to determine the relationship between racial identity, self-esteem, and ideological representations of Black women: The Racial Identity Attitude Scale-B (RIAS-B) (Parham & Helms, 1981), which measures racial identity attitudes; Rosenberg Self-Esteem Scale (RSE) (Rosenberg, 1965), which asks respondents to respond to negative and positive self-statements; and Stereotypic Roles For Black Women Scale (SRBWS) (Thomas et al., 2004), which examines perceptions and stereotypes of African American women that correspond to the stereotypes Mammy, Jezebel, Sapphire, and Superwoman. Results show that African American women identify with some of these stereotypes and often hold stereotypic attitudes toward themselves and other African American women. Stereotypic images of Mammy were negatively correlated to self-esteem, while only the Mammy and Sapphire images were negatively related to self-esteem. African American women often internalize the Mammy role, resulting in a neglect of their own needs in favor of serving and taking care of others, ultimately leading to low self-esteem. Women who internalize the Sapphire image of the loud, aggressive woman may also suffer from low self-esteem because they are not able to express their frustrations and anger. The results did not indicate a relationship between the stereotypic roles of Jezebel and Superwoman and self-esteem.

A study by Pyant and Yanico (1991) examined whether racial identity attitudes and gender-role attitudes were implicated in the psychological well-being of adult Black women. They sampled 143 adult Black women using the following instruments: Racial Identity Attitude Scale (RIAS-B), Attitudes Toward Women Scale (AWS), Well-Being Scale from the California Psychological Inventory (CPI), the Beck Depression Inventory (BDI), and the Rosenberg Self-Esteem Scale (RSE). They found that there was an association between racial identity attitudes and psychological health in Black women. They also found that Black women who harbored pro-white/anti-Black attitudes reported more psychological and physical symptoms and lower self-esteem. Their findings also indicate that gender was not a significant predictor of mental health variables, suggesting that racism is a more salient issue for Black women than sexism.

King (2003) looked at how group consciousness among middle- and upper-class African American female university students influenced prejudice attributions. She focused on three main forms of group consciousness: ethnic, feminist, and womanist. Her objective was to determine if higher group consciousness results in a greater propensity to identify and perceive incidents of prejudice toward one's own group. She was also interested in determining the extent to which African American women's perceptions of racism, sexism, and ethgender prejudice were influenced by ethnic, feminist, and womanist consciousness. Ethgender is a term that was coined by Jeffries and Ransford (1980) to describe the unique social position and standpoint of women who experience both gender and race oppression. Participants completed several measures, including a 39-item unidimensional version of the Ethnic Identity Orientation Measure (King, 1993, 1999), which assesses ethnic identity orientation, particularly attitudes about African American identity and group affiliation; the Short Version of the Feminist Perspectives Scale (Spaulding & Henley, 1997), which measures a wide array of feminist beliefs; and the Womanist Consciousness Scale (King & Fujino, 1994), which measures the degree to which women of color perceive their identity as comprising equally and inseparably of both their ethnic and feminist consciousness.

King's (2003) findings indicate that stronger ethnic and ethgender consciousness were both associated with an increased propensity to attribute unfair treatment to prejudice. The study also suggests that African American women often feel uncertain about how attributions should be made about potentially discriminatory events and, as a result, make their own determinations about the reasons for negative and unjust interactions with dominant group members. These determinations are often shaped by ethnic and womanist consciousness. The findings also show that ethnic consciousness was related to perceived ethnic prejudice, womanist consciousness was related to perceived ethgender and gender prejudice, and feminist consciousness was not related to sexism or any prejudice attributions. Findings show that womanist consciousness may be more useful in assessing gender consciousness among African American women than feminist consciousness, and that women of color do not disentangle gender from race or gender when they make sense of their experiences.

Mental Health Impact of Discrimination on Black Women

Historical trauma experienced by Black people in North America is characterized by the intergenerational stress of colonialism, creating an enduring burden on their spiritual, physical, and mental health. Stress and stress-related diseases such as cardiovascular disease, diabetes, depression, suicide, substance abuse, hypertension, cancer, and obesity (McGibbon, Waldron, & Jackson, 2013) are embedded in historical, systemic, institutional, and everyday structures that are experienced by Black and other racialized women in specific ways.

Schulz et al. (2000) examined the cumulative effects of socioeconomic status, experiences of unfair treatment, and acute life events by race and residential location on the health status of African American and white women living within the city of Detroit and in the surrounding metropolitan area. They found that African American women (regardless of whether they live inside or outside the city) report more frequent experiences with everyday unfair treatment than white women. They also found that African American women residing in the city reported a greater number of acute life events than white women residing outside the city. African Americans are also more likely to experience stressful conditions and are more negatively affected by these stressors than higher status groups. Overall, African American women reported less favorable general health status than did white women. In general, the results show that the relationship between race and general health status is partly accounted for by disparities in unfair treatment and life events.

Depression in Black women can be attributed to racial disparities, microaggressions, poverty, cultural socialization, social health, obesity and diabetes, and exposure to interpersonal and community violence. The disproportionate exposure of Black women to race, gender, and class inequities puts them at higher risk for mental illness. As discussed earlier in this paper, experiences of sadness among Black women may be masked by pressures they and others put on them to persevere in the face of adversity and to maintain high levels of productivity, social engagement, and service to others (Martin, Boadi, Fernandes, Watt, & Robinson-Wood, 2013). Despite the very real social and economic stressors weighing down on African Americans, the National Mental Health Association (NMHA) survey on attitudes and beliefs about depression in African American communities found that nearly 63% of African Americans believe that depression is a "personal weakness." About 30% of the respondents stated that they would "handle it" if depressed. Prayer and faith were viewed as approaches that would successfully treat depression "almost all of the time" or "some of the time" among nearly 66% of African Americans (Cordian & O'Connell, 2003).

Amutah-Onukagha, Doamekpor, and Gardner (2017) identify allostatic load (AL) as a useful tool for assessing the body's physiological response to stressors and for explaining why Black women have an increased risk of Major Depressive Disorder (MDD). AL measures the effects of stress on the body that have been created by social conditions. It can be used to explain the cumulative wear and tear on the body's systems resulting from adaptation over time to psychosocial stressors. The risk of physical and mental disorders can increase due to prolonged activation of these systems. Study findings show that there is a relationship between income and health, with poverty income ratio (PIR) found to be significantly correlated with MDD symptoms.

The cognitive appraisal of discriminatory treatment can be experienced as stressful and may elicit emotional responses (Lazarus, 1999). A stressor is an event in which the "relationship between the individual and the environment is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p. 19). Versey and Curtin (2016) found that experiences of discrimination often lead people to question individual self-worth, particularly if they rarely experience discrimination. For white women in their sample, discrimination was a threat to communion that adversely impacts their health. Black women were less likely to devalue the self as a result of unfair treatment because they were more likely to be exposed to discrimination based on race and gender during their lifetime (Versey & Curtin, 2016).

Several scholars (Baker, 1994; Barbee, 1994; Garretson, 1993) point to the specific ways in which Black women express or show symptoms of depression and other types of mental illness. Garretson (1993) observes that the ways in which African American women show symptoms of mental illness is greatly influenced by culturally determined beliefs about symptom presentation. Garretson also observes that the outward manifestation of affective and cognitive states will vary along ethnic, racial, and cultural lines. African Americans tend to present symptoms of depression through physical complaints more than whites. Clinicians' unfamiliarity with the ways in which African Americans present symptoms of depression often leads to the under-diagnosis of this condition among African Americans. Garretson also found that other symptoms that lead to the most frequent mis-diagnoses of "mental illness" among African Americans are hallucinations, delusions, suspiciousness, and flat or inappropriate affect.

Barbee (1994) examined how the cultural orientation of African American women influences and transforms what is usually viewed as a pathological state into a vehicle for self-help and renewal. She found that African American women conceptualize mental health problems in culturally specific ways, and characterize their problems by using labels that reflect their cultural and racial affiliations. These labels often differ significantly from the labels used in the psychiatric literature. She identifies three categories of depressed moods: feeling down/low; “the blues”; and depression. Feeling down/low was considered to be the mildest form of depressed moods among these women, while depression was considered the most severe. The blues is an African American cultural construct whose meaning differs qualitatively from the meaning in the psychiatric literature, where “the blues” is defined as a feeling of dysphoria that acts as a transition state between feeling down and mild depression. For African American women, forms of dysphoria, like “the blues,” are not perceived to be as disabling in the same way that it is in the psychiatric literature.

Black Feminist Consciousness: A Reservoir for Coping and Help-Seeking

While Black women’s experiences of mental illness result from their self-consciousness as Black women whose race, gender, class, and other identities have subjected them to experiences of structural violence within various social institutions, it is precisely their self-consciousness as Black women that provides them with a reservoir from which to draw to cope with, manage, and seek help for mental health problems. Optimal psychology focuses on how coping and strategies of resistance might impact depression in Black women. Myers’s Theory of Optimal Psychology (Myers et al., 1991) is grounded in an Afrocentric worldview that compares a suboptimal and an optimal worldview. The suboptimal worldview reflects the Eurocentric value system, where spirit and matter are viewed as separate and independent entities and where self-worth comes from external validation that leads people to look for meaning and peace in their lives from factors outside of themselves. Therefore, a sense of oneself comes from material forces that the eye can see. The optimal worldview, on the other hand, reflects an Afrocentric value system that acknowledges the relationship between spirit and matter and that views self-worth as being based on intrinsic value. The optimal worldview is, therefore, holistic in that it views the “self . . . as multidimensional encompassing the ancestor, those yet unborn, nature, and community” (Myers et al., 1991, p. 56). Myers’s theory is premised on the notion that individuals are on a quest for self-knowledge, motivated by a desire to live the set of conditions called optimal. Optimal conditions are a life that yields peace, joy, and harmony, and that recognizes that these factors increase the well-being of the whole (Martin et al., 2013).

Robinson and Ward (1991) developed a theory of resistance for Black adolescent girls to address the intersections of race and gender in their lives. One of the main goals of Resistance Theory was to guide Black girls and women in identifying, naming, and resisting race, gender, and class oppression that impact their lives. Resistance Theory was also developed to help Black women recognize and utilize optimal resistance strategies reflected in Myers's Theory of Optimal Psychology (1991), as well as to help them recognize and actively avoid suboptimal resistance strategies. Optimal resistance reflects an awareness of environmental stressors and institutional oppression that impact Black women, as well as strategies for naming and opposing a sociopolitical consciousness of oppression (Robinson & Ward, 1991). Unlike suboptimal resistance, which is associated with a disempowered state that is linked to depression and feelings of insecurity and inferiority, optimal resistance encompasses a state of being that supports health and healing, and may include community involvement and other proactive, deliberate, conscious, and methodological measures. These may include seeking help from a mental health care professional to address depression, as well as a reliance on multiple other resources, such as psychotherapy, pharmacology, exercise, and community and spiritual resources (Martin et al., 2013).

West, Donovan, and Roemer (2010) found that the coping style one uses will shape the extent to which perceived racial discrimination (PRD) experiences affect psychological functioning. In their study, the participants endorsed high levels of PRD experiences. Only 6% (5) of participants stated that they never experienced any form of racial discrimination. No significant relationship between PRD and depressive symptoms was found. This may be because the sample in this study, unlike most previous ones, was comprised of Black women exclusively, suggesting that there may be something unique about being a Black woman that does not support the previously found significant relationship between PRD and depressive symptoms. The findings may also indicate that participants' experiences of depressive symptoms related to PRD were not fully captured, since the Schedule of Racist Events (SRE) tool measures PRD over the past year and lifetime while the Depression Anxiety Stress Scale (DASS-21) only measures depressive symptoms over the last week.

Findings also show that problem-focused coping moderated the relationship between lifetime racial discrimination and depressive symptoms. Problem-focused coping can be defined as coping styles focused on problem-solving and active engagement to change the source of stress. Lifetime experiences of PRD were positively associated with depressive symptoms for Black women who reported low levels of problem-focused coping. Lifetime experiences of PRD were negatively associated with depressive symptoms for Black women who reported high levels of problem-focused coping. This suggests that higher levels of problem-focused coping may buffer the effects of racial discrimination on depressive symptoms. Avoidant coping also moderated the relationships for both recent racial discrimination and depressive symptoms, and lifetime racial discrimination and depressive symptoms. Avoidant coping encompasses behavioral or cognitive efforts that keep someone from thinking about a stressful problem or situation. Recent and lifetime experiences of PRD were positively associated with depressive symptoms for Black women who reported high levels of avoidant coping. Recent and lifetime experiences of PRD were negatively associated with depressive symptoms for Black women who reported low levels of avoidant coping (West et al., 2010).

A history of oppression and cultural mistrust toward the health care system are contributory factors for the negative attitudes that African Americans hold about seeking health services. There is also considerable stigma about mental illness in the African American community, which contributes to system- and individual-level barriers they face. Other system-level barriers African Americans face in seeking help for mental illness include accessibility issues such as inaccessible location, transportation problems, and lack of health insurance; issues related to availability of services, such as few opportunities for group counseling and in-home services; social issues, such as lack of child care, and poor quality of care, such as limited access to culturally competent clinicians and case management; and issues related to cultural matching, such as few opportunities to work with racial and ethnic minority clinicians (Ward, Clark, & Heidrich, 2009).

Given these attitudes and barriers, African Americans are more likely to cope with mental illness through informal support networks, such as family, friends, and church leaders. Ward et al. (2009) found that while some African American women in their study held beliefs about mental illness that were consistent with the *Diagnostic and Statistical Manual of Mental Disorders*, some of the women lacked awareness about mental illness or denied its existence in the African American community because they perceived Black people as strong. While the women believed that mental illness can be treated with individual or group counseling, they were ambivalent about the use of medication due to its possible side effects. The women were also in favor of various coping behaviors, including seeking professional help, using informal support networks, prayer, and avoidance (Ward et al., 2009).

Several studies indicate that a strong devotion to non-disclosure has for many years silenced Black women in personal crisis. Boyd (1990) observes that Black women underutilize mental health services because they have been taught that personal disclosure outside the Black community is synonymous with treason. A fear of being stereotyped and misunderstood by therapists who will view their cultural behaviors as pathological rather than legitimate survival responses is the reason why Black women avoid therapy, according to Boyd. Copeland (1982) notes that Black women have been exposed to societal conditioning that teaches them to be autonomous, resourceful, assertive, and strong. Therefore, when they do seek help, they frequently do not return for additional services.

Schreiber et al. (1998) observe that African Canadian women from the Caribbean are reluctant to seek psychiatric help because of the stigma surrounding mental illness in their culture, and the fear that they would suffer social isolation and sanctions in their community. Many of these women commented on how easy it was for white people in Canada to seek psychiatric care without fear of the consequences. Although a local social network of extended family and friends can provide a forum for these women to talk about the issues that impact their mental health, these women believed that there would be little support for those suffering from depression.

Class and education level influenced the type of help-seeking that African American women engage in, according to a study by Caldwell (1996). While less-educated and poor African American women were found to utilize more informal interventions (e.g., friends, family, and church), those with higher levels of education and consequently more exposure to and knowledge about the various resources available to them were more likely to utilize both informal and formal services (e.g., psychiatry, therapy, and counseling). Despite this, Dunston (1990) found that the high cost of health care and the restrictions on public mental health treatment may prevent both middle-class and working-class Black women from accessing formal sources of support.

Several authors have examined the specific coping styles of African Americans. Smyth and Yarandi (1996) used the 66-item Ways of Coping Questionnaire (Lazarus & Folkman, 1984) and found that African American women were most likely to engage in active coping, which involved seeking emotional support from a network of friends and family in order to cope with situational stress, a finding that is in keeping with the value that African Americans, in general, place on interdependence and cooperation. Respondents also engaged in avoidance strategies that comprised of solitary behaviors, repression, and denial, all of which have been shown to be ineffective for dealing with stress. Finally, the women in the study also minimized the situation, which is a coping strategy characterized by individualized defenses against threats aroused in specific situations.

Similarly, Lykes (1983) looked at how race, gender, and employment contexts played a role in African American women's choice of coping strategy, using oral histories of 35 African American women who made significant contributions to the Black community in the 1940s and 1950s. Findings show that African American women used a variety of coping styles to deal with discriminatory incidents. For example, those who were employed in white-dominant institutions tended to ignore racist incidents, while African American women employed in African American institutions used emotion-focused or avoidant strategies that were purposeful to confront the racist perpetrator.

Using a sample of 196 African American women who completed questionnaires, Shorter-Gooden (2004) examined the coping strategies Black women use to deal with the stress of racism and sexism. Similar to Lykes (1983), she found that African American women use a variety of coping strategies to deal with discriminatory encounters and experiences. These coping strategies include those that serve as ongoing internal and external resources, as well as those that arise out of discriminatory encounters and situations. The internal and external resources provide everyday buffers against discrimination, whereas the strategies arising out of encounters tend to be situation specific and are utilized when needed. Coping strategies that rely on internal resources are characterized by worldviews or belief systems that inform how women perceive themselves in the context of the larger world. They include reliance on faith and spirituality, identification with African heritage and African American culture, and self-esteem and self-worth. Coping strategies that rely on external resources are internalized belief systems and worldviews that include relying on the support of others, including family, partners, and friends. The coping strategies that arise out of specific situations are used to cope with more immediate and specific discriminatory events, and include role flexing, avoiding, and defending oneself. Role flexing refers to altering one's speech, behavior, or dress to fit in with the dominant group and reduce stereotypical assumptions of one's group. Avoiding involves distancing oneself from people, situations, or topic discussions around bias and prejudice. Defending oneself or standing up and fighting back includes challenging discriminatory actions through direct confrontation.

Several authors have shown that belief in a higher power has long played a significant role in offsetting the stresses and anxieties that may lead to depression and suicide among Black people and Black women (Bowen-Reid & Harrell, 2002; Boyd-Franklin, 1991; Brown & Gary, 1994; Handel, Black-Lopez, & Moergan, 1989; Paris, 1995; The Princeton Religion Research Center, 1987; Schreiber et al., 1998; Stolley & Koenig, 1997; Taylor & Chatters, 1988). Baer (1981) and Paris (1995) observe that a common belief in a transcendent, divine, and almighty power is one that Black people around the world share. The Princeton Religion Research Center (1987) found that women, the less educated, and those of lower social classes have been consistently associated with greater religious activity. Taylor and Chatters (1988) indicate that church members provide a substantial amount of support to many older African Americans.

Bowen-Reid and Harrell (2002) found that spirituality significantly buffered the relationship between perceived racial stress and psychological health outcomes, with individuals who were less spiritual experiencing negative health outcomes as a result of racial stress. Respondents who were more spiritual and who prayed and meditated were better able to cope with racist incidents and suffered less negative health outcomes. African Americans who are active in the church experience fewer depressive symptoms, according to Brown and Gary (1994). Handel et al. (1989) conclude that African American women who do not participate in religious activities have higher levels of psychological distress than those who do. Boyd-Franklin (1991, p. 37) also stated that spirituality provides a major psychological coping or survival mechanism for many African American women who experience psychological conflict due to issues of their own sexuality and morality. Schreiber et al. (1998) found that while Canadian Black women of Caribbean descent depended quite heavily on God, they varied in their belief in Christian doctrine. At one end of the continuum were women who "gave their troubles over" to God, seeking solace and comfort in prayer. At the other end of the continuum were those women who believed in a God who gave them strength and faith to do what they needed to do to solve their problems.

While reliance on a higher power for coping with emotional problems should never be dismissed, it is often not the solution for addressing more serious and chronic forms of mental illness. Therefore, it is crucial that mental health services begin to address in more serious ways the mental health problems that Black women and other racialized women face. The significant barriers that Black women experience accessing appropriate mental health services are often due to systemic discrimination, which is often not named and is, for the most part, unintentional. For Black women, discrimination based on race and gender is the key factor in producing mental health problems and in determining the quality of the clinical services they receive.

Feminist therapy emerged in the 1970s as a response to second-wave feminism, which was premised on addressing power inequities by guaranteeing economic and social equality regardless of gender. It focused on the impacts of traditional, patriarchal structures of the therapeutic process on women, including power inequities in the male therapist–female client relationship, in which the man is seen as the expert and the woman is expected to adhere to traditional and patriarchal gender norms and roles (Jones & Guy-Sheftall, 2015). What has been less acknowledged in the practice of and research on feminist therapy are the experiences of Black women. The realities of Black women have been misguided and misconstrued at the conceptual, theoretical, and methodological levels in favor of a focus on the experiences of middle-class white women.

Black feminist therapists have advocated for conceptual frameworks and therapeutic processes that acknowledge the multiple oppressions that operate simultaneously to impact the mental health of Black women, including race, gender, class, sexual orientation, and other "isms" (Jones & Guy-Sheftall, 2015). Black feminist therapists have also supported therapeutic interventions that help Black women to move beyond models of pathology to those of risk, reliance, and wellness by guiding them in sorting out their personal struggles from experiences of racism, sexism, classism, and homophobia that constrain them. Therapeutic interventions for Black women must also provide Black women with opportunities to think through how negative psychological symptoms such as depression, anxiety, low self-esteem, and decreased sense of mastery and control are linked to the internalization of stereotypes about Black womanhood. In other words, strategies that enable Black women to engage in self-actualization promote their liberation from both the internal psychological distress and the societal barriers that impact Black women in unique ways (Jones & Guy-Sheftall, 2015).

Summary

Black women's structural location at the intersection of race, gender, and class has not only informed societal representations of Black womanhood but also led to the development of a Black feminist consciousness that embodies both the internalization of damaging myths that have had damaging effects on Black women's sense of self and mental well-being, and a source for coping with, managing, and seeking help for mental health problems.

Pervasive stereotypes that construe Black women as Mammy, Matriarch, Welfare Mother, Jezebel, Angry Black Woman, and Black Superwoman have their roots in slavery and persist in every aspect of social life today. While Black women have internalized these damaging and controlling archetypes of Black womanhood, they have also engaged in efforts to invert, subvert, and resist them. In many ways, then, the development of a Black feminist consciousness is rooted both in the internalization of these stereotypes and the agency Black women have demonstrated to challenge myth-making that have impacted their self-esteem and sense of self. In other words, a Black feminist consciousness highlights the paradox of archetypes that present Black women as resilient, strong, and invulnerable and, therefore, hesitant to seek help for mental illness, but that also serve as a kind of reservoir for survival and self-efficacy. Therefore, while the mental health problems Black women experience can be attributed to the multiple forms of structural violence they are subjected to, it is precisely their self-consciousness as Black women who are oppressed by race and gender that they draw from to cope with, manage, and seek help for mental health problems.

For many Black women, non-disclosure and silence have characterized their response to the mental health issues they face, primarily due to a history of oppression and cultural mistrust Black people have long had toward healthcare. Other factors deterring or preventing Black people from seeking help from mental health services include stigma about mental illness in their community, inaccessible transportation, lack of health insurance, lack of child care, limited access to culturally competent clinicians, and few opportunities to work with racial and ethnic minority clinicians. In addition, Black people have traditionally relied on religion, faith, the church, and their belief in a higher power to offset the stresses and anxieties that may lead to depression and other mental health problems.

It is important to note, however, that though reliance on a higher power for dealing with emotional problems should not be undermined, it should not be the only option for addressing mental health problems, particularly those that are more serious and chronic. Therapeutic interventions that incorporate a Black feminist analysis may be useful in addressing the mental health problems experienced by Black women because they not only acknowledge the ways in which multiple oppressions impact the mental health of Black women but also guide Black women in moving beyond models of pathology to processes of self-definition which equip them with the tools to reject externally defined controlling images and expectations of Black women and instead construct individual and collective definitions of Black womanhood.

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Chapter 3
Disability Culture

Alexis Buettgen and Rachel Gorman

Purpose Statement

In this chapter, you will learn about disability in the context of cultural participation and community leadership. The chapter highlights a few of the leading Canadian organizers and activists involved in the disability justice and rights movements. From a critical disability studies perspective, the chapter will explain how influential the social environment, and respect for culture and diversity is to individuals with disabilities in society. The chapter also draws from community psychology to bring attention to the need for practitioner training that is informed by the voices and experiences of disabled people themselves. Here we aspire to promote a new understanding of disability in terms of various cultural norms and inclusion of diversity.

Introduction: What Is Disability Culture?

Disabled people are integral parts of our families, communities, and cultures. In many cultural contexts, especially western capitalist national contexts, disabled people face discrimination in many aspects of social and cultural life, including

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education, the labor market, healthcare, media representation, family life, and the community. In western capitalist contexts, discrimination is explained as being the "fault" or "problem" of the person experiencing the discrimination. In mainstream cultural contexts, disability is understood overwhelmingly as a problem of individual biology, and often as an individual tragedy. In fact, there is no such thing as a self-evident, essential "disability" that exists outside of its social, cultural, and historical context. Disability is therefore always about culture. Furthermore, impairment and difference, and ideas about impairment and difference, exist across and within most cultures. Finally, disabled people[1] have organized locally and internationally to fight disability discrimination, also known as ableism. Disability social justice movements have from their inception, criticized the ways that disabled people are misrepresented and ignored in mainstream arts, culture, and media.

Defining Disability

Because it is a historically and culturally contingent and contested social category, Disability is surprisingly difficult to define. The UN Convention on the Rights of Persons with Disabilities (UNCRPD) states:

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Definitions also vary by country. For example, some states have disability laws and policies that include people with mental health labels, while others do not. Anti-psychiatry, ex-patient, and Mad movements have been only recently included in disability movements. Women and trans-people struggled for a long time to get people with chronic illness recognized as part of the disability community. Disability justice activists have struggled to make space for disabilities that are disproportionately experienced by Black, Indigenous and people of color, including conditions related to environmental toxicity, war, and experiences of violence, exploitation, and racism.

Over the past 20 years, disability social justice movements have shifted from a focus on legal rights and policy change toward a greater emphasis on cultural production. Disabled artist/activists have been articulating an aesthetic that challenges social norms as well as the boundaries of the artistic disciplines that they are engaging in. Disabled artists have been fighting for access to arts education and art production, and have been making art that contributes to social and cultural change. At the heart of the disability arts movement has been the belief that negative and absent representations of disabled people are intrinsic to disability oppression, and the

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[1] Some activists prefer people first language, and therefore prefer the term "people with disabilities." Other activists argue that they are proud to be disabled, and that therefore they prefer the term "disabled people."

belief that the democratization of art production is necessary for us to generate positive representations of disabled people.

The concept of disability culture captures the idea that people with lived experiences of disability in general, and disability discrimination in particular, share some cultural reference points. The concept also recognizes that disability justice movements and disability rights movements are social and cultural in nature, and that collectively, these movements may produce new "cultures" or ways of understanding and being in the world. The term disability culture can be misleading in that it can imply that disability stands in for culture, or that disability is one culture in a multicultural society. In reality, people from many cultural, linguistic, and national backgrounds have contributed to the international development of disability social justice movements and disability arts.

Deaf culture both predates and is contemporaneous with disability culture, and is deeply rooted in shared sign language and, often, shared experiences of growing up in schools for the Deaf, which have often also been residential. Some Deaf community members and organizers consider themselves to be part of a cultural group and do not consider themselves disabled—in this way, Deaf culture is related to, but in no way reducible to the idea disability culture. Sign languages—for example, American Sign Language (ASL); Langue des signes du Québec (LSQ)—are living languages, and Deaf people have produced genres of art in these languages, including Deaf poetry and Deaf theater (Padden & Humphries, 2005). These Deaf cultures have themselves been organized through histories of prevailing social cultural power relations; for example, twentieth-century US Deaf African Americans experience segregation in their schools and Deaf cultural organizations (Burch, 2002).

In an early articulation of disability culture, Steven Brown (2002) notes that disability culture is in part a response to a history of oppression of disabled people, long described as "in-valid, impaired, limited, crippled" (p. 35). Disability culture reclaims disability identity with pride, empowerment, and awareness.

> For years we have discussed integration like it was our business to fit in with mainstream society. As we become more aware of our own unique gifts some of us have also become more convinced that this is a backwards perspective. It is absolutely not our job it fit into mainstream society. Rather it is our destiny to demonstrate to mainstream society that it is to their benefit to figure out that we come attached to our wheelchairs, our ventilators, our canes, our hearing aids, etc. and to receive the benefit of our knowledge and experience mainstream society needs to figure not how we fit in, but how we can be of benefit exactly the way we are (Brown, 2002, p. 48).

Disabled people generate art, music, literature, and other expressions of their lives and culture infused by their experience of disability. This expression of disability values interdependence over independence and diversity over sameness. Disability arts and culture movements have emerged as collective, and often live, performance-based endeavors, often taking place at dedicated disability arts festivals and community events (Abbas, Church, Frazee, & Panitch, 2004).

In the past decade in the North American context, disabled people of color, as well as disabled LGBTQ people, have developed approaches to disability organizing and disability arts. People of color and LGBTQ people had always been part of disability social justice and arts movements; however, their contributions were often marginalized within disability movements, often in retrospect as histories of the movement were being written (Bell, 2006).

Highlighting Intersectionality

Ethno-Racial People with Disabilities Coalition of Ontario (ERDCO)

ERDCO is a cross-disability, non-profit organization that was established in 1993 to address the needs and issues of ethno-racial people with disabilities. ERDCO's mission is to advance the social inclusion, rights, and diverse voices of ethno-racial people with disabilities through advocacy, education, research, resource development, and partnerships that reduce barriers to their full community participation. This work is guided by the principles of anti-racism, anti-oppression, universal access, equity, and inclusion. (See www.erdco.ca or visit their Facebook page for more information.)

These new approaches have sparked exciting arts projects, like San Francisco-based Sins Invalid,

> Sins Invalid is a performance project that incubates and celebrates artists with disabilities, centralizing artists of color and queer and gender-variant artists as communities who have been historically marginalized. Our performance work explores the themes of sexuality, embodiment and the disabled body… Sins Invalid is committed to social and economic justice for all disabled people – in lockdowns, in shelters, on the streets, visibly disabled, invisibly disabled, sensory minority, environmentally injured, psychiatric survivors – moving beyond individual legal rights to collective human rights. Our stories, imbedded in analysis, offer paths from identity politics to unity amongst all oppressed people, laying a foundation for a collective claim of liberation and beauty.[2]

As with art that emerges from social movements, disability arts and culture movements reflect the social, cultural, and political struggles that diverse disabled people engage in. Disability culture is the difference between being alone, isolated, and individualized, and being in community (Kuppers, 2011).

Disability in the Mainstream

There has been significant progress over the past few decades to expose disability as something other than an individual deficiency and to open up the possibilities for re-conceptualization. The field of disability studies arose with the purpose of deconstructing, re-examining, and building a new understanding of disability in society (e.g., Gleeson, 1997; Linton, 1998; Oliver, 1990; Rioux, 2003; Scull, 1984; Szasz, 1974). The field has developed a broad conceptualization of its goals and purpose

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[2] Sins Invalid "Our mission" and "Our vision" http://www.sinsinvalid.org/, accessed June 12, 2016.

which is to seek full citizenship for disabled people and respect for disability as an inherent aspect of human diversity (Devlin & Pothier, 2006). Based on the need for systemic change, these goals require radical transformation in the way society perceives and acts toward disabled people.

Critical disability studies bring evidence of the social construction of disability to the forefront of thinking about "normal" versus "abnormal" and contend that achieving equality, well-being, and empowerment of disabled people is not an issue of medicine, health, rehabilitation, or charity; rather it is a question of politics, power, and powerlessness (Devlin & Pothier, 2006). Disability is understood through models of thought and action that are pervasive at certain times or sites in culture (Withers, 2012). According to Withers (2012), a disabled activist and author, there are many ways of inventing and understanding disability "because disability is not a fixed category. Rather, it is a fluid definition that depends not only on the context in which it is defined, but also who defines it" (p. 3). To explicate this fluidity, this chapter has begun to highlight the diversity of disability culture in the arts and across ethno-racial cultures. We would now like to juxtapose these images with other ways of understanding disability which depict pity, tragedy, and heroism.

Charity and the Pitiful Disabled The charity and/or tragedy approach to disability depicts disabled people as victims of circumstance who are deserving of pity and in need of help via welfare approaches. This view hearkens back to the English Poor Law Amendment Act of 1834 (i.e., New Poor Laws) such that during the years of the New Poor Laws in Britain, the "undeserving" and the "deserving" poor were distinguished as two separate groups (Borsay, 2005). The "deserving" included disabled people who were excused responsibility for their poverty because of their physical, cognitive, or sensory impairments. The "deserving" were offered accommodation and employment in institutions known as workhouses. According to Borsay, the purpose of the workhouse was "to implement the principle of economic rationality by extracting labour from the [undeserving poor] able bodied unemployed and teaching them the virtues of the work ethic" (p. 42). Yet the able-bodied unemployed were the minority and the majority were disabled people, some of whom were compulsorily detained in these workhouses because of mental impairment (Wright, 2000). This view of disabled people as incapable of employment and deserving social welfare to soften the impacts of poverty continues to hold today (Prince, 2009). Rioux and Prince (2002) argue that the categorization of disabled people as the deserving poor exemplifies the view of disability as an individual impairment or pathology. They describe how this categorization means that in today's society, disabled people are treated as unemployable *objects* of charity. Disability is based in individual bodies that are presented "as innocent victims of the tragic disabilities that they bear" (Withers, 2012, p. 58). Disability that is viewed as an individual tragedy leads to solutions that aim to eliminate, remove, or reduce disability from society rather than address social barriers.

Mercy Killing or Murder: The Tracy Latimer Story

In 2000, Michele Decottignies, founder and director of *Stage Left Productions* in Calgary, gave a forum theater workshop that included people who had been labeled with intellectual disabilities. "Our ultimate goal was to research, develop, workshop, rehearse and perform a multimedia exploration of the death of Tracy Latimer, a girl with cerebral palsy who was killed by her father in 1993" (Decottignies, 2005, p. 67). Robert Latimer's crime was tried in the courts, and debated in the national media, as a "mercy killing"—reflecting a dangerous and genocidal public perception that disabled people's lives weren't worth living, and that non-disabled people were somehow justified in murdering disabled people. With Michele as writer and director, the play was developed and performed by a cast that included five actors labeled with intellectual disabilities, one of whom had disabilities similar to Tracy Latimer's. The play premiered in Calgary in 2001, and the script was published in the *Canadian Theatre Review* in 2005. Michele explains as follows:

> We compiled over 10,000 pages of material, including Internet postings, a published work of non-fiction about the Latimer case, an unpublished Master's thesis, trial transcripts and media reports. We also conducted many hours of personal interviews with people affected by the case.

(Decottignies, 2005, p. 69)

Ultimately, the script captured the responses and perspectives of the disabled actors, who had the final say over their roles and the statements they make in the play. In some of the most powerful scenes, the disabled chorus interrupts the judge and lawyer, who are speaking lines taken from the trial transcripts. The actors "talk back" to a legal system and to a world that was refusing to seek justice for Tracy's murder. Visit www.stageleftists.weebly.com to learn more about the work of Stage Left Productions (Fig. 3.1). For more information on Stage Left Productions, visit www.stage-left.org.

Fig. 3.1 Donald Norman, James Doyle, and Lee Davis "object" as the Lawyer (Stafford Perry) protests and the Judge (Laurel Oneil) lords over them all. Photo courtesy of Stage Left Productions

Today, many disability charity organizations continue to portray the tragic lives of disabled people, contrasting the perspectives presented by organizations like Stage Left Productions described above. Most disability charity organizations ask people to end the suffering of disabled people by donating or pledging money to find a cure. This ask was exemplified in the long running Jerry Lewis Telethon for muscular dystrophy. Since 1952, this telethon raised an estimated $2 billion for the Muscular Dystrophy Association (MDA) whose stated aim is to fight "to free individuals—and the families who love them—from the devastating effects of muscular dystrophy" (https://www.mda.org/). As Withers (2012) describes it,

> The story of the MDA telethon…remains relatively similar from year to year. Jerry Lewis tells some jokes, musicians, dancers and other acts perform, and in between we hear of the tragedy that is muscular dystrophy. Some of this we are told by the host, but some we are shown through the sad eyes of the children who are trotted out across the telethon stage. We are told about these children, their sad lives, the hopes that they have that may never be realized and how they might die terribly young (p. 62).

This is one example of a countless number of initiatives and organizations that support the quest to cure disability "to the exclusion of supporting independent living and civil rights for disabled people" (Clare, 1999, p. 104). There is no critique of the political, social, and economic system, but rather the individual's capacity to function within that system. According to Withers (2012), the North American charity approach often constructs disabled people as white, pitiful children. Withers argues this is because children, unlike adults with disabilities, are not perceived as economic drains on society. Children are viewed as potential contributors to society *if* their productive citizenry can be realized. For example, Withers describes how the Cystic Fibrosis Foundation uses children to raise funds:

> One ad shows a blond seven-year-old boy. Above him are the words of Broc Glover, an accomplished motocross racer and the child's father: 'Some parents dream about their kids growing up to be motorcycle champions. I just dream about my son getting a chance to grow up.' The next text, from the cute, sad boy reads, 'Please help my dad find a cure' (Broc Glover's Breathe Easy Ride Against Cystic Fibrosis, 2009, n.p.). The consumer is implored to make a donation to help this adorable, innocent child have a future. The ad does not mention that most kids with cystic fibrosis do grow up to become adults, with the mean age being 37.4 years old (Medline Plus, n.d.). (p. 66).

The disproportionate representation of white disabled people in North American charity advertising negates the fact that approximately 80% of disabled people live in the Global South (WHO, 2006). This white depiction also fails to recognize that racialized communities in North America are disproportionately labeled as disabled. On the other hand, there are other charities that almost exclusively depict Black children in their advertising. As Withers describes,

> You have seen these ads: small Black children with wide, vacant eyes and distended bellies, sometimes with flies on them, sometimes in bed staring at the camera. These children, disabled because of their hunger and lack of health care (or, sometimes, because of landmines) implore the (white) North American viewer to give their pity and money…Pity is marketed to us at the expense of the many complexities that exist about disability and the many truths that define what it means to be disabled (p. 68).

In essence, pity sells. To sell us tragedy, charities construct visual cues about what disability looks like in order to evoke the desired emotional response of pity and sadness. In other cases disability is portrayed as a feat of heroism and resilience in another juxtaposition of disability and achievement.

The Heroic Abled-Disabled The abled-disabled are those who signify resiliency by demonstrating their ability to participate in society as normally as possible. The abled-disabled demonstrably exceed their disability limitations, often through the use and forms of prosthetics that leave the majority of disabled people behind (Mitchell & Snyder, 2015). Mitchell and Snyder (2015) describe how the image of buffed, muscular, yet technologically supplemented bodies represents the promise to transcend the limitations of impairments by a medicalized culture of disability.

Mitchell and Snyder (2016) present the image of Oscar Pistorius, a double amputee turned Paralympic then Olympic athlete, as an example of the supercrip/abled-disabled. “Pistorius’ prowess for running on prosthetic coils…was commonly pictured as embodying the hyper-capacity of a field-and-track machine; a post-organismic cyborg biology enabled to surpass the limits of the normatively capacitated (two-legged variety)” (p. 6). Pistorius is displayed as an engineering feat of mechanic supplementation, leaving the viewer with a focus on the need or desire for technological compensation.

Withers (2012) suggests that charities exploit the image of the supercrip/abled-disabled as a promise of what is possible, given enough donations. This inspirational promise also hinges on the notion that *overcoming*, rather than embracing, disability is beneficial to disabled people. As Withers describes,

> The lives of disabled people run the gamut, like everyone, between normal, extraordinary, monotonous, bizarre, dull, eccentric, fantastic, boring and everything in between. Our lives are not constrained to the aspirations of being abled-disabled or to pity and inadequacy. Our motives and ambitions are not dictated by this dichotomy (while we can internalize it and it can heavily influence our sense of self). However, the charity industry constructs disabled lives in this way rather than depicting our lives as the beautiful, diverse, difficult, rewarding lives that they are. While the supercrip and the infantilized, white, pitiful disabled person are problematic and damaging sales pitches, the industry also markets false ideas about resistance and change. They tell us that only you can make the difference that is needed to help make disabled people’s lives better (p. 72).

Titchkosky (2003) similarly writes that the images and stories of the abled-disabled demonstrate that disabled people can fit in and take up an appearance that is undoubtedly oriented to an unquestioned normalcy. Thus, the abled-disabled are portrayed to elicit feelings of inspiration in others.

The heroic disabled are those who are able to achieve in life, despite their disability. Disability and achievement are frequently presented as a contradiction, such that any person with a disability who overcomes this contradiction is heroic (Clare, 1999). Disabled people may evoke inspiration for doing normal things like getting married, getting a job, or playing sports. Disabled people may also evoke inspiration for extraordinary achievements such as pushing a wheelchair across 34 countries to raise money for spinal cord injuries (Rick Hansen), or embarking on a cross-Canada run with one amputated leg to raise money and awareness for cancer research (Terry Fox). These charity approaches that use the image of the abled-disabled assert that curing the individual is the change we need (Withers, 2012).

Charities and organizations that take up this curing approach either ignore or are complicit in the social problems and barriers that create the notion of abnormality, systemic discrimination, and oppression. This is not to say that impairment does not pose challenges for individuals, nor that the experience of impairment may implore the need for support and relief. This does, however, point to the need to address the root of the problems affecting disabled people, such as racism, poverty, and ableism. According to Withers (2012), the charity/tragedy/abled-disabled approach to disability leads to a quest for individual change rather than a collective act of resistance. There is no examination or identification of the systemic obstacles to employment, rampant discrimination and prejudice, lack of accommodations, segregation, etc. which keep people from meaningful participation in community and social life. Many hope that one day disabled people can live ordinary, not tragic or heroic, lives (e.g., Clare, 1999).

Garland-Thomson (2011) recently built on these ideas to consider the utility of the concept of "misfit" within the intersection of feminism and disability studies which she suggests,

> [R]eflects the shift in feminist theory from an emphasis on the discursive toward the material by centering its analytical focus on the co-constituting relationship between flesh and environment. The materiality that matters in this perspective involves the encounter between bodies in particular shapes and capabilities and the particular shape and structure of the world (p. 594).

Garland-Thomson argues that although "misfitting" can lead to segregation, exclusion from the rights of citizenship, and alienation from a majority community, "it can also foster intense awareness of social injustice and the formation of a community of misfits that can collaborate to achieve a more liberatory politics and praxis" (p. 597). Several other authors argue that disability exposes the western fantasy of invulnerability, liberal individualism, and self-mastery, as well as threatens the illusion of absolute sovereignty of the embodied self (e.g., Shildrick, 2009). It is important then to think about where and how disability fits with the concept of well-being.

Disability and the Social Determinants of Well-Being

Historically and currently, much of the mainstream literature on disability focuses on the need to "cure," "modify," "rehabilitate," and train individuals with disabilities to better fit into society. This places the onus of responsibility on the individual rather than looking to societal norms, values, and practices that could be modified to better accommodate and include disabled people. Critical disability theorists, researchers, and activists have raised key questions about the individualization and medicalization of disability within the context of capitalist society. There is now a growing body of evidence to help explain systemic marginalization, oppression, and the deprivation of disabled people (e.g., Gleeson, 1997; Linton, 1998; Oliver, 1990; Rioux, 2003; Scull, 1984; Szasz, 1974). This critical approach, known as the social model, has become internationally influential and changed the way disabled people see themselves and organize for social change.

The social model separates “disability” from “impairment” such that disability is a consequence of the way society is organized, rather than a person’s impairment or difference. The social model begins with a definition of impairment as “lacking all or part of a limb, organism or mechanism of the body” (Oliver, 1996, p. 22) which also includes psycho-social, intellectual, and sensory impairments. Disability is then created by a society that limits and restricts the full participation of impaired people. For example, if one’s impairment is a limited use of their legs, they may use a wheelchair. If the wheelchair user wants to get into a building with steps at the entrance, they are disabled by not being able to enter a building because there is no ramp. Their disability is not the limited use of their legs; it is the lack of physical access to the building. The social model changes the focus of the problem of disability away from the impaired individual and looks to societal norms, practices, and structures to understand the barriers disabled people experience. In contrast to the charity approaches described earlier, this approach focuses on the social, attitudinal, and physical barriers that restrict the life choices and participation of disabled people.

While the social model of disability has made strides in shifting the focus from the individual to society, there are critiques of its impairment/disability binary (e.g., Shakespeare, 2006; Shildrick, 2009; Withers, 2012). These critiques highlight the resistance to paradigm change and the evolving conceptualization of disability. For example, Tom Shakespeare (2006) believes that the social model goes too far in delegating disability issues to external barriers and challenges. He believes that individual impairment must be given greater consideration in our understanding of disability because one’s impairment can profoundly influence an individual’s daily experience. Impairments have real impacts for health and individual capacity, and different impairments generate different responses from the broader cultural and social milieu.

As the social model has developed, there has also been a rise in profile of disability rights at both the national and international levels. Some key events have contributed to this rise such as the inclusion of disability in the Canadian Charter of Rights and Freedoms in 1982, the establishment of the Americans with Disabilities Act (ADA) in 1990, and the adoption of the UNCRPD in 2006. The human rights perspective means viewing people with disabilities as subjects and not as objects. This is a shift from viewing disabled people as problems toward viewing them as holders of rights. “The debate about the rights of the disabled is therefore connected to a larger debate about the place of difference in society” (Quinn & Degener, 2002, p. 1). The disability rights paradigm emphasizes the equal dignity of all persons and acknowledges their autonomy in directing their own development (Stein, 2007).

For example, the UNCRPD provides a roadmap for service provision and social policies that goes beyond charity and protection to advance the rights of people with disabilities. Harpur (2012) points out that the UNCRPD effectively builds on the social model and provides scholarship and politics with a common focus. Harpur notes that existing human rights conventions (e.g., CEDAW and ICESCR) provide general protections to all persons but have had limited success ensuring people with disabilities can exercise their rights. Thus, the advent of the UNCRPD increases focus on the implementation of rights for people with disabilities and provides a benchmark for good governance by including the voices of people with disabilities in the process.

The Lived Experiences of Disabled People Around the world, disabled people have fewer economic opportunities, higher rates of poverty, poorer health, and lower education than people without disabilities (World Health Organization & World Bank, 2011). In Canada, access to adequate income is a problem for upwards of two million disabled people (Prince, 2009). Further, inaccessible built environments in towns, suburbs, and cities keep disabled people from entering and accessing public spaces. Disabled people confront discrimination, prejudice, and persistent barriers to participation in politics, education, employment, and other realms of community living (Prince, 2009).

Disability Rights in Practice

Rabia Khedr: Canadian Association of Muslims with Disabilities

Rabia Khedr is founder and executive director of the Canadian Association of Muslims with Disabilities (CAM-D). CAM-D advocates for the rights of people with disabilities and Deaf people to participate fully in spiritual and cultural centers and schools. Guided by universal values, CAM-D is non-denominational, national organization focusing on community-based approaches for building capacity to meet the needs of people with disabilities and Deaf people and their families. As the founder, Rabia has spent years advocating for her two brothers, who have been labeled with intellectual disabilities, as well as speaking from her own experience of being blind. On her identity, Rabia says the following:

> I am a hyphen with many hijabs: Rabia Khedr, Muslim-Punjabi-Pakistani-Canadian, woman, wife, mother of four, sibling of individuals with intellectual disabilities, facilitator, consultant, human rights advocate, etc. and person with a disability—blind. The world sees me as a blind, brown woman or a brown, blind woman. The jury is not in on the order of which comes first—blind or brown.

Rabia was also a founding member of Ethno-Racial People with Disabilities Coalition of Ontario (ERDCO) in the 1900s, contributing to its development as Senior Project Coordinator, Chair, Special Consultant to the Board of Directors, and volunteer. ERDCO has been an innovator in community-based research on intersectionality that honors the experiences of people of color with disabilities. Rabia was awarded a Queen Elizabeth Diamond Jubilee Medal in 2012, earned her MA in Critical Disability Studies at York University in 2013, ran as a candidate for Mississauga City Council in 2014, and was appointed to the Ontario Human Rights Commission in 2016 (Fig. 3.2).

Fig. 3.2 Rabia Khedr. Photo courtesy of Hossam Khedr

In Canada, disabled people comprise approximately 15% of the population which is more than five million people (Devlin & Pothier, 2006). Despite these numbers, disabled Canadians are largely considered *absent citizens* (Prince, 2009). Disabled people have historically been made absent through processes of infanticide, eugenics, forced sterilization, institutionalization, and immigration policies that prevent entry and inclusion in Canadian life. While some of these processes have transformed over the years, many disabled people continue to experience significant cultural, material, and political disadvantages. Similarly, White (2005) points out that across North America,

> Many disabled people report their community experience to be disconcerting. Experiences range from being invisible and unnoticed by others to being viewed as the objects of pity. Disabled people are often thought to be incapable of contributing meaningfully to society. If they are invited to participate, they feel it is a great burden to continually prove themselves worthy of such involvement (p. 405).

The concept and barrier of ableism presents one of the greatest challenges facing disabled people. “Ableism is a non-factual negative judgment about the attributes and capabilities of an individual with a disabling condition” (White, 2005, p. 406). Ableism takes many forms including practices and dominant attitudes in society that devalue and limit the potential of disabled people. Ableism is a form of discrimination in favor of able-bodied people which varies in relation to different definitions of normalcy. Disabled people have had to contend with assigned identification and categorical labels based on their diagnoses and deficits. Often, disabled people are labeled and viewed by society as their impairment first, and as a person second. The words used to identify and describe specific groups affect how they are perceived and valued in a society whether the words are used to describe ethnicity, gender, religion, sexuality, or level of ability (White, 2005). These and many other issues foster the experience of oppression and marginalization, and prevent disabled people from participating in community, economic, social, and political life.

Poverty and Disability Negative attitudes, low expectations, and structural barriers often limit opportunities for education, training, employment, and income generation for disabled people. Such exclusion from education and employment opportunities contributes, in part, to the profound poverty of disabled people (Elwan, 1999; Filmer, 2008; Oliver, 1990; Yeo & Moore, 2003). Access to education is affected by physical accessibility of training and education institutions, availability of support services (e.g., Braille, sign language, and special education for learning impairments), teacher and peer attitudes, as well as family finances (e.g., Buettgen et al., 2015). Moreover, pedagogical theory can be inherently exclusionary within "flawed notions of meritocracy [as] powerful inhibitors to the right to education for those who are perceived as 'different'" (Rioux, 2013, p. 131). Public and governmental attitudes reflect a hegemony favoring the idea that the economic well-being of nations is dependent on schools training a productive labor force which often excludes disabled people (Rioux, 2013). The inference here is that disability is a condition inherent to an individual rather than the structural and pedagogical practices of education and training institutions. However, focusing on the skill development of individuals does not address the wider issue of discrimination toward disabled people, nor does it necessarily meet the needs of employers or the labor market.

Highlighting Intersectionality

DisAbled Women's Network Canada (DAWN-RAFH)

In 1985, 17 women with disabilities from across Canada met in Ottawa for an inaugural meeting that would lead to the formation of the DisAbled Women's Network of Canada (DAWN). The foundation was set for a national, feminist, cross-disability organization that has provided opportunities for self-determination and leadership development for women with disabilities for 30 years. In the early years, DAWN Canada produced a large number of resources and influential research that still stands as a framework for understanding the issues faced by women with disabilities. Today, DAWN continues their mission to end the poverty, isolation, discrimination, and violence experienced by Canadian women with disabilities and Deaf women. DAWN Canada remains the only national feminist disability organization in the country and one of only a handful in the world that works toward the advancement and inclusion of women and girls with disabilities and Deaf women. Grounded in the lived experiences of women with disabilities and Deaf women, and using an evidence-based approach, DAWN Canada works to create change at a systemic level in order to directly improve the quality of life for women with disabilities. DAWN amplifies the voice of women with disabilities and Deaf women by ensuring that they are represented at decision-making tables in the areas that matter most, including violence prevention, health equity, and access to justice. DAWN works to increase the capacity of women with disabilities and Deaf women in their communities to support their leadership in articulating their needs. (See http://www.dawncanada.net/ for more information.)

Employment can be a pathway to increased income, empowerment, quality of life, and well-being. But for disabled people, job opportunities are limited and employment supports often are inadequate (e.g., Barnes & Mercer, 2010; Oliver, 1990; Devlin & Pothier, 2006; Thomas, 1999). In Canada, previous research suggests that when disabled people are able to secure employment, they are disproportionately concentrated in precarious work such as temporary or part-time jobs that are poorly paid with few opportunities for promotion (Law Commission of Ontario, 2012; Wilton, 2006). Some evidence suggests that disabled people are not engaged in these forms of employment voluntarily and many would prefer full-time permanent work (Tompa et al., 2007). Low levels of individual and household income for Canadians with disabilities contribute and shape their experience of precariousness. Further, the low income available in employment coupled with systemic discrimination in the workforce and a lack of appropriate workplace accommodations and supports can be a disincentive for disabled people to enter the workforce, particularly where they may be eligible for government income support (Law Commission of Ontario, 2012).

Disabled people experience disproportionately high rates of poverty due, in part, to the limited opportunities for education, skills development, and a job that earns a competitive income. Being poor dramatically increases the likelihood of getting or worsening an impairment, and becoming further disabled. In this way, disability and poverty operate in a cycle that is hard for people to escape (Elwan, 1999; Filmer, 2008; Oliver, 1990; Yeo & Moore, 2003). As the social model explicates, impairment can lead to disability and discrimination. Disability and discrimination can then lead to:

- exclusion from education and employment opportunities
- limited social contacts
- low expectations from community and of self
- exclusion from political and legal processes
- exclusion from health care
- lack of resources for potentially high costs associated with impairment (e.g., care and support services)

The experience of exclusion, limited contacts, and lack of support can lead to individuals with fewer skills, low self-esteem, a lack of ability to assert rights, and poorer physical and mental health. Once in this position, the potential for income generating activities (e.g., employment or entrepreneurship) is further reduced and leads to income and chronic poverty.

Chronic poverty leads to exclusion in the forms of:

- limited access to education and employment
- limited access to quality housing
- exclusion from political and legal processes
- limited access to quality health care
- insufficient or unhealthy food

Those who experience these forms of exclusion are often forced to accept hazardous and/or precarious working conditions, live in unhealthy, overcrowded, or unsafe living situations, a lack of ability to assert rights, as well as the risk of malnutrition, poorer health, and physical weakness. These conditions can present higher risk of illness, accident, and impairment which can lead to further disablement and discrimination and perpetuates the cycle of exclusion, loss of income, and poverty.

An examination of the disability–poverty cycle can lead one to focus on the need for impairment prevention. However, many in the disability community do not see this as a viable solution to their poverty, nor are many impairments preventable or treatable. As Yeo and Moore (2003) point out,

> Medical intervention should not be seen as an alternative to building an inclusive environment. It is not inevitable that impairment, illness or injury lead to discrimination and disability. It is at this point that the cycle of disability and poverty can be broken, and on this relationship that there has been insufficient focus (p. 575).

Krogh and Johnson (2006) argue that participation of the disability community in policy making is a precondition for the design and implementation of equitable and democratic policies that address poverty as a systemic issue. But to lobby for policy change, the relative power of disability groups needs to be compared to other groups of actors in the social field at issue. Krogh and Johnson point out that it is difficult to effect change without sufficient social, economic, or cultural power, or if this power is not valued by policy makers.

The disability culture movement appears to represent the possibilities for the way toward social change. Addressing the social determinants of well-being and the challenges of poverty for disabled people can start with solid values based on the principles of inclusion, commitment and empowerment, and ecology or holism. These principles are at the core of disability studies, disability culture, and overlap with psychological theory, research and practice based in community. The implementation of these principles can facilitate transformative change practices that help to break the cycle of poverty and disability, and promote the social determinants of well-being.

Disability and the Clinical Encounter

As we have described above, the medical model is the primary paradigm through which disability is understood in mainstream society. Issues of disability have been given a great deal of attention in the academic fields of medicine and psychology (Oliver, 1990). As a result, issues of disability revolve around identifying, understanding, and controlling the illness, physical condition, or deviant anatomy that is part of an individual's own body. Under this model, disability is a medical issue, inherent in an individual, which is worthy of resources that work toward a cure, treatment, or prevention of disability and impairment.

The medical model calls for the use of diagnostic tools to identify pathology and develop appropriate interventions in order to cure or minimize it (Withers, 2012). Criticisms of the model are based on the failure of medical and other professionals to involve disabled people in a meaningful way, except as passive objects of intervention, treatment, and rehabilitation (e.g., Finkelstein, 1980; Oliver, 1990). According to Oliver (1990), research and the development of knowledge on disability have been exclusive and non-participatory. As a result, the medical model has had oppressive consequences for disabled people because it focuses on an individual's limitation(s), deficiencies, deviance from the norm, and overall challenges to fit into society. Solutions are focused on ways in which to "fix" an individual to better fit into society, rather than how society can better accommodate difference.

The rise of disability studies began as a response by disabled people to the medicalized, individual focus on disability. Similarly, the rise of community psychology began in response to the rise of social movements in the USA during the 1960s, the lack of recognition of how sociopolitical conditions impact the competence and well-being of individuals, and dissatisfaction with the medical model of mental health. As Nelson and Prilleltensky (2005) describe,

> Psychology has traditionally focused on the individual level of analysis. While applied psychology sometimes pays attention to micro-systems, such as the family or peer group, most of the major theories of personality and clinical psychology emphasize individualistic explanations of behaviour and individual strategies of change such as psychotherapy. This is a very western view that puts the individual in the foreground over the collective, whereas other parts of the world do the opposite. In contrast, CP [community psychology] is the study of people in context. There is a more holistic, ecological analysis of the person within multiple social systems, ranging from micro-systems (for example the family) to macro-sociopolitical structures. There is a strong belief that people cannot be understood apart from their context (p. 5).

As such, community psychology and disability studies agree that disability and impairments are not randomly distributed throughout the world but are culturally produced based on various social, historical, cultural, and economic contexts and factors. Community psychology and disability studies reject individualized foci on disability and well-being. Both fields also hold similar critiques of the helping professions such that traditional modes of service delivery leave many people who need help, without sufficient support. This may be due, in part, to the lack of services that recognize the importance of the social environment for the development of well-being, or because quality services are financially unaffordable to many people in need. Community psychology and disability studies are concerned with social change and addressing the social determinants of well-being and poverty of disabled people and other marginalized or oppressed groups. These goals are guided by a set of values and principles that are "concerned with what should be, not what is" (Nelson & Prilleltensky, 2005, p. 32). These goals are expressed in the following principles and conceptual tools.

Inclusion As western societies have become more culturally diverse, there has been greater attention to diversity and the promotion of inclusion. Juilan Rappaport (1977) and Vic Finkelstein (1980), pioneers of community psychology and disability studies, respectively, have argued that disadvantaged people, such as disabled people, should have the right to be different and not to be judged by one single standard or norm. Community psychologists and disability study scholars have shown how racism, sexism, classism, heterosexism, and ableism are all forms of sociopolitical oppression (e.g., Mitchell & Snyder, 2015; Serrano-García & Bond, 1994; Trickett et al., 1994; Watts, 1992; Withers, 2012).

To overcome exclusion and promote inclusion, interventions need to occur at multiple levels (Nelson & Prilleltensky, 2005). At the individual level, a positive identity and awareness of sociopolitical conditions that create shame, stigma, and discrimination are important parts of the journey of disadvantaged people, such as disabled people. At the relational level, settings that are run by and for disabled people, such as the Ethno-Racial Disabled people Coalition of Ontario, appear to provide supportive contexts. These contexts can promote a positive alternative community narrative and support the development of collective organizing for social change. At the macro/system level, policies that meaningfully strive to recognize and enhance the participation, contributions, and equity of disabled people are needed to promote an inclusive society. Such policies would address structural problems such as lack of affordable housing, unemployment, and poverty.

Commitment and Empowerment According to Nelson and Prilleltensky (2005), working with oppressed groups requires accountability on the part of professionals working with the oppressed. This involves a commitment to social change and working in solidarity with group members. Professionals should make a conscious effort to "depower" themselves by sharing resources and shifting decision-making to empower disabled people and their organizations. Professionals should raise their level of knowledge and awareness of oppression and the power dynamics in anti-oppression, anti-poverty work. Disabled people should be treated and viewed as people with strengths who actively resist the unjust social conditions in which they live. But this isn't easy. Often, professionals are paid by the Canadian Government or other organizations and thereby accountable to the funding bodies that support them. As such, professionals hold power and can be viewed as such. Reflexivity, clarification, and negotiation with disabled people are important in shifting and sharing this power.

Ecology Using the metaphor of an eco-system in studying the interactions between people and their environments is arguably "more appropriate than the dominant mechanistic, reductionistic [*sic*] metaphor used in individual psychology to study basic human processes of learning, cognition, perception and brain-behaviour relations" (Nelson & Prilleltensky, 2005, p. 33). The ecological metaphor views human problems within the context of individual characteristics (e.g., coping skills and level of income), micro-level analysis (e.g., family and peer group), meso-level analysis (e.g., work settings and schools) that mediate between smaller individual and micro-level systems and the larger society at the macro-level of analysis (e.g., social policies, social class, and social norms). As described by Bronfenbrenner (1979), smaller systems are nested within and interdependent of the larger systems. Thinking and acting ecologically broadens the focus and shifts away from individualism (Fig. 3.3).

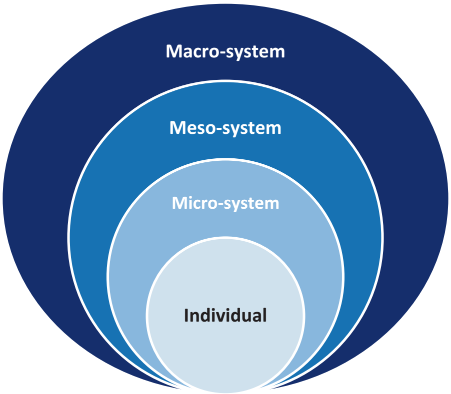

Fig. 3.3 The ecological metaphor

Being an Inclusive Practitioner

Being an inclusive practitioner requires working from a set of values that reflect the principles of inclusion, commitment, empowerment, and ecological holism. While North American societies take pride in promoting themselves as bastions of liberty, equality, and inclusion, not all share equally in the good life or feel adequately included (Devlin & Pothier, 2006). Being an inclusive practitioner requires recognition of this fact. Western capitalist society is designed in such a way to exclude the majority of the population from access to power, freedom, and choice. There is a need for a shift in psychological practice from an individualistic approach to one that values community, interdependence, and is concerned with social problems, as well as with how social systems affect the lives of individuals. As noted by Dalton, Elias, and Wandersman (2001), "The assumptions that people make about problems, especially when we are unaware that we are making them, determine the ways that we approach and try to solve a problem" (p. 3). In terms of disability, several scholars argue that impairment and disability are ideologically loaded terms based on medical discourses that assume a perfect norm and the impaired/disabled (read defective) other (e.g., Davis, 2002; Oliver, 1990; Shildrick, 2009; Thomas, 1999). Withers (2012) argues that definitions of disability, "like all definitions of marginalized people, are used as forms of control, creating large groups of 'others' when it is useful" (p. 113). Thus, an inclusive practitioner recognizes and addresses the social, cultural, political, and economic factors that contribute to disability, marginalization, and *dis*-citizenship (Barnes & Mercer, 2010; Oliver, 1990; Devlin & Pothier, 2006; Thomas, 1999).

Such a purpose can be supported by international standards on the rights of disabled people. The UNCPRD (www.un.org/disabilities/convention/conventionfull.shtml) provides a potential roadmap for service provision and social policies that goes beyond charity and protection to advance the rights of disabled people. The Convention was adopted by the UN in 2006 which marked a shift in views on disability from a social welfare to a human rights issue. As of June 2016, the UNCRPD has been ratified by more than 150 countries, including Canada. Ratification of the

Convention implies that states accept their legal obligation under the UNCRPD and enact the necessary legislation. The UNCRPD explicitly addresses culture in Article 30 which explicates the right of disabled people to take part on an equal basis with others in cultural life, such that the state shall take all appropriate measures to ensure that persons with disabilities:

- Enjoy access to cultural materials in accessible formats;
- Enjoy access to television programs, films, theater, and other cultural activities, in accessible formats;
- Enjoy access to places for cultural performances or services, such as theaters, museums, cinemas, libraries, and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.

Moreover, states are required to take appropriate measures to enable disabled people to have the opportunity to develop and utilize their creative, artistic, and intellectual potential, not only for their own benefit but also for the enrichment of society. Disabled people shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.

Above all else, *an inclusive practitioner recognizes disabled people as the experts on their experiences*. Disabled people intimately understand the impacts of discrimination, marginalization, oppression, and poverty. The disability culture movement provides an alternative and progressive view toward the skills, abilities, and contributions of disabled people. An inclusive practitioner recognizes the juxtaposition of this view in contrast to the charity, abled-disabled, and medically focused images of disability in mainstream society.

We understand the challenge of thinking differently about disability and to critically evaluate the status quo and mainstream images of disability. In this chapter, we have provided a list of references and links to some websites and organizations that serve as exemplars, or points of entry, to support your journey of inclusive practice. We encourage you to open up the conversation about what it means to be disabled in our multicultural society. Do not shy away from that discussion. Disabled people are the experts on their experiences and exemplify the need for social justice and cultural change.

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Chapter 4
Deaf Mental Health: Enhancing Linguistically and Culturally Appropriate Clinical Practice

Tracey A. Bone

The word "culture" is defined as "a way of life and learned ways of acting, feeling and thinking based on a group who share common language, beliefs, values, traditions, social norms, and identity in a society" (Canadian Hearing Society, 2013). Deaf culture shares all of these sociological criteria including shared language, values, traditions, social norms, and identity. It is a unique, but defined, culture (Deaf Culture Center, 2013; Ladd, 2003). Respect for and use of a signed language is the central defining feature binding and identifying members of Deaf culture. Spoken languages use words which are produced using the mouth and voice to make sounds and convey thoughts, ask questions, and express ideas (NIDCD, 2017b). Signed languages are manual languages that incorporate hand orientation, movement, and positioning (some signs require one hand, others two hands), as well as facial expression, body postures, and movement (Perlmutter, n.d.) to communicate thoughts, ask questions, and express ideas. Signed languages, like spoken languages, have their own structure, syntax, vocabulary, and grammar. As with spoken languages, there is no single or universal sign language, rather many countries have their own sign languages and dialects. Unlike some spoken languages, sign languages have no written equivalent.

Cultures are also broadly defined as individualist or collectivist cultures. These differ by their view on issues such as identity, loyalty, sense of obligation, and independence (Queensland Health, 2008). In individualist communities, such as in dominant hearing communities, independence, self-reliance, personal choices and opinions, and an "individual-first" attitude prevail. Deaf culture, on the other hand, is a collectivist culture. In collectivist cultures, members place the needs of the group first and value group decision making. Community members assist and support each other, pool resources, have clear insider/outsider boundaries, and share a loyalty and obligation to their group (Queensland Health, 2008, p. 20). Collectivist

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communities, including the Deaf community, also have their own political and religious groups, sporting and social clubs, festivals, and other events.

Hamerdinger, Schafer, and Haupt (2016) define members of the Deaf community as heterogeneous, with variation in cognitive, social, and emotional development, as well as communication preferences. Unlike other minority communities, whether minority by language or culture, members of the Deaf community are not bound by invisible geographical lines or fences, and do not necessarily concentrate in any particular area of a city or province. Deaf people may gravitate to areas where other Deaf people are, but particularly with the dissolution of common meeting places like Deaf clubs, and increasing access through technology, there is no formal “Deaf” geographical area. Given the cohesiveness of the community, members are more likely to know if another member has a mental health problem. Mental health stigma is high in the Deaf community because lack of exposure to mental health information results in limited mental health literacy. Because of the small size of the Deaf community, exclusion or ostracism from the group is viewed as the “worst punishment” (Queensland Health, 2008, p. 21). To avoid mental health stigma, many members hide their mental health problems (Bone, 2018).

Deaf culture is also a high context culture, with members of the Deaf culture sharing the same cultural experiences (Queensland Health, 2008, p. 23). While one might assume that being part of a collectivist, high context community might offer protection between members, Bone (2013) found that members diagnosed with mental illness were often shunned, as they were deemed to reflect badly on the entire community.

The Deaf Experience in Mental Health

Members of the Deaf community and culture experience health inequities differently from other minority communities (Beate, Mette Perly, Von Telzchner, & Falkum, 2015; Black & Glickman, 2006; Tate, 2008). Research indicates that Deaf people find it more difficult to establish relationships with health and allied professionals, and to access mental health services because of audism, lack of understanding of Deaf culture and language, and practical obstacles that prevent equal access to the health system, including mental health.

The following case example depicts many of the challenges and barriers faced by Deaf people in accessing mental health services.

Case Example: Barry’s Story—“My Garbage Can Is Full” (Bone, 2013)

Barry (not his real name) was born hearing to a two-parent family in the early 1960s. All members of his immediate and extended family were hearing. Barry’s infancy and early childhood were uneventful, as he achieved all milestones for normal physical development, including speech and language development (NIDCD, 2017a, p. 3). He entered pre-school, developed appropriate relationships with his classmates, and continued to achieve all expected speech and language milestones.

When Barry was 5 years of age, he contracted meningitis which resulted in moderate sensorineural hearing loss (SNHL). As Barry's family had no prior experience or knowledge of deafness, they were ill equipped to deal with the unique challenges of Barry's deafness.

Barry was fitted with hearing aids and his family sought to maintain Barry's hearing identity: as did Barry himself. The family continued to communicate orally with Barry, and he continued to attend the dominant school system. Barry did not fit in. His hearing aids provided some amplification, though not enough to understand class lessons, or understand his friends, and this difference led to bullying. Though he often missed parts of conversations, his heard it when his classmates called him "retarded," because that they said loudly. He started to fall behind in school.

At family dinners, Barry struggled to understand conversations. He asked what his family was being talked about, but was told "we'll tell you later." Later never came. He continued to grow as isolated in his own family as he was in school because of a lack of shared communication.

Barry became increasingly angry with his isolation and began to fight with his classmates. When Barry was 14, the school principal suggested Barry move to a school for the deaf. Barry's grades had continued to decline each year because of communication challenges. He had also started to experiment with alcohol to manage his isolation, and skipped classes to avoid the near-daily communication conflicts. One day he arrived at school intoxicated, which bolstered his confidence but not his hearing. He misinterpreted the verbal comments from a school representative. Embarrassed, Barry stormed out of the classroom. He was frustrated, but had no one to talk to about any of it.

Barry was moved to the local School for the Deaf. As he had had no prior exposure to American Sign Language, however, his transition was difficult. Though in a School for the Deaf, he was again isolated from both his peers and teachers because of a lack of common language.

At home, his family resisted his new "deaf" identity. His parents refused to learn sign language because they were embarrassed by what they viewed as "hand flapping." They discouraged his use of sign language in public as they felt it drew attention to him. His parents' reaction to his deafness made him self-conscious about who he was. His drinking escalated, as did his violence with others.

Barry fell into a state of depression when a long-term relationship deteriorated. He finally visited a walk-in clinic, but had difficulty making himself understood by the receptionist and physician because of a lack of common language. The physician examined him via spoken and written English, even though Barry had requested an interpreter. The doctor diagnosed Barry and gave him a prescription. As there was no shared method of communication, Barry understood neither the diagnosis nor medication regime. He stopped the prescription 2 days later as he was confused by the side effects of the medication he was experiencing.

Misunderstood and untreated, Barry continued to feel isolated, angry, and confused until he saw a new physician who invited a sign language interpreter into the appointment. For the first time, Barry was able to participate fully in an assessment for his symptoms. He was finally able to tell someone about his isolation, his experiences with bullying, his failures in employment, and his use of alcohol to manage all that he was coping with. He told the doctor that he felt like all the “crap” he had experienced would “fill a garbage can, maybe two”; but up until then, without a common language to discuss his feelings with a professional, he had “no way to empty the garbage cans”.

Though the case of Barry is fictitious, his experiences noted above are commonly reported by members of the Deaf community when seeking mental health services by professionals not familiar with Deaf culture or, in the case of North America, American Sign Language (ASL).

Understanding Hearing Loss and Its Impacts

According to the World Health Organization (WHO), approximately 5% of the world’s population have disabling hearing loss, which equates to some 466 million people (432 million adults and 34 million children) worldwide (2018, p. 1). Onset of deafness that occurs prior to language, otherwise known as pre-lingual deafness, occurs in approximately 7/10,000 people (Fellinger, Holzinger, & Pollard, 2012).

Normal hearing is defined as a hearing threshold of 25 decibels (dB) or better in both ears. A person not able to hear at this threshold is said to have hearing loss. Hearing loss can range from mild to severe. Queensland Health, Australia (2008), created a Deafness Continuum (see Fig. 4.1). Along this continuum, those with no

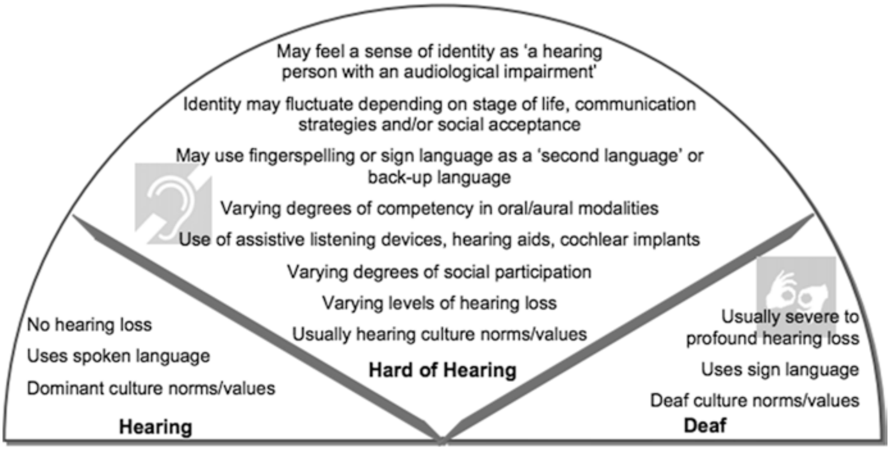

Fig. 4.1 Deafness Continuum Queensland Health, (2008) *Guidelines for Working with People who are Deaf or Hard of Hearing*. Part 1: Deafness and mental Health, p. 8. Used with permission

hearing loss use a spoken method of communication and maintain a "hearing" identity. Those with some hearing loss that impacts oral communication may maintain an identity as a "hearing person with a hearing loss." They often view their hearing loss as a disability. Persons in this group may use an assistive device such as a hearing aid if there is loss in one ear, or hearing aids if they experience bilateral hearing loss, or even a cochlear implant to enhance their hearing in an attempt to facilitate spoken communication. These individuals usually maintain their identity in hearing culture and values. Some individuals experience hearing loss post-lingually (i.e., after having gained the ability to communicate in spoken language); they are referred to as "late-deafened." Some within this group maintain a hearing identity, while others may participate in varying degrees within the Deaf community, including gaining fluency in signed language.

Disabling hearing loss generally refers to hearing loss greater than 40 dB in the better hearing ear in adults, and hearing loss greater than 30 dB in the better hearing ear in children (WHO, 2018). Deaf and hard of hearing children often have additional disabilities. In the USA, a 1999 study (Van Naarden, Decoufle, & Caldwell) reported additional conditions such as learning disabilities (9%), developmental delay (5%), specific learning disabilities (8%), visual impairment (4%), and autism (2%) (as cited in Fellinger et al., 2012). It is further reported that the absence of early auditory stimulation and delay in acquiring language appear to affect various neurocognitive processing domains, such as "auditory and visual working memory, attention and inhibition" (Pisoni, Conway, Kronenberger Horn, Karpicke, & Henning, 2007). These factors can contribute to higher experiences of mental health problems.

Models of Deafness: Medical Model (Deaf) Versus Socio-Cultural Model (Deaf)

There are two primary views of deafness. The medical model views hearing loss as a "sensory deficit," and thereby a pathological condition or disability that requires remediation (Queensland Health, 2008, p. 8). This group of people may be defined as hard of hearing, or (lower case d) deaf. Some use spoken language and speech reading, often incorrectly referred to as lipreading, in combination with a hearing aid, communication device, or a cochlear implant to communicate. These individuals often maintain a hearing identity, and view their deafness as a disability. They do not identify with the Deaf community (Canadian Association of the Deaf, Terminology, 2015a). The medical model privileges competency in a spoken language as the desired means through which to achieve cognitive development and competency in communication (Munoz-Baell & Ruiz, 2000). In the medical model, deafness is viewed as a source of stigma.

The socio-cultural model defines deafness or degree of hearing loss not as a disability or handicap but rather as only one factor of human uniqueness and diversity (Queensland Health, 2008). The degree of audiological hearing loss is less important, with individuals viewing their loss as a cultural rather than medical term. In the socio-cultural model, hearing loss is viewed as a cultural factor that identifies individuals as members of a distinct culture and value system organized around a signed language. These individuals identify their deafness as part of a "cultural-linguistic experience" (Queensland Health, 2008, p. 9) that is a source of pride and cultural identity. Individuals who identify as members of this distinct culture and community are characteristically identified through the use of the word "Deaf" (uppercase D). The World Federation of the Deaf defines Deaf identity as "belonging to a cultural and linguistic community who uses sign language as a mother tongue or natural language to communicate" (Campaign Key Messages—Deaf Identity, 2016).

The exact number of Deaf Sign Language users in Canada is unknown. One reason is there has never been a consistent definition of the word "deaf" or Deaf used in nationwide census studies (CAD, 2015a). The Canadian Association of the Deaf attribute some of the confusion to the wording of the questions used in national censuses. The wording may not be consistently understood by members of the Deaf community, resulting in inconsistent responses to the census questions. While the exact number of culturally Deaf people in Canada is unknown, the CAD estimates that there are approximately 3.57 million people with hearing loss and 357,000 culturally Deaf people in Canada (CAD, 2015b).

Mental Health and the Deaf Community: Contributing Factors

Research indicates that approximately 90% of deaf children are born to hearing parents (Mitchell & Karmer, 2004), parents who often have had no prior exposure to deaf people, deaf culture, or a signed language. Hearing loss does not in itself predispose deaf children to mental health problems. The language and communication environment of the family, however, is a significant factor affecting the psychosocial well-being of deaf children. Those deaf children who lack effective two-way communication within the family are "four times" more likely to be affected by mental disorders, and are more likely to be victims of school maltreatment than those living in families with effective communication (Fellinger, Holzinger, Sattel, Laucht, & Goldberg, 2009). Further, Fellinger et al. (2009) found that lack of a common language within the family contributes to a lifetime diagnosis of any psychiatric disorder, as well as an increased risk of depression in those who had been "teased, maltreated by classmates and isolated" (p. 635). As one's ability to communicate with family and peers is critical to self-awareness, self-esteem, and identity, early-age challenges with communication must be considered when studying the mental health concerns of Deaf people. Studies (Fellinger et al., 2009) suggest strong links between a lack of effective two-way communication as children with poor social engagement, behavioral challenges, and mental health.

Hill and Nelson (2000) found that linguistic isolation and "daily systemic discrimination" (Executive Summary, p. i) can occur if the deaf child lacks fluency in the dominant spoken language, and the child's family, friends, and/or community are unable to communicate in that deaf child's visual language. Austen (2006) added that the ongoing challenges of living among a larger society with a language one will never gain full fluency in significantly contribute to the ongoing emotional and personal challenges for the deaf child. These all escalate the child's risk for mental illness. The literature also suggests that these issues increase the deaf child's risk for childhood physical and sexual abuse, which contributes to a higher incidence of severe stress and trauma in deaf children (Fellinger et al., 2009). As a result, language and communication approaches used in the home as well as the school environment must be taken into consideration when examining mental health problems in Deaf communities.

Barnett, McKee, Smith, and Pearson (2011) found low health literacy of Deaf people resulting from language barriers that limit access to common health information otherwise accessible to the dominant hearing community; communication barriers which interrupt the patient–physician relationship; and, for some, the existence of a comorbid health issue contributes to health access inequities. Inadequate access to mental health promotion and prevention information (Cabral, Muhr, & Savageau, 2013; McKee, Barnett, Block, & Pearson, 2011), misdiagnosis due to inadequate communication with hearing professionals (Bone, 2013; Iezzoni, O'Day, Killeen, & Harker, 2004), and a mental health delivery system that is culturally insensitive and poorly prepared to serve this population also contribute.

As reported in a US study, communication challenges within health-related settings result in "fear, mistrust and frustration in health care encounters" (Kuenburg, Fellinger, & Fellinger, 2016). These often lead to misunderstanding in the assessment or diagnostic phase, as well as the therapeutic phase (Kuenburg et al., 2016). Misdiagnosis can also occur if a hearing professional applies intelligence tests, personality tests, neuropsychological or other psychological screening tools developed and validated based on verbal communication skills, without appreciating that many Deaf adults often have a reading comprehension of grade 4–5 (Lowrie & Kerridge, 2015). Many Deaf people whose first or preferred language is a signed language are "medically underserved" (Barnett et al., 2011, p. 2235). Agency participants in Mathos, Lokar, and Post's (2011) study agreed that their lack of mental health personnel familiar with Deaf language and culture was the most significant challenge to providing quality mental health services to this population.

Bridging the Communication Divide: Sign Language Interpreters

The Canadian Association of the Deaf reports that the inclusion of sign language interpreters is the most efficient way to bridge the communication divide between non-signing health professionals and members of the Deaf community (CAD, 2015c). Signed languages are visual-gestural languages that are used as the primary or preferred language of many Deaf people in the USA, Canada, and around the world (Gallaudet University, 2018). These are manual languages that use specific hand shapes and movements, though also engage the eyes, eyebrows, facial expressions, and body posture to convey meaning (NIDCD, 2017a).

Signed languages are not universal, with over 250 distinct sign languages, dialects, or other sign systems identified around the world (Gallaudet University, 2018). Each signed language has its own structure, syntax, vocabulary, and grammar, distinct from spoken languages (Perlmutter, n.d.).

Canada has two official languages, English and French. Of those reporting a “non-official language spoken at home” in the most recent Canadian census (2016), 9080 people identified sign language as their single, non-Aboriginal “Language spoken at home”; and 18,430 reported sign language as one of the languages “spoken at home” (Statistics Canada, 2016). There are also regional dialects such as Maritimes Sign Language (MSL). The United Nations Convention on the Rights of Persons with Disabilities (2006) formally recognizes sign languages and confirmed these languages’ rights, protections, and equal status to spoken/written languages in the signatory countries, which include Canada.

The CAD views artificially developed systems as a form of cultural oppression and discourages their use by non-deaf people (CAD, 2015d). These “artificially invented” systems of manual communication are designed around the grammar and sentence structure of spoken language rather than signed languages naturally developed by Deaf people themselves. They are viewed as pseudo “sign languages” by the Deaf community. Examples of these are Sign Exact English, Cued Speech, and Signed English (CAD, 2015d).

There are a number of behavioral factors commonly associated with signed language. Eye contact is a fundamental feature of signed languages (Metro South, 2016). Initiating and maintaining eye contact indicates continued attention with the person speaking. A lack of eye contact or breaking eye contact is significant, as it suggests a lack of interest in the speaker. In Deaf culture, tactile and visual methods of gaining a person’s attention such as touching someone on the shoulder or arm, waving hands, stomping on the floor, banging on surfaces such as a table, and/or flicking lights on and off (Metro South, 2016, p. 7) are common behavioral strategies to get a Deaf person’s attention. These are not signs of aggression or rudeness, but rather behaviors and customs of those who depend on their vision for communication both with hearing and non-hearing people.

Challenges in Mental Health Care Access for Deaf People

It is difficult to assess the actual depth of the issue in the Deaf population. Glickman and Pollard (2013, p. 360) reported that study within the area of Deaf mental health (DMH) is some 40 years behind that based on the general population. One of the reasons for this is because deafness was historically pathologized and the focus was on strategies to eliminate deafness. It wasn't until the 1960s, when Stokoe, a linguistic professor, recognized that American Sign Language is a formal language, that attention to and within the Deaf community shifted. Notwithstanding this acknowledgement that sign language is a formal language, few professionals have had exposure to this language or Deaf culture, creating challenges in establishing effective two-way communication between hearing health professionals and Deaf service users.

Discrimination and practical obstacles related to lack of understanding of Deaf language and culture creates unique barriers for Deaf people to access services, which then leads to clinical ramifications for this population (Cabral et al., 2013; Cornes & Napier, 2005; Fellinger et al., 2012; Mathos et al., 2011; McDonnall, Crudden, LeJeune, & Stevenson, 2017).

Research suggests there is a high prevalence of mental health problems in the minority Deaf community (Barnett, McKee, et al., 2011; Critchfield, 2002; Kvam, Loeb, & Tambs, 2007; Vernon & Leigh, 2007). Queensland Health, Australia (2008), suggested that, at a minimum, the incidence of mental illness in the Deaf community is approximately similar to that in the hearing population. Austen (2006) suggested a higher prevalence of serious mental disturbances in Deaf adults and children when compared to the hearing populous, and Hill and Nelson (2000) suggested that the prevalence of mental illness might be as much as four times higher in the Deaf population than in the hearing population.

As the literature reports, few clinical staff have worked with a Deaf person, and so may not fully understand the barriers Deaf people experience in accessing mental health care (Landsberger & Diaz, 2010; Mathos et al., 2011; McDonnall et al., 2017; Woodcock & Pole, 2007).

The challenges experienced by Deaf people accessing a mental health assessment, intervention, or follow-up may include the following:

- Difficulties booking an appointment because of over reliance on telephone bookings
- Patients' difficulties explaining their health problem to a clinician or allied mental health professional in the absence of a shared language
- Professionals' assumption that Deaf people are literate in written English, and use of written English to conduct an assessment and communicate diagnosis, medication dosage, medication side effects, a treatment plan, and/or follow-up
- The use of mental health assessment tools not validated for Deaf Sign Language users and applied through the Deaf person's second language of written or spoken English
- Difficulties booking interpreters due to a lack of interpreter availability

- Lack of accessible information—most mental health prevention or promotion materials are presented in a written format, rendering much of the content inaccessible to Deaf consumers
- Too few crisis hotlines that are ASL based
- Stigma of mental illness in the Deaf community, preventing people from seeking assessment and services
- Reluctance of some mental health intervention or support services to provide ASL interpreters due to cost
- While having an interpreter in the room may facilitate communication, the presence of a third party in the room may inhibit the discussion of private health issues by the Deaf person.

Strategies for Facilitating Effective Two-Way Access to Communication

McKee et al. (2011) found that concordant patient–provider communication resulted in higher use of appropriate preventative medical services by the Deaf ASL users in their study (see Barnett, 2002). Active participation of mental health consumers in the treatment planning process is consistent with the recovery philosophy (Smith, 2000; Walsh, 2013).

The Canadian Association of the Deaf (CAD) reports that the most effective way to ensure accurate two-way communication between a non-deaf person and a Deaf person is through a qualified or certified ASL English interpreter (2015c). To enhance the effectiveness of the interpretation, it is recommended that any written materials to be used in the meeting, including an overall agenda, be shared with the interpreter in advance of the meeting, so the interpreter can familiarize themselves with the concepts to be discussed. The seating layout is also important, with the interpreter seated alongside the speaker (see Fig. 4.2—seating arrangement). This allows the Deaf person to easily visually move between watching the speaker and

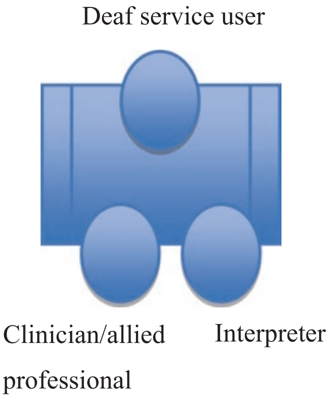

Fig. 4.2 Seating arrangements including ASL interpreter

the signing interpreter. This also allows the speaker to maintain eye contact with the Deaf person, thereby enhancing the therapeutic relationship. In the case of a larger group, a round table should be used to ensure that all attendees remain in the field of vision of the Deaf person (Michigan works, 2011).

Sign language interpreters must have specialized training in how language in general can be impaired by mental health symptoms such as psychosis, and the types of questions commonly asked in mental health diagnostic interviews. They should also receive education specific to the norms and dynamics of different mental health service settings, such as emergency rooms, psychiatric centers, inpatient- and outpatient-based services, and other community-based resources. Training on different types of mental health screeners and assessment tools (i.e., Beck Depression Inventory-II revised for Deaf consumers), as well as common and general medical evaluation questions, will better prepare the interpreter to engage with the patient, and the Deaf patient in their health and mental health care process. The literature warns that mental health services provided through a third party, even if a certified American Sign Language (ASL) English interpreter is involved, may not provide equal access to services (Leigh, Corbett, Gutman, & Morere, 1996). While ASL English interpreters are intended to be "impartial conduits" in the therapeutic process, neither subtracting from or adding to the therapeutic relationship, Brunson and Lawrence (2002) found that the interpreter's mood negatively impacted the Deaf service recipient's mood, even when the therapist's mood was "neutral/cheerful" (p. 1). Also, errors can occur in the interpretation process from English to ASL, and vice versa (Napier, 2004). These factors will influence the quality of services that members of the Deaf community receive when compared to the dominant hearing community.

Deaf clients requesting an ASL English interpreter should be offered the opportunity to select their interpreter whenever possible (Bone, 2013), given the heterogeneity in the Deaf community by language preference, skill, and prior relationship. In cases where the Deaf person has limited communication skills or uses a non-standard sign language, it may be necessary to engage the services of a Deaf interpreter (DI) as part of the interpreting team. A Deaf interpreter translates what the hearing interpreter is saying, through the communication strategy most understood by the deaf person. It may include an appropriate level of ASL, a series of informal signs, gestures, or other communication strategies the deaf person understands (Canadian Hearing Society, 2018).

Practical Strategies When Working with an ASL English Interpreter

Factors such as the layout of the room, lighting, and inclusion of a Deaf interpreter (DI) will enhance service access for Deaf participants.

– Layout of room: See Fig. 4.2: Seating arrangements including ASL interpreter.

- Lighting: There must be sufficient light in the room for the Deaf person to see the ASL interpreter clearly. To avoid distraction, neither the interpreter nor the Deaf person should be seated directly in front of a bright light or window with bright light outside. This makes viewing the signed communication difficult. Blinds may need to be drawn or seating repositioned to avoid light distractions.
- See the checklist (pre and post) for interpreter engagement below (Appendix A). A dedicated amount of time should be allocated prior to, or at the start of, the meeting for the Deaf person and the interpreter to communicate so as to establish their form of communication.

Effective two-way communication between the hearing professional and Deaf consumer may occur through either a voice message or video relay services. Voice Message Relay Services (MRS) do exist, through are considered outdated technology and used less often by many Deaf people who prefer wireless phones for the communication through texting services. Video Relay Services (VRS) involve a voice sign language interpreter/operator interpreting between spoken and signed communication (Canadian Radio-Television and Telecommunication Commission, 2014). VRS allows deaf people, or those whose first language is a sign language, to communicate in their first language with the same “fluency, range of expression, ease, and speed” they otherwise communicate in using their first language (CRTC, 2014). VRS is viewed as superior to non-specialized or generic video chat applications such as Skype, as the latter does not provide access to a qualified sign language interpreter.

Recommendations for Creating Accessible Environments

Enhanced technology in mental health-related waiting rooms would support access for Deaf users. Technology such as electronic check-in monitors (computer screens to allow independent check-in) would reduce dependence on receptionists calling a Deaf patient. Receptionist staff could physically signal to the Deaf person when being called to their appointment (rather than simply calling out the name). With the patient’s permission, a note could also be put on their file (i.e., Patient Deaf or Patient Hard of hearing—Interpreter required) with details on how to contact an identified interpreter. The inclusion of ASL-based educational and informational videos, as found in the Deaf Wellbeing Program website (Vancouver Coastal Health, 2019), in clinician’s waiting rooms would also enhance access for Deaf people to mental health content and resources. Linguistically accessible mental health materials would enhance the mental health literacy of this population overall (McKee et al., 2015), and begin to address the issue of mental health stigma in this minority community.

Conclusion

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) clearly states that all disabled people should experience "equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (2006, Article 1). This includes the elimination of "obstacles and barriers to accessibility" (2006, Article 9, Accessibility). As evidenced in the literature, members of the Deaf community experience unequal access to mental health assessment, intervention, and follow-up when compared to the dominant community.

The Deaf community experiences many challenges preventing their equal access to mental health services, including too few professionals familiar with the Deaf community, culture, and language; inaccessible mental health materials; and resistance of community-based programs to accommodate the costs associated with sign language interpreters. A number of strategies have been proposed to reduce these barriers. Increased support for Deaf people to receive the training necessary to become mental health professionals would enhance access for this minority culture, and reduce the prevalence of mental health challenges in this population.

Definition of Terms

Audism Term first coined by T. Humphries, a deaf researcher, in his 1977 doctoral dissertation "Communicating across cultures (deaf/hearing) and language learning." He defined the word Audism (o-diz-m) as the notion that one is superior based on one's ability to hear or behave in the manner of one who hears. Eckert and Rowley (2013) further defined audism as a "stratifying system of oppression" that can be experienced through the practice of overt, covert, and aversive practices of discrimination (p. 101). (See also Bauman, 2004).

Closed-captioning Closed captioning makes TV programming and other video content accessible to deaf and hard of hearing individuals by translating audio into text captions that are displayed on the screen Canadian Radio-Television and Telecommunication Commission (CRTC), (2014).

Deaf (lower case d) The word deaf is a medical/audiological term referring to those people who have little or no functional hearing. It may also be used as a collective noun ("the deaf") to refer to people who are medically deaf but who do not necessarily identify with the Deaf community (CAD, 2015a).

Deaf (upper case D) A sociological term referring to those individuals who are medically deaf or hard of hearing, who identify with and participate in the culture, society, and language of Deaf people, and whose primary or preferred language is sign language (CAD, 2015c).

Deafened (Also known as late-deafened) The term is both a medical and sociological term that generally refers to those individuals who lost their hearing after the acquisition of speech and language. Individuals who are late-deafened generally share the cultural experience of being "hearing." A number of psychological consequences are associated with being late-deafened, with some "viewing themselves as having a disability" (De Graf & Bijl, 2002), reporting sense of "loss or social isolation," and having lower levels of psychological adjustment (Polat, 2003).

Deaf interpreter (DI) Deaf interpreters are Deaf individuals who are fluent in ASL and have interpreting experience. They provide interpreting services to deaf immigrants with limited ASL, deaf people with learning or language challenges, or those whose illness or injury limits or prevents the deaf person signing. The hearing interpreter translates from spoken English to ASL; the DI translates what was signed in ASL to the deaf person via ASL, sign, gestures, or other communication strategies the deaf person requires (Canadian Hearing Society, 2018).

Hard of hearing A person is hard of hearing when their hearing loss ranges from mild to profound, regardless of the cause of loss, whose primary mode of communication is speech. Hard of hearing is regarded as both a sociological and medical term.

Oral deaf "A deaf person whose preferred mode of communication is verbal and auditory and/or lipreading. An oral deaf person who can both Sign and speak can be considered 'Deaf' if he/she is accepted as such by other Deaf persons and uses Sign within the Deaf community" (CAD, 2015c).

Sign Language The official language of Deaf communities around the world. There is no universal sign language, with more than 137 sign languages documented around the world (Lewis et al. 2013). Many of the worlds' sign languages have developed independently from one another, and as such are linguistically diverse.

Telehealth Defined as "live video conferencing technology" (Wilson & Schild, 2014, p. 324). Wilson and Schild reviewed the extent to which service providers are using this technology to provide services to Deaf ASL users where face-to-face services do not exist. Further research is required to explore the full capacity of this technology for this client population.

Video relay service (VRS) A video service that connects a deaf signer with a hearing person directly through an ASL interpreter. The service was launched in Canada on September 28, 2016. Canadians with a sufficient internet connection can access VRS at no cost through their computer (Mac and PC), tablet (iOS or Android), and smartphone.

Resources to Facilitate Successful Engagement with Deaf Service Users

Pre and Post Assessment Meeting with Interpreter

Checklist

When conducting any type of assessment with an interpreter, complete the following checklist.

Pre-session

Item	Check
The interpreter has explained his or her role.	
I have explained the overarching purpose of the session to the interpreter.	
I have explained the key principles and concepts of the meeting, treatment, or therapy to the interpreter.	
I have shared the relevant facts of the client's case for the purpose of accurate interpretation.	
I have provided the interpreter with a copy of any assessment item(s) I plan to use.	
The interpreter has highlighted areas of the assessment that they foresee may have linguistic or cultural difficulty.	
I have provided an opportunity for the interpreter to calibrate to the language that I will use in the assessment or treatment. Calibrating refers to the process of adjusting to the language level, patterns, and idiosyncrasies of each individual in the communication exchange. Calibrating is an important part of maintaining the integrity of the meaning intended in each communication exchange	

Post-session

Item	Check
I clarified with the interpreter any linguistic or cultural concerns that were raised in the meeting or session.	
I asked the interpreter if they had any difficulties in translation or have any culturally relevant information that may influence my assessment.	
If the Deaf person and staff person myself are satisfied with the interpretation, I inquired whether it is possible to book the interpreter for regular appointments.	

Metro South Health, Queensland, Australia (2016, p. 60). Adapted and used with permission

Service Accessibility Considerations

Checklist

To improve the accessibility for Deaf people, complete the checklist.

Item	Check
Have I accommodated the communication needs of the Deaf person?	
Have I ensured relevant staff knows how to book and engage an ASL English interpreter?	
Do I, and all necessary staff, understand the role of a Deaf interpreter (DI)? If requested, do I know where and how to book a Deaf interpreter (DI)?	
Have I planned for sufficient time to accommodate the purpose of the meeting (often two to three times the length of time without an interpreter)? Depending on the length of the meeting, have I confirmed with the interpreter service whether I will require more than one interpreter?	
Does the setting have *sufficient lighting* to accommodate visual language users?	
Does the setting have *sufficient space* to accommodate a Deaf interpreter (if requested), and ASL English interpreter in addition to the Deaf consumer and staff person(s)?	
Does the institution have access to the necessary technology to facilitate communication between the Deaf offender and community supports in a way hearing offenders have access to telephone? This may include video conferencing, or video relay services for interpretation purposes.	
If the institution has appropriate communication technology, is it in good working condition? Do all necessary staff know how to use the technology and facilitate access for the Deaf offender?	

Metro South Health (2016). Metro South Addiction and Mental Health Services: Guidelines for working with people who are Deaf or hard of hearing, v. 3. (p. 61). Adapted and used with permission

Educational videos for working with Deaf ASL first-language users individuals

Deaf People in Medical Setting [Video file]. (2016). Retrieved from https://www.youtube.com/watch?v=NpyvD6_uzZ0 Time: 2:26

The Holley Institute: In-Service Training for Deaf Patients [Video File]. (2017). Retrieved from https://www.youtube.com/watch?v=hzzSZYbsRyM Time: 7:17

UC San Diego Health [Video File] (2015). Improving Health Communications with Deaf Patients. Retrieved from https://www.youtube.com/watch?v=Cr0I41ZCb2o Time: 4:46

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Part II
Immigrant and Indigenous Mental Health

Chapter 5
Best Practices and Research Perspectives with Immigrant Groups

Alfonso Mercado, Amanda Venta, and Ricardo Irizarry

As a son of immigrant parents and a psychologist that provides psychological services to the immigrant population in a border community and conducts research at a Hispanic Serving Institution on Latin x and immigrant groups, I was honored to contribute a chapter on the best practices and research perspectives to be considered when working with this important population. I was elated to co-write this chapter with my dear colleagues, Dr. Amanda Venta, a Latina psychologist, and Dr. Ricardo Irizarry, a Latino psychiatrist, thus bringing together our wealth of knowledge and experience to further others' understanding on the best practices for working with this unique population, whether in a clinical setting or the research realm. As I write this chapter, I am teaching at the University Central De Ecuador, where I have a visiting professorship role in the Facultad de Ciencias Psicologicas. This cultural emergence experience continues to fuel my passion for psychology across international borders. I have collaborated with researchers from Universidad de Guadalajara, Universidad Autonoma De Nueveo Leon in Mexico, and Universidad Central de Ecuador, and have presented in international platforms on my work with Latinos in

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the US and the immigrant population. This chapter aims to highlight the importance of working with culturally diverse immigrant groups and lays out critical research and clinical perspectives that contribute to advances in mental health.

The Journey

Many individuals and families migrate to the USA for an array of reasons. Our continuous contact with this population in clinical and research settings has revealed reasons of trauma as many immigrant groups are escaping violence and poverty, while many others are reuniting with family members who have been living in the USA for a long time or seeking educational and economic opportunities. The USA is currently home to approximately 40.4 million immigrants (U.S. Census Bureau, 2011), of which one-third are from Mexico and 55% originate from Latin-America (U.S. Census Bureau, 2011). There has also been a more recent increase in immigrants and refugees from the Middle East, given the unrest in that part of the world (Kiely, Fairley, & Gore, 2015). One in five individuals living in the USA is a first- or second-generation immigrant, and almost a quarter of children under the age of 18 have an immigrant parent (Mather, 2009), while current estimates of undocumented individuals sit at 11.7 million (Passel, Cohn, & Gonzalez-Barrera, 2013).

Practicing in a border community, we have seen a rise in unaccompanied minors and immigrant mothers and their children crossing the Rio Grande River, which borders Northern Mexico and Texas. This is a distinct region in the USA, which is a predominantly Latino community and is where many immigrant groups and an array of cultures meet (Mercado et al., 2016). There has been an increase of 131% in the number of children and families crossing the Southwestern border of the USA between 2015 and 2016 (U.S. Border Patrol, Southwest Border Sectors, 2016). Approximately 52,000 minors aged five and up, most from Honduras, Guatemala, and El Salvador, crossed the border in 2015. The number of undocumented and unaccompanied youth entering the USA have significantly increased throughout the last 2 years, something that is evident in the border community where we practice and conduct research. Due to these diverse demographics, psychologists and mental health professionals are increasingly serving immigrant children and adults, both documented and undocumented, presenting with a multitude of problems across settings including schools, clinics, hospitals, and prisons (Casas, 2017). Thus, clinicians should be aware of this important population as practitioners and researchers in an ever-growing multicultural society.

APA's Crossroads Report

In 2013, the American Psychological Association's Presidential Task Force on Immigration published *Crossroads: The Psychology of Immigration in the New Century*, "an evidence-based report on the psychological factors related to the immigration experience…. focusing on factors that impede and facilitate adjustment (APA's, 2013)." The report was also intended to facilitate decision-making in regard to immigration, which has become a societal, political, and legal issue in contemporary America.

The report outlines three guiding principles: (1) immigrants are resilient and resourceful, (2) immigrants are influenced by their social contexts and, thus, ecological circumstances should be considered when framing their experiences, and (3) it is essential to use cultural lenses with the diverse immigrant-origin population (APA Guidelines on Multicultural Education, Training, Research, Practice, and Organizational Change for Psychologists, 2013). The report indicates that first-generation immigrants often display greater physical and behavioral health than subsequent generations, despite having to face many challenges such as language barriers, racial discrimination, poverty, occupational disappointments, social isolation, and educational difficulties (APA, 2013). Racial discrimination is one of the most difficult stressors that newly arrived immigrants are faced with, and it is also one of the most researched. Discrimination is dealt with in the workplace, neighborhood, schools, and even service agencies. For many immigrants, immigration to the USA provides their first encounter with racial discrimination (APA, 2013). Even without the undue burden of racial discrimination, acculturation is not without its own challenges. Age is a factor in how well immigrants acculturate to their new environment, with younger immigrants generally acculturating faster and with greater ease than their older counterparts (APA, 2013). Although immigrants may come to adopt many of the values and behavioral practices of the new culture, the values and practices of the country of origin are rarely abandoned entirely (APA, 2013). The process of acculturation has the potential to strain the dynamics of the parent–child relationship, as children may begin to lose faith in their parent's ability to understand and help them cope with the challenges they face in the new culture as children (APA, 2013).

Immigrants are often disadvantaged and perform below their actual competencies when tested with clinical and educational assessments that may not be sufficiently attuned to their cultural background or frame of reference (APA, 2013). In the clinical realm, immigrants are particularly disadvantaged when administered ability, aptitude, and achievement testing. Although many first-generation immigrants are less adapted to the language of their new country, they often display certain advantages in educational contexts such as optimism, high aspirations, dedication to hard work, positive attitudes toward school, and family support (APA, 2013). However, they tend to perform poorly on "high-stakes testing," according to the report. The needs of immigrant students are often inadequately addressed within the educational system, and they are often at a significant disadvantage.

The report states that immigrants have not been shown to suffer from mental illnesses more frequently than non-immigrants, with the exception of refugees (APA, 2013). However, when such illnesses do occur within this population, they are frequently a product of the immigration process—"loss of and separation from [the] country of origin, family members, and familiar customs and traditions; changes in social class and/or socioeconomic status; exposure to a new physical environment;

and the need to navigate unfamiliar cultural contexts" (APA, 2013). The issues of immigrants can often be classified according to three categories: (1) acculturation-based problems, (2) trauma-based presenting problems, and (3) discrimination, racism, and xenophobia-based problems (APA, 2013). The report highlights that recognition and appropriate utilization of culture-specific coping should be promoted within the clinical context. The report identifies three kinds of barriers to culturally sensitive treatment with immigrants: (1) social-cultural barriers, such as differences in frame of reference regarding the causes and treatments of mental illness, (2) contextual-structural barriers, which includes lack of access or knowledge of culturally sensitive mental health services, and (3) clinical-procedural barriers, which may be described as "clinical bias" due to lack of cultural sensitivity, language barriers, misdiagnosis, and lack of recognition for culture-specific forms of coping and resiliency (APA, 2013).

Overall, the field of psychology and immigration was enhanced by this important report that former APA president, Dr. Melba Vasquez, initiated during her presidency at APA. Members of the task force compiled pertinent data and reviewed critical literature to set forth these important guiding principles and frameworks when working with immigrant groups.

Research Perspectives: Immigration and Mental Health/Acculturation and Resiliency

The aim of this section is to review the existing data on three critical variables: immigration status, acculturation, and resiliency in relation to mental health.

Immigration

Existing literature regarding the relation between immigration and mental health has created a construct called the *Immigrant Paradox*, which suggests that first-generation immigrants are at a lower risk for a range of health problems and psychopathology than their native-born counterparts, despite sociological disadvantage (Acevedo-Garcia & Bates, 2008; Lui, 2015; MacDonald & Saunders, 2012; Vaughn, Salas-Wright, DeLisi, & Maynard, 2014; Wolff, Baglivio, Intravia, & Piquero, 2015). The effect has been documented in various psychological outcomes, as well as related outcomes such as the emotional and sexual abuse of children (Millett, 2016). Similarly, the *Hispanic Health Paradox* refers to an existing literature base showing that, despite exposure to many health risks like low socioeconomic status, limited access to health care and insurance, and reduced education and employment, Hispanics in the USA generally report greater health than non-Hispanic Whites (Ruiz, Hamann, Mehl, & O'Connor, 2016). The effect is even more pronounced among Hispanic immigrants (i.e., foreign-born) (Singh, Rodriguez-Lainz, & Kogan, 2013).

However, some research focused on the mental health of immigrant populations actually suggests a *disadvantage*. For instance, in some studies, immigrants report a higher prevalence of conduct problems, phobias, and early substance use (Breslau et al., 2011); decreased mental health functioning than their native-born ethnic counterparts (Farley, Galves, Dickinson, & Perez, 2005); and psychiatric disorder rates comparable to non-Latino White subjects (Alegría et al., 2008). Overall, findings are inconsistent, and a review of the *Immigrant Paradox* and *Hispanic Health Paradox* literature bases suggests that it does not apply evenly across ethnic groups, age groups, or genders, with, for example, Mexican American mothers at an increased risk of adverse perinatal outcomes than immigrant Asian Indian mothers (Gould, Madan, Qin, & Chavez, 2003; Teruya & Bazargan-Hejazi, 2013). Teruya and Bazargan-Hejazi (Teruya & Bazargan-Hejazi, 2013), in conducting a review of extant literature, observe that immigrants who do not have health insurance are older at the time of migration, and who have spent more time in the USA (see Acculturation section, below) experience the worst outcomes. Moreover, they state that "immigrant adolescents in general appear to be the most vulnerable to psychosocial stressors, with Latino populations at greatest risk" (Teruya & Bazargan-Hejazi, 2013, p. 501).

The latter may be accounted for, at least in part, by unprecedented increases in the migration of adolescents to the USA from Central America—particularly El Salvador, Guatemala, and Honduras—where crime, death, and violence have reached record levels. This shift is recent, with Honduras reporting the highest homicide rate globally in 2011, 2013 marking the end of a truce between major gang powers in El Salvador, and crime victimization cited as a major reason for Central American migration in 2014 (Hiskey, Cordova, Orces, & Malone, 2016). As the socio-political climate of Central America has changed, so have patterns of Hispanic immigration to the USA. Indeed, between 2015 and 2016 alone, there was a 131% increase in the number of children and families crossing the Southwestern border of the USA, reflecting large numbers of families seeking "humanitarian protection" (U.S. Border Patrol, Southwest Border Sectors, 2016). The unprecedented danger in Central America has been cited as a "humanitarian emergency" by President Obama, with children and families being described as requiring "special attention" (Declaration by The Government Of The United States Of America and The Government Of The United Mexican States Concerning Twenty-First Century Border Management, 2010) and "particular focus" (Federal Strategic Action Plan on Services for Victims of Human Trafficking in the United States, 2014) by several government agencies. Dramatic increases in rates of crime, violence, and death in Central America have corresponded to increases in reports of trauma and posttraumatic symptoms among recent waves of Hispanic immigrants (U.S. Conference on Catholic Bishops, 2014).

Research with other immigrant groups has also demonstrated that individuals who are displaced due to violence in society, abuse in the home, persecution, or deprivation are at a higher risk for developing psychopathology (Ehntholt & Yule, 2006; Fazel, Reed, Panter-Brick, & Stein, 2012; Reed, Fazel, Jones, Panter-Brick, & Stein, 2012); this distinguishes many recent Hispanic immigrants from individuals who immigrated freely to the USA. Indeed, studies examining psychopathology in Hispanic adolescent immigrants in the USA confirm high rates of psychopathology (Locke, Southwick, McCloskey, & Fernández-Esquer, 1996; Perreira & Ornelas, 2013; Potochnick & Perreira, 2010) and suggest that the *Immigrant Paradox* or *Hispanic Paradox* may not apply. Likewise, a review of risk and protective factors for mental health in youth who are displaced from their home countries and resettled in high-income countries after immigration reveals high rates of adversity during migration and in their home country, with related increases in posttraumatic stress, internalizing problems, and social maladjustment (Fazel et al., 2012). Across the literature on this topic, exposure to pre-migration violence, being female, migrating without a guardian, perceived discrimination after migration, exposure to post-migration violence, changes of residence after migration, parental exposure to violence, limited financial means, single parent families, and parental psychopathology were identified as risk factors for immigrant youth mental health (Fazel et al., 2012). High parental/familial support, self-reported peer support, positive school experiences, and placement with a foster care family of the same ethnic background emerged as protective factors in this review (Fazel et al., 2012).

Across literatures related to Hispanics and non-Hispanic immigrants, as well as youth and adult immigrants, the relation between immigration and mental health is inconsistent. Relations identified in prior research appear to depend upon exposure to contextual risk factors as well as individual variables and pre-existing vulnerability (e.g., exposure to violence in home country). Across many aforementioned studies, the role of acculturation is modeled or theorized. A review of that literature occupies the next section.

Acculturation

Acculturation refers to a bi-dimensional process in which an individual will range from high to low on affiliation with their host (post-migration) culture and, on a separate axis, from high to low on affiliation with their culture of origin (Sam & Berry, 2010). Individuals high in affiliation with their host culture and low in affiliation with their culture of origin, for instance, are described as “assimilated,” where as individuals high on both axes are referred to as “bicultural/integrated.” Individuals low in both metrics are described as “marginalized” and individuals with high affiliation with their culture of origin only are referred to as “traditional/separated.” Overall, acculturation among immigrants is conceptualized as a change in cultural identity, which includes shifts in various cultural dimensions including typical practices, values, and identifications (Schwartz, Unger, Zamboanga, & Szapocznik, 2010).

Literature regarding the link between acculturation and mental health is mixed, with some studies of the *Immigrant Paradox* reporting that lower acculturation with the host country accounts for health benefits (e.g., Kaplan & Marks, 1990) and others showing that low acculturation among immigrants is risk factor for negative mental health outcomes (e.g., Hwang & Ting, 2008). Indeed, the aforementioned *Immigrant* and *Hispanic Paradox* literatures cite that individuals with lower acculturation to the USA experience greater benefits (Teruya & Bazargan-Hejazi, 2013), and some of the identified health benefits noted in the *Paradox* research erode with increasing time and generations in the USA as Hispanic acculturation to US culture increases and damaging health behaviors (e.g., smoking) increase (Kondo, Rossi, Schwartz, Zamboanga, & Scalf, 2016). Numerous explanations have been put forth to explain these inconsistent findings, including heterogeneity within and across immigrant groups, inconsistent measurement of acculturation, and lack of measurement of related variables regarding ethnic identity (Bulut & Gayman, 2016). In studies that have endeavored to address these limitations, acculturation emerges as a complex construct without simple relations to mental health. Indeed, findings do not link simple conceptualizations of high or low acculturation to mental health, but rather identify risk in specific interactions between both axes put forth by Sam and Berry (2010). Specifically, marginalization appears to be relatively associated with negative mental health outcomes, whereas integration is associated with positive mental health outcomes (Yoon et al., 2013). Support for this conclusion has been documented with regard to both Latino and Asian immigrants (Bulut & Gayman, 2016), and the worst outcomes have been noted among recently arrived immigrants.

Critiques of existing literature on acculturation in the context of mental health, however, have cited inconsistent measurement and definition of acculturation across studies (Bulut & Gayman, 2016; Teruya & Bazargan-Hejazi, 2013). Indeed, acculturation is often treated as though it is synonymous with acculturative stress—self-reported distress during the acculturation process (e.g., distress associated with speaking with an accent). Existing literature regarding acculturative stress is relatively consistent across immigrant groups, suggesting that distress while adjusting to acculturation has a negative impact on all ethnic groups' mental health (Caplan, 2007; Teruya & Bazargan-Hejazi, 2013; Turner, Lloyd, & Taylor, 2006), with particularly profound impacts on the substance use of Hispanics in the USA (Turner et al., 2006). Relatedly, perceived racism and discrimination have been linked to negative mental health and academic outcomes in immigrant youth in the USA (Smokowski & Bacallao, 2006; Suárez-Orozco, Rhodes, & Milburn, 2009). In studies that account for both acculturation level and acculturative stress, the latter emerges as the significant risk factor for psychopathology (Hwang & Ting, 2008), indicating that experiences of perceived discrimination and related distress are more relevant to mental health in immigrant groups than cultural identification alone.

Resiliency

One important characteristic that is apparent when working with immigrant groups in the clinical and research setting is the level of resiliency they exude. Many researchers have highlighted the Latino culture and how it affects health outcomes.

For example, Gallo, Penedo, de los Monteros, and Arguelles (2009) and colleagues conceptualize the Reserve Capacity Model, which helps explain how multiple types of psychosocial factors might contribute to the disparities related to SES. Individuals with less reserve capacity may have fewer social factors to help deal with stress. These factors can be interpersonal (support, relationships, social roles), intrapersonal (perception of control, future, optimistic views), and/or tangible (transportation, saving, day care). To be able to have a better chance of being resilient, the more reserve capacity an individual has, the higher chance they have at overcoming obstacles. This may represent a protective factor that enhances resiliency in individuals who maintain high levels of reserve capacity even in the context of adverse circumstances. Latino cultural values can play a significant role in resiliency. Some main values include allocentrism, familismo, and simpatia. Allocentrism and familismo focus on the idea that the group or family needs come before the individual. This allows for individuals to have greater social networks and support. Simpatia reflects a drive toward non-confrontational social interactions.

Another prominent model, The *Hispanic Health Paradox*, is one of the sociocultural resilience factors put forth by Ruiz et al. (2016). This model posits that the Hispanic health advantage is driven by sociocultural resilience factors that promote positive health—specifically, collectivist values including "family (*familismo*), interpersonal harmony (*simpatía*), and valuing of elder community members (*respeto*)" (Ruiz et al., 2016, p. 467). This model will be examined later in the future directions section, as there is a great need for research to be done on resilience factors and the health of immigrant groups in the USA.

Practice Perspectives

Assessments

The overwhelming majority of relevant empirical and position papers address the psychological assessment of ethnic minorities. While not specific to immigrant groups, this literature base has been central in identifying psychometric considerations that are critical in determining whether it is appropriate to extend assessment instruments developed in one cultural group to another. In this section, we review Pina, Gonzales, Holly, Zerr, and Wynne's (2013) approach to evidence-based assessment with ethnic minorities, focusing on the psychometric concepts of measurement equivalence and method bias. Overall, these topics go beyond calculation of basic psychometric properties like internal consistency or validity to examine whether psychometric properties are consistent across meaningful population subgroups (e.g., cultural groups or immigrant groups)—considerations cited in the *Standards for Educational and Psychological Testing* (AERA, APA, & NCME, 1999) and in the American Psychological Association's Handbook of Clinical Psychology (Norcross, VandenBos, Freedheim, & Domenech Rodríguez, 2016).

Psychometric Considerations

Measurement equivalence includes both item equivalence (which can include configural, metric, threshold, and item uniqueness invariance) and construct validity equivalence (which includes functional and scalar equivalence) (Hui & Triandis, 1985; Knight, Tein, Prost, & Gonzales, 2002; Pina et al., 2013). Broadly, configural invariance asks whether an assessment instrument demonstrates the same factor structure across groups (Ghorpade, Hattrup, & Lackritz, 1999; Millsap & Tein, 2004; Pina et al., 2013; Vandenberg & Lance, 2000). If the configural invariance of an instrument is low, some items from that instrument do not load onto their hypothesized and previously documented factor when the scale is completed in a different cultural group. Pina et al. (2013) are careful to note that evidence of configural invariance is insufficient to support the use of an instrument across groups, citing that metric invariance—the extent to which the meaning of individual assessment items differs across groups (Labouvie & Ruetsch, 1995; Pina et al., 2013; Raykov, 2004)—may be a more important clinical consideration. Indeed, Pina et al. (2013) note that culturally embedded terms like "nervios" in Spanish may be mistaken for less culturally laden terms, like the more general "nervous," thereby leading to different interpretations of an item across groups. Similarly, items intended to assess depression by probing feelings of "punishment" may not perform equivalently in cultural groups where religious notions of punishment are common (Azocar, Arean, Miranda, & Muñoz, 2001). Finally, threshold invariance (Pina et al., 2013; Widaman & Reise, 1997) asks how severely a construct must be experienced before the client endorses a given item, and item uniqueness invariance (Byrne, Shavelson, & Muthén, 1989; Pina et al., 2013) refers to the unexplained variance in item endorsement. Ideally, assessment instruments would be subjected to empirical analyses of configural, metric, threshold, and item uniqueness invariance in an effort to establish item equivalence between the group in which the measure was developed and the group to which the assessment client belongs.

In order to fully evaluate measurement equivalence, empirical work would also endeavor to examine construct validity equivalence—the notion that "the construct being assessed has similar precursors, consequences, and/or correlates across groups" (Pina et al., 2013). Specifically, functional equivalence would assess whether the slopes of construct validity relations are consistent across groups, whereas scalar equivalence would evaluate the intercepts of those relations (Knight et al., 2002; Knight & Hill, 1998). An assessment instrument should have demonstrated both construct validity equivalence and item equivalence with respect to the client's cultural, ethnic, or racial group before being included in an evidence-based assessment. The same standard could be applied to other meaningful subpopulations, like immigrant groups.

A final consideration noted by Pina et al. (2013) centers upon method bias—the notion that assessment methods like interviews or questionnaires produce nonequivalent data across groups (e.g., Van de Vijver & Leung, 2011). For instance, Asian American ratings of social anxiety are significantly higher than European

Americans on questionnaire-based measures but significantly lower on interview-based measures, suggesting method bias in the assessment of social anxiety (Matsumoto & Kupperbusch, 2001). Attention to method variance introduces a number of other assessment considerations related to the language of assessment.

Linguistic Considerations

A number of studies have cited concerns regarding how psychological assessment in one's non-native language (a common experience among immigrant groups) may affect the quality of clinical assessment. Existing data suggests that conducting psychodiagnostic interviews—both semi- and unstructured—in a second language may influence the emotional content described by the client and the affective states observed by the clinician, possibly biasing assessment data (Oquendo, 1996; Venta, Muñoz, & Bailey, 2017). It should be noted that determining the language in which to conduct a psychological assessment is a complex area of empirical research on its own (see the Multidimensional Assessment Model for Bilingual Individuals by Ortiz & Ochoa, 2005, for instance). Moreover, it is established within cognitive and achievement testing realms that linguistic dominance interacts with cultural loading in relation to test validity issues (e.g., Rhodes, Ochoa, & Ortiz, 2005).

The Culture-Language Test Classification system (Flanagan & Ortiz, 2001; Flanagan, Ortiz, & Alfonso, 2007; McGrew & Flanagan, 1998) was developed in order to address the question of whether low cognitive or achievement test scores reflect cultural/linguistic differences or disorder (i.e., "difference versus disorder") (Ortiz, Ochoa, & Dynda, 2012). Specifically, existing norm-referenced tests were categorized according to their hypothesized cultural loading (based on bilingual examinee performance) on the Culture-Language Test Classifications matrix and on its successor, the Culture-Language Interpretive Matrix. The current iteration of Flanagan and Ortiz's (2001) Culture-Language Interpretive Matrix arranges psychological assessments across axes representing linguistic demand and cultural loading. Client performance is hypothesized to be least affected when both cultural loading and linguistic demand are low and, conversely, most affected when both are high. Interested clinicians are referred to the Cross-Battery Assessment Software System (X-BASS v. 1.3), available for purchase, which includes interactive worksheets to determine the linguistic demand and cultural loading for specific, commonly used assessment instruments (Ortiz, Flanagan, & Alfonso, 2017).

Practical Solutions

Clinicians are encouraged to select instruments that have demonstrated measurement equivalence and consider the cultural loading and linguistic demands of instruments prior to inclusion in their evidence-based assessment batteries. Pina et al.

(2013) provide a comprehensive review of existing literature of cross-ethnic measurement equivalence studies of broad-band, internalizing, and externalizing rating scales as well as diagnostic interviews available for youth in their chapter "Toward Evidence-Based Clinical Assessment of Ethnic Minority Youth." Clinicians engaged in intellectual testing may benefit from Ortiz et al. (2012) chapter entitled "Testing with Culturally and Linguistically Diverse Populations: Moving beyond the Verbal-Performance Dichotomy into Evidence-Based Practice." A broad review of assessment instruments for adults and children is provided by Suzuki and Wilton (2015) in their chapter, "Assessment with Racial/Ethnic Minorities and Special Populations" within the American Psychological Association's Handbook of Clinical Psychology. Clinicians practicing within a special emphasis area, such as forensic clinical psychology, may have only a few articles providing guidance regarding assessments across cultural or ethnic groups (e.g., Canales, Kan, & Varela, 2016; Weiss & Rosenfeld, 2012).

Still, existing literature often assumes homogeneity across ethnic groups with little consideration for critical variables reviewed in this chapter like immigration status and acculturation. Moreover, measurement equivalence and method bias studies are limited, partly because they require substantial resources and pose unique methodological challenges (Fernandez, Boccaccini, & Noland, 2007). At this time, clinicians are encouraged to take the scientist-practitioner model to heart—reviewing available empirical support for the instruments they use and acknowledging limitations in the existing data when describing the validity of assessment instruments included in their chosen battery. Indeed, regardless of focus area, clinicians may find the four-step approach put forth by Fernandez et al. (2007) helpful. First, clinicians identify tests available in their language of interest; second, available research must be reviewed so that; third, research can be reviewed for its applicability to the specific client; and finally, the clinician can make an overall determination about the level of research support for using the selected test with the identified client. Though the four-step approach was originally devised for clinicians seeking to identify and select translated tests, it is based on the professional testing standards put forth by the *Standards for Educational and Psychological Testing* (AERA, APA, & NCME, 1999) which addresses "fairness in testing" more generally and may therefore be useful to clinicians working with immigrant populations.

Counseling Perspectives

In order to provide the most effective mental health interventions to immigrant groups, several guiding principles have been proposed by Casas (2017) and La Roche, Christopher, and West (2017). One important movement in psychotherapy has been cultural evidenced-based psychotherapies (CEBPs). CEBPs refer to evidenced-based counseling interventions that emphasize race and ethnicity, and also integrates cultural proximal variables, such as socioeconomic status, neighborhood violence, and religion (La Roche et al. 2017). By integrating cultural and proximal factors, clinicians can have a better understanding of the psychotherapeutic process. One important consideration La Roche et al. (2017) highlight is the importance of operationally defining race, ethnicity, and culture, and examining the effects of cultural variables as each impacts the psychotherapeutic process. Doing so can further enhance the efficacy of cultural competency recommendations.

Casas (2017) also postulates imperative guiding principles for clinicians to work effectively with culturally diverse groups, yet specifically identifies the immigrant population. First, the author suggests using an ecological framework proposed by Bronfenbrenner and Morris (2006) to guide interventions. This perspective highlights the human experience as a result of reciprocal interactions between people and the environment, and how it varies from individuals, contexts, culture, and time (Casas, 2017). This allows clinicians to understand the immigrant experience and thus develop appropriate interventions. A second guiding principle includes the necessity of integrating evidenced-based practice with practice-based interventions (Casas, 2017; La Roche et al. 2017). The third guiding principle supports The APA's Presidential Task Force on Immigration (2012) report postulating the importance of cultural competency, which includes cultural knowledge, the therapist's attitudes and beliefs, as well as the skills needed for the effective delivery of culturally appropriate interventions. A fourth guiding principle involves the significance of utilizing comprehensive community-based interventions. This allows the clinician to collaborate with the various systems that are part of the client's life, such as primary care, mental health, social, legal, and educational branches. Collaborating with various social service entities allows the client to be validated and empowered (Casas, 2017). The fifth and final guiding principle used in effective delivery of clinical interventions with immigrant groups includes the importance of using a social justice perspective as a driving force for all services (Casas, 2017). We have found this to be a vital factor in the implementation of effective treatment delivery. The belief that all people have a right for equitable treatment and fair allocation of societal resources is critical and is a paradigm shift among mental health providers. There are obstacles that some may face, however, playing an active role in advocacy and policymaking for humane treatment of all persons including immigrant groups is of utmost importance. Advocacy in local, state, and national platforms is critical in order to advance social justice and mental health.

New Psychiatric Perspectives

Psychiatric disorders are brain disorders, and generally speaking most people have brains that are anatomically similar. The conversation about ethnicities and cultural competence in the field of psychiatry is essential to understanding these disorders. Although it can be said that most of us have brains composed of the same major anatomical areas such as Frontal, Temporal, Occipital Lobes, and subcortical areas like the Amygdala, Thalamus, and others, all of our brains are different. What makes one brain different from another lies in the development of particular pathways, tracts, and connections contained within those structures. All of these trillions of connections are shaped through the developmental stages from birth to the mid-20s. Although the brain has an intrinsic ability to form these connections, the environment has been found to be crucial in how they are made. Culture is an essential aspect of the environmental factors affecting the millions of connections that are made during the life of a person. Culture not only affects brain development but also builds our perception of our self and our relationship with our environment.

According to the U.S. Census in 2017, there are approximately 57.5 million Latinos or Hispanics. It has been found in statistical data that about 15% of this population suffer from psychiatric disorders each year (NIMH Census Study, 2012). While some believe that Latinos have a negative attitude toward psychiatric disorders, there is very little evidence to support this perception. This belief is probably a remnant of previous generations and their attitudes. It is quite common to hear stories from patients describing how these attitudes have changed over time. It is possible to assume that those Latinos who have recently immigrated to the USA may experience more difficulties regarding treatment of psychiatric conditions. Psychiatric disorders in general are embedded with stigma, and this is in part related to the dualism of mental conditions—the belief that mental conditions originate somewhere other than the brain. The Latino culture has always attempted to explain abnormal behavior by blaming an outside entity, that being parents, friends, or via spirituality. It is common to meet Hispanic parents that present to the clinic suffering depression after their child has developed a mental disorder. Many Hispanics may decide to prolong the treatment of mental conditions, believing that their suffering is rooted in a spiritual or personal weakness.

What studies have shown is that, in the USA, the problem doesn't lie with negative attitudes toward mental disorders but rather that Hispanics have more positive attitudes toward mental disorders than non-Hispanic Whites. This suggests that the barriers to treatment are structural in nature, including socioeconomic factors as well as language. The lifetime prevalence of mental illness for Latino populations in the USA is lower than that of non-Latino Whites (30–40% vs. 50%). Latinos that have immigrated to the USA actually have a lower prevalence of mental illness than those who are US born. Many factors can be associated with these findings. This data is essential for clinicians when diagnosing and treating Latinos.

Another epidemiological factor of concern is related to the prevalence of suicide ideas and suicidal attempts within the Latino community. Centre for Disease Control (CDC) data reported in 2012 shows that Latino males in high school have the same prevalence of suicidal ideas as non-Latino Whites (10.7 vs. 10.5), but tend to have more suicidal attempts (6.9 vs. 4.6). This data is even more concerning when looking at females in the same age range. Latino females are twice as likely to think about suicide and to attempt suicide compared to their male counterparts (13.5%) (CDC Data on Adolescent Suicide, 2014). These rates are higher than those found in non-Latino individuals. When a clinician encounters a Latino, keeping these factors in consideration would allow for a more tailored approach to their treatment.

For example, recognizing that Latino females in high school have a high prevalence of suicide ideas should trigger a more focused interview for this population.

Interestingly, acculturation in the Latino population has been studied and the results were unexpected to a certain extent. Most Latinos that immigrate to the USA do so as part of an effort to better their socioeconomic status. Studies have shown that in the Latino population, the more acculturation achieved by the individual, the more prevalence of mental disorders (Lanouette, Folsom, Sciolla, & Jeste, 2009). Acculturation is defined by the process in which an individual acquires the attitudes, values, beliefs, and customs of another culture. It is unclear if this correlation shows a protective factor from the innate culture or a liability acquired with the new culture, or if it is just the result of stress related to being an immigrant and leaving home behind. More studies need to be done in this area.

Treatment adherence in the Latino population is also an area of concern. For example, it has been noted that an average of 50% of Latino patients return to see their psychologist, based on a report from the American Psychological Association. This compares to about a 70% rate of return by non-Latino Whites. The American Psychiatric Association reported in their Fact Sheet (2014) that only 36% of Hispanics with depression ever receive treatment, versus 60% of Whites. One of the concerns shared by the APA is a language barrier. Another concern was that Latinos are usually under-treated compared to Whites. Reasons for this under-treatment should be investigated further. It is a universal understanding in the field of mental health that social support, including family, is essential to the adherence of treatment and for achieving remission of symptoms. The US Latino population doesn't maintain, as a general rule, the same level of family interaction that is seen in Latino countries, which may be a factor that triggers worse outcomes in the USA compared to Latino countries.

A meta-analysis of treatment adherence in the Latino population demonstrated that there are various factors that were associated with better adherence. Some factors were, as expected, family support, being married, and having better finances. Other factors that were interesting included more severe cases of depression and use of Selective Serotonin Receptor Inhibitors (SSRI's) (Lanouette et al., 2009). Apparently in severe depression syndromes, Latinos experience an increase in adherence to treatment, showing more resilience. Also, Latino patients suffering with depression tend to be more adherent to SSRIs than to non-SSRI medications. It is possible that there is genetic predisposition to being more tolerant of this class of medications than to other antidepressants, as a general rule. Latinos that were involved in therapy by attending more than eight sessions in a year with a non-medical therapist would be more adherent to their psychotropics. In certain systems in the USA, access to psychologists and master-level counselors is very limited, and care is limited to the prescription of medications. Under these circumstances, the Latino patient will most likely experience a low adherence. It is important to always involve a therapist or psychologist in the treatment of mental illness. It seems the Latino patient benefits substantially from these interventions and increases in overall adherence to treatment.

Another study found that Latinos are less likely to have discussions regarding their medications with their physicians. This same study also found that Latinos are less likely to complain about side effects than non-Latino Whites (Alegría et al., 2008). In the Latino culture, physicians and health providers are still perceived as figures of authority. The Latino patient seems to be more self-conscious about this dynamic, which in turn impedes the delivery of necessary services. A Latino patient may be more concerned about upsetting his provider for not following treatment recommendations. It is important for the provider to develop a non-judgmental approach to the Latino patient, focusing on developing rapport and establishing a relationship of collaboration that is evident from the beginning. The patient should be empowered with participating in the decision-making process related to their treatment. There are no evidence-based guidelines for improving adherence in the Latino population, but some general recommendations can be made based on the literature review, such as reassessing adherence frequently during patient encounters and using pharmacy records in addition to family reports to detect non-adherence. The physician should make it a point to discuss medication adherence and side effects at each visit, and encourage the patient to participate in these discussions. Medication information should be provided in Spanish, including effects, side effects, and what to expect from the medications. Remember that including a therapist in the treatment plan also increases adherence in Latino patients.

The rate of Latino patients in the USA without insurance is about 35.7%, compared to non-Latino Whites at 12.6%. The physician and prescriber should be mindful about this factor when prescribing medications and always attempt to provide medications that would be more cost-effective for the patient, including using generics. Since this is a population which has problems accessing health care, a caring physician who maintains good rapport and allows the Latino patient to be an important member of the treatment team would improve compliance and consequently better prognosis. Even clinics with bilingual programs have been shown to have barriers to treatment. Language may not necessarily be a predominant barrier when the clinician takes into account the important factors in the delivery of services to a Latino patient.

When treating a Latino patient with behavioral health symptoms, one of the most important aspects to consider is the prevalence of Metabolic Syndrome (MetS). The clinician should be aware of the high prevalence of MetS in the Latino population, since this affects compliance as well as effectiveness in treatment. Psychiatric medications are well known for carrying an increased risk of MetS, specifically antipsychotics. This group of medications has been associated with an increase in weight, as well as increased lipid parameters and hyperglycemia. The combination of changes in these parameters can lead to MetS. Schizophrenia in particular has been associated with increased levels in these parameters, and treatment can ultimately multiply these risks. This problem is magnified in the Latino population. A study by Manuel Ortiz and colleagues from University of California showed that there is a particular increase for the predisposition of MetS in the Latino population (Psychosocial Predictors of Metabolic Syndrome Among Latino Group in the Multi-Ethnic Study of Atherosclerosis, Ortiz, Myers, Schetter, Rodriguez, & Seeman; PLOS ONE, April

Ortiz, Myers, Schetter, Rodriguez, & Seeman, 2015). Furthermore, they were able to demonstrate that even when not looking at medication-related risks, the presence of chronic stress as an isolated factor tends to increase the prevalence of MetS in Latinos, and predominantly in Mexican American and Puerto Rican Americans. When treating Latinos with antipsychotic medications, one must pay particular attention to monitoring weight, lipid profiles, and glucose levels. The best approach is to educate the person early on during the initiation of treatment. In our experience, best results are seen when these parameters are discussed at every session.

The integration of behavioral health and primary care has been one of the most interesting challenges of the last decade. The understanding that psychiatric patients have an increased mortality rate compared to the general population has led us to understand that integration of care is essential to the prevention of disease within this population. This is especially true when addressing MetS. In the medical integration model of Primary Care and Behavioral Health, the patient is seen in a holistic perspective and the members of the team pay particular attention to the interactions between general health and behavioral health interventions. A true integration effort should have both departments within the same building and sharing the same electronic medical record. Communication between providers is essential to diminish all risks associated with the psychiatric condition, as well as the medical interventions they require. Integration models have shown that they are effective in reducing morbidity related to medical interventions.

Smoking cessation is a one of the clinical challenges that is more effectively addressed within the integrative model of care. Smoking not only has harmful effects on the body—the main component, nicotine, has psychopharmacological properties and diminishes the effectiveness of psychiatric medications. Much has been said about the impact of smoking in the psychiatric patient. In Schizophrenia, the person finds nicotine to be anxiolytic and is able to reduce some of the internal restlessness that is the result of complex changes in neurotransmitters related to this condition. Interestingly enough, some studies have shown that smoking has a specific impact on the Latino patient, with an increased prevalence of depression (2014). This finding is significant and must be evaluated in the Latino patient that suffers from a psychiatric condition and simultaneously has a Nicotine Use Disorder. Since Schizophrenia is already associated with an increased incidence of smoking than the general population, it can be assumed that in the Latino population it may carry an increased loading of depressive symptoms as well. This may even explain the high prevalence of Schizoaffective Disorders, Depressed type found in the Latino population. The clinician should always inquire about the smoking status of the Latino person, and a positive response should lead to further investigating of depressive symptoms. PHQ-3 and PHQ-9 are screening tools that can be useful in persons with Schizophrenia and should frequently be screened due to the increased risk of depression and nicotine use.

Some observations based on clinical experience as well as various small studies suggest that Latinos, in general, believe that medications used in psychiatry are addictive (Vargas et al., 2015). The Latino patient is ambivalent about psychiatric treatment in general. This is seen quite frequently in our community mental health clinics with a predominantly Latino population. The perception that psychiatric medications are addictive probably stems from the early use of benzodiazepines as main treatments for depression. The consequence of this perception is that Latino patients will have less adherence to treatment than other minorities or ethnicities. The Latino patient will generalize this perception to most medications in the treatment, leading to a resistance to such medications. The patient may refuse to start medications when they may be indicated, or may decide to stop the medications or take them only as needed to prevent a potential addiction. Since this is a predominant idea in the Latino population, it is important to provide as much education as possible regarding the fact that most antidepressants and other medications in psychiatry are not addictive or cause physiological dependence. Another false perception related to addiction is the belief that once they are started on a medication, they will need to take the medication for the rest of their lives. The clinician needs to be disciplined in maintaining the treatment until the risk of recurrence has diminished enough to attempt reducing or even tapering down the medication, especially with regard to antidepressants.

Future Directions

The vast majority of mental health research conducted on immigrant families assesses the functioning of children and parents who have been residing within the USA for a number of years, allowing time for a certain level of acculturation. There appears to be a large gap in the study of immigrant families at the point upon which immigrants of Latin-American origin have immediately arrived within the confines of the US border. An important future direction is to explore critical psychological factors in newly arrived immigrant groups. This is something that the authors of this chapter are currently exploring with immigrant groups on the Texas–Mexico border, where there has been a recent influx of immigrants of approximately 15,500 Latinos from Central and South America, in addition to a surge of Cubans and Haitians in the month of November 2016 alone, according to the U.S. Customs and Border Protection Office of Field Operations (The Monitor, 2017).

Another important future consideration is to further investigate The *Hispanic Health Paradox*. This model refers to an existing literature base showing that, despite exposure to many health risks like low socioeconomic status, limited access to health care and insurance, and reduced education and employment, Hispanics in the USA generally report greater health than non-Hispanic Whites (Ruiz et al., 2016). The Hispanic health advantage is evident in life expectancy (Heron, 2015), infant mortality (Collins, Soskolne, Rankin, & Bennett, 2013), cardiovascular disease (Mozaffarian et al., 2015), and cancer (Ruiz et al., 2016). The effect is even more pronounced among Hispanic immigrants (i.e., foreign-born) (Singh et al., 2013). Critically, the advantage erodes with increasing time and generations in the USA as Hispanic acculturation to US culture increases and damaging health behaviors (e.g., smoking) increase (Kondo et al., 2015).

The *Hispanic Health Paradox* is one of the sociocultural resilience factors put forth by Ruiz et al. (2016). This model posits that the Hispanic health advantage (including both susceptibility to disease and survival) is driven by sociocultural resilience factors that promote positive health—specifically, collectivist values including "family (*familismo*), interpersonal harmony (*simpatía*), and valuing of elder community members (*respeto*)" (Ruiz et al., 2016, p. 467). The possible protective role of these sociocultural values has been largely speculated as an explanation for the *Hispanic Health Paradox*, and its erosion as acculturation to US culture increases. However, empirical support for this model is limited by a research base that rarely assesses these sociocultural values directly. Instead, studies have linked "proxies of Latino culture" (Ruiz, Campos, & Garcia, 2016, p. 64) such as higher neighborhood ethnic density (Shaw & Pickett, 2013), foreign nativity (Holmes, Driscoll, & Heron, 2015), and low US acculturation (Kondo et al., 2015) to positive health and *assumed* that increased endorsement of Hispanic cultural values drives the observed relations. Calls to directly assess relations between proposed sociocultural resilience factors and health have dominated recent commentaries on the Hispanic health advantage (e.g., Ruiz and colleagues).

To date, there is little research directly assessing the relation between Hispanic sociocultural factors and physical health in recent immigrants. Without that data, resilience models of the Hispanic Health Paradox fail to identify sociocultural values that may be targets for public health intervention in American-born Hispanics and other ethnic groups. One recent study exploring trauma and cultural values in the health of recent immigrants has identified mental health as the only crisis in the U.S. Southern border (Mercado, Venta, Henderson, & Pimentel, 2019) highlighting the alarming rates of trauma and need for culturally sensitive trauma measures (Venta & Mercado 2018). Moreover, previous studies and models describing sociocultural factors in relation to Hispanic immigrant health have failed to include psychological variables to date, despite tremendous increases in crime, violence, and death in much of Central America. Identifying factors that relate both positively and negatively to the physical health of Hispanic immigrant women and children is a critical variable in identifying vulnerabilities in need of future research and ultimate intervention studies, as well as protective factors warranting public health attention for health promotion in other communities. Research addressing this disparity has implications for a large number of Latinos currently living in the USA, as well as the large number of Latino immigrants that continue crossing its Southwestern border each day. Considering both cultural and psychological variables in a conceptual model of physical health may serve as a model for future research addressing the physical health of other immigrant groups, a pressing need in light of current global crises of unprecedented Middle Eastern and North African family migration.

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Chapter 6
A Health Promotion Framework for Women with Precarious Immigration Status in Canada

Nazilla Khanlou, Attia Khan, and Catriona Mill

Introduction

The right to health encompasses access to health care *and also* support of the underlying determinants of health. Despite evidence supporting a relationship between citizenship status and its effects on both access to health care and subsequent health outcomes (WHO, 2008), policies restricting access to health and social care for migrant women persist in Canada (Magalhaes, Carrasco, & Gastaldo, 2010) and elsewhere (Martinez et al., 2015). Barriers that limit or impede undocumented migrants' ability to receive adequate medical care range from delay (Rousseau et al., 2008) and denial of care at community health centers or hospital emergency rooms where hospitals lack policies and resources to provide them care (Bernhard, Goldring, Young, Berinstein, & Wilson, 2007), lack of financial resources to pay for their care, exclusion from publicly funded healthcare, and inability to seek private insurance due to their status.

Over 10 years ago, Oxman-Martinez and her colleagues in Canada identified precarious immigration status as a barrier to healthcare (Oxman-Martinez et al., 2005). Since that time, worldwide economic, political, and social trends have impacted migration and resettlement policies. Some of this changing context derives

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from growing anti-immigration nationalism in developed countries; restrictive laws and rights, granting bare minimum access rights to public services and healthcare; and is impacted by the negative perceptions of undocumented immigrants by interest groups in power, scapegoated for domestic economic and social problems, as seen through examples from Australia (Johnston, 2009), the USA (Chavez, 2012), and France (Larchanche, 2012). Laws may directly or indirectly—through changes in environment and in behavior—affect individual health status (e.g., lack of access to health services and poor health outcomes), and population health (e.g., morbidity and mortality rates) (Martinez et al., 2015; Rousseau et al., 2008).

Women and children are significantly impacted by lack of access to basic health and social services in the post-migration context. Migrant women typically originate from the Middle East and Africa, Asia, and Central and South America (Esthimer, 2014). More often than not, they are of childbearing age, and fleeing not just war, and also other life-threatening circumstances, such as intimate partner violence, physical threats to their children, as well as gang and community violence (UNHCR, 2015). After a dangerous journey through non-traditional channels of migration, and for reasons that challenge the United Nations' definition for refugee protection, they arrive with the hope of resettling in a new country (Access Alliance Multicultural Community Health Centre [AAMCHC], 2005; UNHCR, 2015).

Canada has a long-established pattern of resettling and promoting health outcomes for migrants through healthy public policy. Over time, health promotion models have emerged that explicate the social determinants of health (Canadian Council on Social Determinants of Health [CCSDH], 2015; Mikkonen & Raphael, 2010). However, to our knowledge, none are specifically developed through a qualitative inquiry into the experiences of migrant women with precarious migration status. Without this knowledge, it is difficult to identify pathways to health, improve health promotion policy, or target essential elements for health equity for women with vulnerable migration status.

Migrant persons with precarious status include entrants who are documented (e.g., temporary foreign workers, family sponsored migrants, care workers in domestic services, or students), and undocumented (e.g., asylum seekers, failed refugee claimants, undocumented entrants, or visa over-stayers) (Ministry of Citizenship, Refugee and Immigration Canada [MCRIC], 2015; Rehaag, 2012; Rousseau et al., 2008). These migrants face challenges in accessing health care and tend to experience negative health consequences, including mental health stressors (Hyndman, D'Addario, & Stevens, 2014; Tastsoglou, Abidi, Brigham, & Lange, 2014; Woodgate et al., 2017), medical crises due to little or no health insurance coverage (Bhuyan, Osborne, & Flor Juanico Cruz, 2016; Woodgate et al., 2017), health deterioration due to unstable living conditions (Walsh, Hanley, Ives, & Hordyk, 2016), persistent physical and mental health illnesses (Bhuyan, 2012; Hyndman et al., 2014; Walsh et al., 2016; Woodgate et al., 2017), as well as higher incidences of hospitalization (Hynie, Ardern, & Robertson, 2016; Walsh et al., 2016). Additional challenges to their health include discrimination, abuse, and complications during pregnancy, as well as serious pre-migration stressors, including a history of having been trafficked, kidnapped, or forced to flee family violence (Bernhard et al., 2007; Bhuyan, 2012; Hynie et al., 2016).

There is also evidence that the precarious jobs that migrants end up taking negatively impact women's health much more than their male counterparts (Menendez, Benach, Muntaner, Amable, & O'Campo, 2007). However, there is minimal literature exploring the health of non-status migrants, and limited studies examining the challenges for migrant women with precarious status. There is an urgent need to strengthen evidence that can underpin sound health promotion policy recommendations for migrant women and inform health promotion planning that is specific to women with no legal migration status.

Seeking to address the gap in precarious migrant health research, this chapter proposes a framework of the determinants of health for migrant women with precarious status, informed by our qualitative study. Based on the findings from interviews and complemented through developments in the migrant health literature, the "Health Promotion Framework for Women with Precarious Immigration Status" is proposed.

Methods

Participants and Procedures

Our exploratory study was guided by a qualitative descriptive approach (Sandelowski, 2000, 2010). Ethical approval for the study was received from the University of Toronto's Research Ethics Board. Data was collected through semi-structured interviews and complemented with post-interview field notes, which assisted us with an in-depth understanding of the health outcomes for women as a result of their non-status. The interviews took approximately 60 min to complete and were audio-recorded to assist with data collection and analysis. Field notes taken during and after the interviews by the researchers added contextual details and contained emerging insights, informing the analysis of data and interpretation of the findings.

The study was undertaken in Toronto between 2005 and 2006. Using purposive sampling, six participants were selected; of these, two were policy makers and four were health care professionals. The health care professionals (a physician, nurse practitioner, therapist, and health promoter) were recruited from a community health center (CHC) in Toronto providing care to women, some of whom had neither legal status nor health insurance in Canada. The two policy makers were from the local municipal level. These professionals provided consent and were interviewed to explore perceived health concerns and challenges in providing health care to migrant women with precarious status.

Analysis

A code-driven thematic analysis of the interview data was conducted. General principles of qualitative descriptive analysis guided this work (Sandelowski, 2000, 2010). Sources of data included verbatim transcription notes from the interviews and study field notes. Salient themes were organized thematically and in relation to each other. Arising themes and sub-themes were also corroborated with published literature in migrant health. Trustworthiness was enhanced through triangulation of data source and investigators. Presentations were also given to different stakeholder groups for their input on the emerging findings and as part of member checking.

Results

Women with precarious migration status experience unique determinants of health directly related to their non-status. Figure 6.1 presents the "Health Promotion Framework for Women with Precarious Immigration Status." Our findings point toward individual, intermediate, and systems levels of influences and experiences.

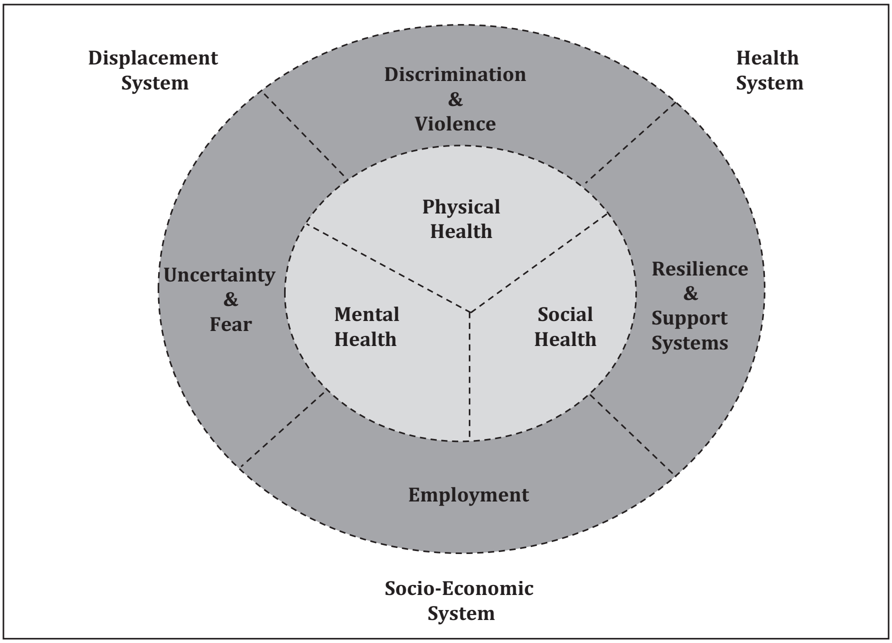

Fig. 6.1 Health promotion framework for women with precarious immigration status. ☐ = Systems level: Displacement, socio-economic, and health systems. ■ = Intermediate level: Women's social context. ▢ = Individual level: Health consequences

For schematic presentation purposes, the *individual level* (*health consequences*) circle is divided into physical, mental, and social health to depict the various dimensions of women's health. The lines within the circle are dotted to illustrate that these are not experienced in isolation, but rather have a dynamic relationship with each other. For example, a sexually transmitted disease (physical health) can affect a woman's mental and social health. Likewise, experience of depression (mental health) affects her physical and social health. The *intermediate level* (*women's social context*) circle entails her experiences of discrimination and violence, uncertainty and fear, employment, and resilience and support systems. A woman's social context has direct consequences on her health and well-being, as illustrated by the dotted lines between the two circles. For example, if a woman is abused by her partner, this will impact her physical, mental, and social health. The outer box represents the *systems level* context. Within this context lie the broader systemic social and structural factors, such as displacement, socio-economic, and health systems. For example, the availability of paid-for health services for a non-status woman will affect whether she accesses services in connection with her reproductive and maternal health.

Displacement, Socio-Economic, and Health Systems

Health care providers and policy makers referred to the determinants shaping daily living and social conditions, and impacting the women's overall health, including physical, mental, and social health outcomes. Individuals who have no official immigration status have different migration experiences, and are not a homogenous population. Their resettlement experiences are profoundly affected by the immigration system—what we refer to as the displacement system, given the women's non-status. However, basic settlement needs are more difficult to secure for women with precarious status, and for some it becomes a chronic long-term struggle: "You find many of them working in very low paying jobs, a lot of them living in poverty for years afterwards. Even if they are here for a very long time, many of them are struggling with basic settlement related issues, like housing and access to services" (P3, health professional).

The phenomenon of undocumented work as an individual or group attempts to improve their quality of life, or the life of the people who are dependent on the person's income, has received limited attention in international health literature. For undocumented workers, their lack of status inhibits their ability to access better paying jobs and forces them into chronic poverty: "They are at the mercy of their employers because they are here illegally and therefore not entitled to minimum wage" (P2, health professional).

While there are multiple complex barriers to access for non-status women, some of the most prevalent in our research relate to fear, employment, and the migration and settlement process, and include language barriers and lack of knowledge of the overall health care system and available services. These factors interact between the systems level and a non-status woman's social context (intermediate level), as depicted by the two outer circles of Fig. 6.1, and influence a woman's physical, mental, and social health.

The physical health of non-status women can also be affected by experiences of discrimination, abuse, and violence. They may face varying forms of discrimination and racism. Additionally, newcomers, irrespective of "race," can be subjected to other forms of discrimination (on bases such as immigrant or refugee status, accent, or country of origin). Victims of abuse not only experience immediate physical health consequences directly from the abuse itself, such as injuries, but also long-term physical and mental health consequences from chronic and repeated victimization. Based on the precarious nature of their lives, non-status women may be at an even greater risk for domestic violence. During two interviews, participants gave us insight into the complexity of an abused non-status woman's life (P1 & P3, health professionals). The fear of being reported to immigration officials, often instilled by their abusive partners, limits women's tangible options to seek help, and frequently they remain silent in dangerous and unhealthy relationships: "…you will find that people live in relationships that are not healthy for them because they don't have status. So you hang around with someone who is abusing you. And a lot of women get threatened, 'if you leave me, I am going to tell immigration'" (P3, health professional).

Access to social support services and programs can help to ease the settlement of newcomers. We refer to "support systems" as community and social services and supports. We recognize the woman's own personal social support network as part of her social health, as discussed in the next section. Without proof of legal immigration status, accessing services and programs is difficult.

Health Consequences

The health of individuals is influenced by the social determinants of health, which impact the physical, mental, and social health of non-status woman (depicted by the inner circle of Fig. 6.1). Undocumented women face the same major physical health risks other women face; however, the lack of status increases their exposure to health risks. While women may arrive with pre-existing health concerns, the precarious nature of their lives in the settlement country can exacerbate existing health issues and concerns.

One interview participant stated as follows:

> I can say what I see, and that is the health concerns are increasing because of the precarious status…. There is a high prevalence of diabetes in that [African and Caribbean] population. But for those who are [sic] precarious immigration status, this will be more acute of a problem; or it will take on a different dimension (P1, health professional).

Sexual and reproductive health risks are also of heightened concern for non-status women, particularly those who have been illegally trafficked into the country and forced to work in the sex trade. Often the early screening, identification, and treatment for many physical health concerns are delayed because non-status women may be hesitant to seek assistance through mainstream social service channels. Women fear that by seeking care they may risk being reported to immigration authorities and deported from the country. Women may also not know where or how to access services for non-status immigrants. These delays may exacerbate health problems, ultimately increasing the woman's risk of morbidity and mortality. For example, one interview participant discussed the high rates of reproductive cancer among non-status women working in factories because they have never received preventive screening, such as PAP smears (P6, policy maker).

Due to the unstable nature of the lives of women with non-status, they can suffer from mental health concerns, such as anxiety, depression, and post-traumatic stress disorder (PTSD). As one interview participant stated, "the more precarious the immigration status of the person is, the more prone she is to experience issues related to mental health" (P1, health professional). While the exact causes of higher rates of psychiatric issues remain a contentious issue, it is important to note that some of these mental health problems existed prior to settling in Canada, while others arise from the volatile and stressful nature of their non-status lives in Canada. As one interview participant stated,

> ... there is a huge incidence of depression … dealing with past trauma and post-traumatic stress disorder amongst our patients.…Except for women that are leaving violent situations, I would say that a lot of emotional problems are a result of their current situation here. It is incredibly stressful to come to a new country where you have no status and be entirely dependent on the people that you meet there (P2, health professional).

Indeed, higher rates of psychiatric illness have been reported among migrant women without status compared to other migrant populations, especially for depression and PTSD which are typically identified as major consequences of lack of access to health care. Three healthcare professionals reported that trauma was often a catalyst for these women leaving their home country (P1, P2, & P3, health professionals). In addition to the resettlement stress and trauma, these women are often fleeing from, they are also frequently separated from their families, friends, communities, and social support networks while trying to manage in a new country. As one participant highlighted,

> …they [women with precarious immigration status] don't have any legal status here so they are in constant fear that they will somehow have a run in with the police who will alert immigration to their being here. This makes it difficult for them to visit their families back home, even when they can afford it, because they have to pass back and forth through customs and immigration (P2, health professional).

For a woman with precarious immigration status, establishing a new social support network within the country of settlement is hampered by the secrecy of her new non-status life. Fear often becomes a predominant experience in the lives of these women: "I think that is the biggest challenge for the individual [without status] is how to trust all these people and agencies when you have to be looking behind your back on a constant basis" (P1, health professional).

Studies identify access to health care as a systemic barrier, related to high medical and psychosocial needs, along with low socio-economic status, language barriers, and lack of familiarity with the host country's systems (Kalich, Heinemann, & Ghahari, 2016; Khanlou, Haque, Skinner, Mantini, & Kurtz-Landy, 2017; Ruiz-Casares, Cleveland, Oulhote, Dunkley-Hickin, & Rousseau, 2016). The barriers to health care for undocumented immigrants vary by country, and in countries with more lenient healthcare, fear of deportation is the biggest obstacle to accessing healthcare. Bureaucratic obstacles can be complex and have similar effects to limiting care. Hacker, Anies, Folb, and Zallman (2015), in their review on barriers to healthcare for undocumented migrants, identified three categories of barriers to healthcare: (1) the policy arena (access and limited use of insurance and type of healthcare); (2) the health care system (bureaucracy, capacity, and existing discriminatory practice); and (3) individual factors (fears, stigma, and lack of social and financial capital). Based on the review findings, the authors recommended five ways in which barriers can be overcome: (1) advocacy for policy change to allow full or variable access to healthcare and public services; (2) insurance options (state-run or employee-based, regardless of status); (3) widening the safety net (hospitals and clinics); (4) training of healthcare providers to appropriately care for migrant populations (documented or undocumented); and (5) facilitating utilization and navigation of health and public systems through navigators or cultural ambassadors.

Discussion

As part of a study of women with precarious immigration status in Canada, we examined the health consequences of having no legal immigration status for women in Toronto, a large metropolitan located in the province of Ontario. Often, the gender-specific concerns of non-status women become lost amidst the media and policy attention directed at undocumented male migrants. Because of their limited legal rights, non-status women face significant, multiple, and interlocking barriers. Their day-to-day lives are marked by constant precariousness, resulting in vulnerabilities that affect all dimensions of their lives and threatening their well-being. Despite over a decade passing from our exploratory study, migrant women with precarious status are still failing to obtain either adequate health care or support for their social determinants of health to maintain their, and their families' optimal health outcomes.

The World Health Organization Commission on the Social Determinants of Health underscores links between poverty, gender, race, early life experiences, social exclusion and conditions of work, and health (World Health Organization [WHO], 2008). The right to health encompasses access to healthcare, *and also* support for the underlying determinants of health (Campbell, Klei, Hodges, Fisman, & Kitto, 2014). A UN common human rights-based approach (HRBA) to health aims to fulfill the realization of the right to health and all health-related rights as laid in the human rights legislature, which requires integration of human rights norms into the implementation of public health policies and programs. The HRBA, while laying down the four essential elements—accessibility, access, acceptability, and quality—to the right to health by all, further stresses the elimination of all forms of discrimination and gender mainstreaming (World Health Organization; Office of the High Commissioner for Human Rights [OHCHR], 2009). This understanding of the right to health, if applied fully, would ensure the development of policies that address all levels of personal, structural, and social determinants of health.

Our framework grows out of an interactive approach by encompassing all levels of influences, from "micro" to "macro" systems levels, and reflects previous research on the intersectionalities of influence on the mental health of refugee women (Guruge & Khanlou, 2004) and further details the determinants of health relevant to migrant women with precarious status. In combination, the intermediate and systems level influences comprise the social determinants of health for a non-status woman and affect her individual level health. In Fig. 6.1, the dotted lines throughout the diagram underscore the interactive nature of influences within, and across, each level. For example, the pervasive experience of insecurity for undocumented women (social context), arising from the possibility of being reported to the immigration system (macro systems context), places them in vulnerable employment conditions (social context), and can affect their mental, physical, and social health (health consequences) through barriers to accessing health care services (macro systems context).

The need to consider gendered and racialized groups in delivering health promotion activities is well accepted (Bierman et al., 2012; Guruge & Khanlou, 2004; Ontario Public Health Association [OPHA], 2017). Research that informs public health promotion and policy in an integrated manner, and that is focused on empowerment of women within the context of their families, communities, and society at large, is imperative to improving the health of women with precarious immigration status across Canada and elsewhere.

Study Limitations

Our study had several limitations that we acknowledge. First, our study's small sample size may have limited the data richness and transferability of findings. Due to the explorative nature of the reported study, all of the health professional participants were sampled from the same CHC. However, data source triangulation was achieved through interviewing health professionals from different disciplines as well as policy makers. Future studies should interview participants from different sites, both within Toronto and across Canada. Second, we did not interview women with non-status due to their vulnerable migration status. In the future, sensitive and trauma-informed approaches to interviewing women with non-status should be formulated prior to data gathering, given their vulnerable migrant status and limited rights. And third, although throughout this chapter we have integrated recent developments in migrant health literature, our exploratory study took place over a decade ago. However, we believe the issues facing women with non-status remain and have amplified, given the significant movement of populations with non-status since then, as well as growing anti-immigrant sentiments at both state and local levels in post-migration contexts.

Conclusion

Migrant women with no legal status face complex and interlocking barriers to their health. Due to their precarious migration status, they have limited legal rights and are subject to multiple threats to their well-being. Despite their high vulnerability and resultant health disparities, limited research has examined the health of non-status women from a multi-systems perspective. We propose the "Health Promotion Framework for Women with Precarious Immigration Status," a framework which places women at the center, recognizing that gender is shaped by, and in turn shapes, the social and macro systems context of each woman.

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Chapter 7
Living in a Refugee Camp: The Syrian Case in Jordan

Alean Al-Krenawi

The plight of the refugee is a tale recounted throughout history. The United Nations High Commissions for Refugees (UNHCR) defines a refugee as an individual fleeing his/her country of origin in order to escape various forms of persecution, violence, and war (UNHCR, 2018). In contrast, an internally-displaced person (IDP) is an individual forcibly displaced within his/her home country. Both refugees and IDPs may be vulnerable due to the religion, race, nationality, political body, or social class he/she may be associated with (UNHCR, 2018). A record 66 million people have been identified as displaced worldwide, with approximately half of them belonging to the under 18 demographic (Efird & Birth-Melander, 2018). Escaping the oppression of their homeland, refugees often encounter further turmoil in their host nations. Effects of these conditions may harm the mental, physical, emotional, and social well-being of the population.

As of 2016, the humanitarian crisis in Syria has led to 13.1 IDPs and 5.5 million refugees fleeing the war zone to settle in neighboring countries such as Lebanon, Jordan, Iraq, Egypt, and Turkey. An estimated 630,000 Syrian refugees have trickled across the border from Syria to Jordan (Doocy, Lyles, Akhu-Zaheya, Burnham, & Burton, 2016). This accounts for approximately 20% of Jordan's population (Abbott, Woods, Halim, & Qureshi, 2017; Murshidi, 2016). Of these, more than 80% reside in non-camp settings throughout the urban and rural areas of Jordan, allowing them access to existing health care services in the host community. The Zaatari camp in the north is the largest formal refugee camp in Jordan, with 80,000 Syrians seeking shelter in its premises (Abbott et al., 2017). Others include the Al-Azraq Camp and the Emirati Jordanian Camp.

The events they witnessed cause multi-faceted trauma to the refugees in their new environment. Pre-emigration stressors include loss of close relatives, unsafe

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situations, starvation, bombing, arrest, physical and sexual abuse, as well as torture. Post-traumatic stress disorder (PTSD), depression, and anxiety affect a large quantity of the Syrian refugee population. Post-emigration, refugees are also exposed to social exclusion and discrimination, lack of respect, high unemployment rates, and economic difficulties associated with low levels of access to basic social services, including health services. This is particularly true for sexual health services, a major issue when confronting the increasing cases of sexual violence against women and children, including rape and child marriage (interview with psychologist working on Al-Alzrak camp).

Children are one of the most vulnerable demographics, facing a lack of water, food, shelter, and education in both camp and non-camp settings. They also face higher incidences of physical and sexual violence; all of which culminate into an increase in mental health problems, including feelings of anger, anxiety, depression, and chronic stress. Various studies have also looked at sleeping disorders, post-traumatic disorders, and somatic disorders in the population, causing physical detriment. The most common coping strategy was determined to be avoidance, in addition to familial support, which was also deemed important to Syrians. Less use of problem-solving strategies was observed.

Since the start of the crisis, the international community has worked hand-in-hand with the Jordanian government to provide for the vast influx of Syrians. The Jordan Compact was developed to create 200,000 jobs for refugees. In exchange for trade agreements with the European Union, the Government of Jordan would provide Syrians with opportunities for education and legal employment (Barbelet, Hagen-Zanker, & Mansour-Ille, 2018). However, progress has been slow. Financial barriers and the quality of services to Syrian refugees are obstacles to reaching further educational opportunities for all Syrian children. Additionally, the economic burden placed on Jordan has limited the potential for Syrian employment. In consequence, the Jordan Compact has been slow in improving Syrians' standard of living.

The goals for this paper are to discuss research investigating the mental, physical, emotional, and social conditions in which Syrian child refugees in Jordan are surviving. A particular interest will be paid to Syrian child refugees of Jordanian camp and non-camp settings. This includes the unique situations facing the demographic, including child marriage, child labor, and increased sexual violence. To conclude, coping strategies of the Syrians in Jordan will be evaluated, as well as future directions for possible treatments and therapies that may benefit the population.

The Psychological Effects of Post-emigration Stressors in Camp and Non-camp Settings in Jordan

Due to the overwhelming influx of individuals across the border, the Jordanian government is struggling to maintain and provide the necessary health care services to this extensive population. Prior to 2014, the Jordanian Ministry of Health and

UNHCR determined that Syrian refugees who registered with the UNHCR could receive free primary, secondary, and some tertiary health care services at public health institutions and governmental hospitals across Jordan (Doocy et al., 2016). However, as the conflict in Syria reaches its sixth year, and with limited international financial support, Jordanians have encountered difficulty facing declining wages, rising unemployment, increasing rent, and strained educational and health establishments. The Ministry of Health now requires that following 6 months after registration, refugees pay a minor co-payment fee, equal to that of non-insured Jordanians (Ay, González, & Delgado, 2016; Balsari, Abisaab, Hamill, & Leaning, 2015). However, this often proves too demanding for Syrian families struggling to rebuild their lives and become economically independent in this new environment.

Ay et al. (2016) have investigated other major structural and social barriers to health care services that afflict Syrians in Jordan. These include lack of insurance, extended wait times, access to and expenses of transportation, working hours of health facilities, child care, appointment availability, stigma, language barriers, lack of health awareness, perceived discrimination, acculturation, cost of treatment, lack of trust, fear of deportation, differing health beliefs, low prioritization of health concerns, mistrust, refugee status, and unfamiliarity with a new health system (Ay et al., 2016). As a result, refugee families experience feelings of insecurity, dependence, shame, and anger (Alzoubi, Al-Smadi, & Gougazeh, 2019). Oftentimes, these emotions may evolve into psychological projection, in which feelings of anger and vulnerability are displaced and projected onto surrounding family members.

Al-Zghoul (2016) studied the Al-Zaatari refugee population, focusing on the psychological, economic, and physical consequences of displacement. His study consists of a sample of 120 families living in the camp, and from this he developed several conclusions. First, that international and regional agencies marginalize refugee communities; second, that refugees face severe socio-economic pressures in their new host country; and third, that high levels of anxiety and depression exist within the community. Similarly, Jabbar and Zaza (2014) conducted research comparing anxiety and depression symptoms between Syrian refugee children in the Al-Zaatari Camp and Jordanian children raised in close proximity to refugee residences in non-conflict areas. Higher depression scores were found in the Syrian population, including the highest expression of "thoughts of ending your own life."

Another study investigating depression among Syrian refugees in Jordan was conducted by Nazzal (2017). Using Beck and Gamorov scales, a sample of 149 Syrian refugees was tested, with results indicating moderate levels of depression. Statistically significant differences were found in regard to age, with refugees aged 60 and above ranking highest on both scales of depression. The adult age group (i.e., 20–35 years old) scored lowest for depression.

Hassan (2015) examined the emotional, rational, and material losses that the Syrian refugees experienced. Feelings of grief, sadness, frustration, anxiety, and anger were all observed in the refugees. Cognitive problems such as loss of control, helplessness, worry, boredom, and hopelessness were also common. Physical characteristics included fatigue, insomnia, lack of appetite, and medically unexplained physical ailments. Withdrawal, aggression, and interpersonal difficulties were also noted as being observed in Syrian refugees.

Momani and Al-Fraihat (2016) suggested psychosomatic care centers be available for refugees in both rural and urban settings. They looked at social and demographic factors as predictors of psychosomatic conditions in Syrian populations in Jordan. Gender, age, education level, and residence in a camp were statistically significant in determining psychosomatic disorders. In comparison, pre-emigration trauma, Jordanians' negative attitudes, marital status, fear of reestablishment, and residence in cities and villages were not valid predictors.

Additionally, an investigation by the Norwegian Refugee Council (NRC), Information and Research Center—King Hussein Research Foundation (IRCKHF), and the International Blue Crescent Relief and Development Foundation (IBC) revealed that Syrian refugees in Jordan aged 15–24 were losing hope, facing poverty, a shortage of economic opportunities, feelings of frustration, lack of access to education, and an absence of engagement in society.

Physical, Emotional, and Social Problems Facing Syrian Refugee Children

The stresses to which Syrian refugees are exposed may lead to negative effects on their children. Besides the violence experienced in war zones, children may also experience trauma in relocating to a new country, often becoming separated from family either by accident or to ensure safety. Once they arrive in the host country, the children must settle into new schools and find peer groups, while also balancing home life. Their parents may rely on them to assume adult roles in order to help provide for the family. Such a reality puts the children in a very difficult situation; some of them leave school searching for jobs to help their families, or, in the absence of a father, the oldest son in the family may take on more responsibilities to help his brothers and sisters.

Al-Gharaibeh (2014) investigated levels of PTSD and coping strategies in Syrian refugee adolescents in the Al-Zaatari Camp in Jordan. Moderate levels of PTSD were reported, and statistically significant differences in PTSD levels were observed based on previous trauma exposure and parents' educational level. No statistical differences were found in terms of gender and length of residency. Data analysis revealed statistically significant differences in terms of gender. Males were more likely to turn toward religiousness and social support strategies. There were statistically significant differences in regard to the coping strategies of relaxation and entertainment, varying based on previous exposure to trauma. A positive correlation was also noted between PTSD and coping strategies.

A study by Abu Tarboush (2014) pointed out the psychosocial effects of displacement on Syrian refugee children in Jordan. Findings demonstrated that there was a moderate impact on the children, and that as the number of years in the host country increased, a lessened psychosocial impact was prominent.

Alongside the risk for mental health risks, loss of educational opportunities is also an issue for the majority of Syrian refugee children. According to Sirin and Rogers-Sirin (2015), only 68% of school-age Syrian refugee children in Jordan are enrolled in a school program. Moreover, children who have missed more than 3 years of schooling are not accepted into Jordanian school systems. With the Syrian Crisis disrupting not only their education, but their lives, Syrian children already face many challenges in continuing their educational pursuits in the new host country. The trauma faced in displacement may also affect their cognitive, emotional, and social development, increasing academic challenges. Furthermore, enrollment data may be unreliable, as many students may fail to attend in order to help economically support the family.

Girls are more vulnerable to loss of education. Intergenerational poverty, infant mortality rates, and failing family health and well-being may all result from a refugee girl's failure to pursue her education. This same demographic is more vulnerable to sexual trauma, for instance in the cases of early marriage and sexual exploitation.

The Physical, Emotional, and Mental Detriments of Child Marriage: Syrian Child Refugees

Child marriage is not only a form of gender-based violence but also a human rights violation. As the primary catalysts of child marriage are poverty and gender inequality, any setting in which poverty and distress increase may lead to a parallel increase in child marriage (Bartels, 2018). In Jordan, the number of pregnancies in woman under the age of 18 has increased from 5% in the beginning of 2013 to 8.5% in 2014 (Sahbani, Al-Khateeb, & Hikmat, 2016).

Both boys and girls may be betrothed in a child marriage, whether forced or consensual. However, according to a study by Bartels (2018), the motives for marriage vary for boys from that of girls. Girls are usually married with a sense of urgency, due to the family guardian not being able to provide for her. This pattern may also be explained through the fact that rape and sexual violence in post-emigration settings increase; therefore, the girl marries in order to protect herself from such attacks. Many unmarried girls who are raped are then unable to find a suitor to marry them, thereby motivating guardians to marry them off before this may occur. Bartels (2018) also found that girls willfully entering these marriages often choose to do so in order to escape poor family situations, motivating them to risk marrying men they may have only known for a few days. Sahbani et al. (2016) identify that family overprotection of the girl leads to her feelings of confinement, thus seeing marriage as an escape.

The consequences that come from this child marriage negate any possible benefits the families may perceive. Not only does child marriage lead to an increase in neonatal deaths and stillbirth, it also jeopardizes the girl's health, increasing her risk of pregnancy complications, spousal violence, and sexually transmitted diseases (STDs) (Bartels, 2018; Mourtada, Schlecht, & Dejong, 2017). This form of union also prevents the girl from receiving a proper education, which limits her career potential, thereby decreasing her economic independence (Bartels, 2018).

Bartels (2018) suggest the implementation of an NGO "safe place," a center in which girls can seek comfort and encouragement, and parents will feel a sense of security. These centers will have the capability of raising awareness in the refugee community, teaching young girls about social development, as well as sexual and reproductive health and autonomy. They will also provide these girls with information, skills training, and a stable social network (Mourtada et al., 2017). Coping strategies sensitive to each gender must also be identified and taught; for example, fathers that seek financial security through these marriages should take part in skills training to encourage economic empowerment (Bartels, 2018). Other methods of action include improving access to education (Mourtada et al., 2017). These are just a few of the various solutions that may be applied to these fragile situations. As the situation is multi-faceted however, NGO programming needs to take into consideration the social and economic background of each refugee family; families from rural regions will likely have different cultural beliefs than those from urban regions, as will families of lower economic standing in comparison to families of higher economic standing (Mourtada et al., 2017). One plan that may apply equally to Syrians of all demographics is NGO provisions of aid in exchange for compliance (Sahbani et al., 2016). Advancements must be made in order to give a voice to all Syrian children.

The Physical and Mental Implications of Gender-Based Violence on Syrian Women and Girls in Jordan

Child marriage is not the only pattern of oppression emerging against Syrian children. Gender-based violence has sharply increased, with grave ramifications for women's sexual and reproductive health, as well as their mental health. Most of this violence is targeted at women under the age of 18.

Aljundi (2016) aimed to investigate the social characteristics of the victims of gender-based violence, while simultaneously identifying types of gender-based violence and reasons for victims not reporting cases to authorities. A sample of 120 refugees from a gender-based violence center in the Al-Zaatari Camp was chosen to participate in this study. The majority of the participants were women, and they reported verbal abuse as the primary form of gender-based violence (mean = 3.5). The major reasons for not reporting to authorities were cultural and social norms.

Sami et al. (2014) reported that due to high urban rent, overcrowded conditions in camps, and increasing informal settlements, the risk of gender-based violence continues to increase. The high number of female-headed households also poses a risk for girls, as they may be seen as more vulnerable to attack. In addition, transactional sex, child marriage, and domestic abuse at the hands of a family member are also characterized by gender-based violence (Sami et al., 2014). Girls often fail to report these instances due to a mistrust of authority and a fear of deportation (Yasmine & Moughalian, 2016). It should be noted that most of these Syrian families consist of six or eight members living in one or two bedrooms; therefore, the level of physical, psychological, and sexual violence and abuse are very high; in addition, some of the children reported that they witnessed their parents when they practice sex. I think such a reality increases the chances for sexual abuse among these families, and there is an urgent need for a major study to examine the level of child abuse and neglect among Syrian refugee camps in Jordan (personal interview with a psychologist working in a refugee camp in Jordan).

In 2017, the UNHCR and the UN Refugee Agency investigated sexual violence against Syrian men and boys who had been displaced as refugees. The study included 196 Syrians from Iraq, Lebanon, and Jordan, and utilized interviews and focus group discussions to collect qualitative data. Ages ranged from as young as 10 to as old as 80. Cases often involved victims suffering abuse by other male refugees and males in surrounding areas. Individuals working in the informal economy are at the highest risk, suffering from not only sexual abuse, but blackmailing and harassment as well. Another risk factor is the high rate of child labor in Jordan, with 94% of Syrian refugee boys working for profit. Gay, bisexual, and transgender males were also at a higher risk. The study calls for improved survivor care, stronger prevention programs, better confidentiality arrangements, protection against reprisals, and raised awareness among humanitarian agencies.

A high need for obstetric and gynecological health services for refugees is ever-present in Jordan and other neighboring countries (Ay et al., 2016; Sami et al., 2014; Yasmine & Moughalian, 2016). Families of victims often do not report cases of gender-based violence due to feelings of shame, protection of honor, and possible stigma in the community (Ay et al., 2016). Therefore, special attention needs to be paid to obstetric and gynecological health services, as the need for these services may be underreported. Furthermore, Ay et al. (2016) reported that Syrian refugees in Jordan felt that gynecological service was one of the health specialties with the least access, noting that in some regions it was unavailable. In a study by Yasmine and Moughalian (2016), Syrian girls who were pregnant and unmarried were told by hospital personnel to return with their husband upon the request for an abortion. This may be a result of rising tensions between host nationals and refugee communities. All in all, the gross mistreatment of young victims, as well as the unavailability of necessary services, is inexcusable. More efforts must be raised to address this affliction.

The Pattern of Emerging Child Labor and Its Mental, Physical, and Social Downfalls

The use of children in the workplace has arisen due to the dire straits of Syrian refugees. As refugees in neighboring countries are not officially allowed to work, they rely heavily on international aid to survive; however, even this can be insufficient. Thus, parents often send their children to work in hazardous work settings to earn what little money they can through labor or begging (UNICEF, 2016). As thousands continue to die in Syria, their children are often left orphaned, leading them to search for work on their own upon crossing the border into neighboring host nations.

A report by Save the Children and UNICEF (2015) indicated that, according to surveys, half of all Syrian refugee children in Jordan are joint or sole breadwinners in their families. Children may be involved in activities such as armed conflict, illegal begging, and child trafficking. As a result, child's growth and development suffer, with the children often suffering for long hours each day for little profit; exposure to dangerous toxins and pesticides is also common. Seventy-five percent of child laborers living in the Al-Zaatari Camp were found to suffer health problems due to dangerous workplaces, and 22% of children working in the agricultural sectors of Mafraq and the Jordan Valley have been injured on the job. Aside from health risks, child labor also takes the child away from opportunities in education, creating a cycle of hopelessness.

UNICEF calls for improved access to funding for income-generating pursuits, improving access to safe education for all children, setting initiatives to end the most dangerous forms of child labor, and working on developing and advancing nationally and locally based child protection programs. The Bureau of International Labor Affairs of the U.S. Department of Labor (2018) suggests a legal framework, in which laws prohibit the recruitment of children less than 18 years of age by non-state armed groups, as well as the protection of children working in small agricultural enterprises. In regard to enforcement, it advises that penalties for child labor be increased, publishing disaggregated data on the number of investigations, violations, prosecutions, and convictions of child trafficking. All of these actions require increased government involvement.

While child labor is no doubt on the rise since the beginning of the conflict in 2011, a scarcity of research exists to evaluate possible solutions to this grievous violation of human rights.

Mental Health and Well-being of Syrian Children and the Role of Parental Factors

While there is extensive research available on the psychosocial status of Syrian adult refugees in Jordan (as previously noted), there is a dearth of available research on the mental well-being of child and adolescent refugees. In a study of child refugees in Turkey, 45% of children were described as displaying symptoms of PTSD, 44% revealed major depressive symptoms, and 33% reported somatic conditions (Eruyar, Maltby, & Vostanis, 2018). It is likely that both pre-emigration and post-emigration stressors interact in a synergistic manner; increasing accounts of trauma leads to a higher severity of mental health problems, which are then incited by stressors present in the poor living conditions of post-emigration contexts (Eruyar et al., 2018). It is important to recognize that efforts to advance the mental, physical, emotional, and social well-being of Syrian child refugees are dependent on therapeutic strategies for family intervention. Consequently, efforts to better the conditions of the family unit will also be made possible through this method. Treating the child demographic will serve as an entryway for treating the family.

The family dynamic in post-emigration settings can play a vital role in mediating the effects of conflict on the bio-psychosocial well-being of the child (Sim, Fazel, Bowes, & Gardner, 2018). In past studies of conflict settings in various countries, such as Afghanistan, Sierra Leone, and Rwanda, strong, stable familial bonds provided a positive effect on the mental health development of refugee and internally displaced children (Sim et al., 2018). The impact of trauma in the form of parental mental distress, family acceptance, and domestic abuse was shown to have an intergenerational effect on the psychological outcome in children of these regions (Sim et al., 2018). Therefore, the cascading effect of family dynamics in times of conflict plays a pivotal role in shaping the mental development of future generations of Syrian children (Sim et al., 2018).

The effects of war on parenting are multidimensional, and in a study by Sim et al. (2018), major themes were identified in parent–child relationships in resource-limited settings of displacement. They included the following: (1) economic adversities that prompted parents to struggle to provide the basic needs for their children, often negatively affecting the interactions between them; (2) parental psychological distress, which led to abusive and violent interactions with children; and (3) increased parental control due to feelings of vulnerability (Sim et al., 2018). These feelings of insecurity particularly affected fathers participating in the study, as they often felt that they were failing to provide for their families as the patriarch, thus losing a sense of masculinity in regard to cultural gender roles and social values (Sim et al., 2018). Interestingly, parents in the study perceived their distress to be a result of the daily hardships they faced post-emigration, rather than the result of direct experiences of trauma in the war (Sim et al., 2018).

Future Directions in the Development of Child Refugee Interventions

A lack of research in the advancements of screening and measurement tools are a primary obstruction to the development of child refugee interventions (Gadeberg, Montgomery, Frederiksen, & Norredam, 2017). Gadeberg et al. (2017) particularly note that early intervention methods must be created for child refugees under the age of six, as new research supports that children in this age range can be just as psychologically afflicted by trauma as children in older age ranges. These new findings are supported by the American Psychiatric Association's fifth edition of the DSM, which features a preschool subtype of PTSD (2013).

Besides accounting for differing age groups of child refugees, future assessment tools should also be culturally sensitive, as the refugees embody various ethnic and religious groups, as well as differing social classes (APA, 2013). As they have all experienced most of the same traumatic events throughout the country however, it may be predicted that many of the same characteristics of distress may be displayed (APA, 2013). Mental health practitioners should be aware, though, that therapeutic models in the West may not bode well in treating the Syrian population effectively. Precise training must be made available to professionals preparing to treat this vulnerable population. They must recognize the unique traditions and customs of the Arab/Muslim/Syrian demographic, particularly those associated with family life and which are deeply rooted in religious and cultural practices. Therefore, mental health workers serving Syrian child refugees and their families must be culturally competent. For example, certain group activities may not prove successful due to clients of different religious and cultural backgrounds refusing to interact with one another (Karaman & Ricard, 2016). It is important for professionals to demonstrate sensitivity and effectively address cultural and religious heritage and history when working with diverse patients (Al-Krenawi, Graham, & Habibov, 2016; Karaman & Ricard, 2016).

Western models for treatment may also be unsuccessful due to the need for translators between the patient and the practitioner. The need for a third person may serve as a language barrier that can lead to the practitioner losing rapport with the patient (Karaman & Ricard, 2016). For this reason, it is essential that the practitioner and translator meet to coordinate details of the sessions, focusing on an accurate translation of the assessment and the need for confidentiality. The practitioner should also be aware of the translator's background, particularly if he/she is also a Syrian refugee, in which cultural and religious heritage may interfere with therapy (Karaman & Ricard, 2016).

Whether the studies should have individual or population-based screening depends on the setting, in which the number of refugees and the administrative facility may differ (APA, 2013). Time and resources must also be taken into consideration.

Panter-Brick et al. (2017) suggested that for long-term success to be achieved through interventions, family and social support structures need to be emphasized. Eruyar et al. (2018) emphasized the need for a push toward parent–child joint care interventions, in which adult and child mental health services work hand-in-hand. A cross-sectional correlational study of a group of Syrian refugees in Jordan showed that 88% of the test subjects used social support as a coping strategy, which included support from parents, the community, and formal or informal bodies (Alzoubi et al., 2019). Alzoubi et al. (2019) also found that 39.5% of participants used the coping strategy of problem-solving, while 64.5% relied on avoidance strategies. Factors such as gender, education, and total family income were predictors of coping. Females, those with lower total family incomes and those with lower education levels, were all more likely to search for social support in order to cope. The opposite was true for problem-solving as a coping strategy. Although this study included adult test subjects, further studies may need to be conducted to investigate whether the same patterns can be observed in children's coping strategies. On the whole, more research must be geared toward the youth of the population, as more than half of all Syrian refugees are under the age of 18.

In 2016, Ugurlu, Akca, and Acarturk studied the benefits of art and music therapy on the Syrian child refugee population. The objective was to decrease symptoms of PTSD, depression, and anxiety. A week-long workshop was conducted for 63 children, using expressive arts therapy, movement therapy, and music therapy. Questionnaires were filled by parents and children to evaluate initial symptoms. Post-assessment results showed a marked reduction in trauma, depression, and anxiety traits.

Similarly, Tailakh (2017) conducted an experimental study to evaluate the effectiveness of psychodrama on the reduction of PTSD symptoms in Syrian child refugees in Jordan. Twenty-eight children were divided into control and experimental groups, with the sample having been chosen from children who scored high on the Children's Impact of Event Scale (CRIES-8). Orphans and non-orphans of both genders were chosen. Following 12 sessions for the experimental group, the CRIES-8 test was completed once again by the children. No statistically significant differences were found based on gender or whether the child was an orphan or a non-orphan. Symptoms of PTSD were shown to significantly decrease through the application of psychodrama.

Many factors should be taken into consideration when researching and applying new therapy techniques which could potentially better the lives of Syrian refugees living in displacement.

Conclusions

While pre-emigration stressors may be difficult to eradicate, given the political climate in Syria, post-emigration stressors impairing refugees' daily lives in host nations must be better identified and contained. Thus far, the major stressors include facing discrimination and hostility among the host communities, economic hardships, un-employability, barriers to health care services, and human rights violations, including child marriage, child labor, and gender-based violence. As a result, refugees experience mental and emotional health problems, including anger, anxiety disorders, depression, and stress. Not only does this contribute to physical impairments, but social impairments as well, including a weakened family state. The most vulnerable demographics are women, children, and adolescents.

Further research is needed as a resource in understanding the required screening and measurement tools necessary for staging favorable psychosocial interventions for both adult and child refugees. These include, but are not limited to, creating hotlines that respond to cases of gender-based violence, as well as child abuse. As mentioned before, the Jordanian Ministry of Health and NGOs should work together to create "safe spots" for children and parents to seek mental health care together. Programs raising awareness must also be increased, as oftentimes mental health problems are not reported or treated due to low prioritization of the illness, stigma, and beliefs that mental health services are not readily available.

Culturally competent and sensitive mental health practitioners must also be present to provide the best care for this refugee population. Therapeutic techniques must be developed to take into account the diversity of the Syrian refugee population and the differences between Eastern and Western foundations of mental, physical, emotional, and social health. Only through this awareness and a familiarity with the clients, the practitioner can achieve successful results.

In conclusion, mental health practitioners, policy makers, and political leaders should be aware of the needs of the children/youth, families, and the whole community in refugee camps, as living in such a reality creates psychological, health, economic, and social problems. These need to be addressed in order to help family members and the community to cope with such a complicated reality.

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Chapter 8

Exploring an Islamically Integrated Peer Support Model for Muslim Syrian Refugees

Kashmala Qasim and Michaela Hynie

The rates of mental illness are on the rise globally, resulting in detrimental economic, health, and social outcomes (World Health Organization, 2018). For example, depression, one of the most common mental disorders, affects approximately 300 million people around the world (Pearce 2015). Due to the stigma surrounding the treatment of mental health, it is estimated that only between 35% and 50% of individuals receive the help that they need, or receive poor quality of care from existing support systems (World Health Organization, 2018). There has been a renewed interest in the integration of culture, faith, and spirituality when providing mental health support, and several faith-based therapies, such as Religiously Integrated Cognitive Behavioural Therapy, have also been developed (Haque, Khan, Keshavarzi, & Rothman, 2016; Pargament, 2007; Pearce 2015). A growing body of intervention literature suggests the effectiveness of explicitly integrating clients' spiritual and religious beliefs into psychotherapeutic settings, which in turn can make mental health treatment more accessible and acceptable (Abu-Raiya, 2015; Anderson et al., 2015; Hodge & Nadir, 2008; Keshavarzi & Haque, 2013).

In Europe and North America, the decade of the 2010s has been notable for the increased awareness of migration and asylum seekers, with many of these newcomers identified as being Muslim (Hynie, 2018; Latif, 2018). Although the current response to forced migration has been complex and often contentious, it has also increased the awareness of the need for culturally appropriate mental health services for newcomers who have experienced trauma and hardship prior to arriving, and who can continue to experience a large number of stressors upon arrival, including family separation, poverty, unemployment, and discrimination (Hynie, 2018).

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This attention to Muslim newcomers has been paralleled by a long overdue increase in our awareness of the mental health needs of other Muslim community members (Hamdan, 2008; Rassool, 2015). The Western framework of mental health and illness has historically been suspicious of religious belief. For example, Freud referred to religion as a form of delusion for the masses (Abu-Raiya, 2014), and much of his psychoanalytic work is theorized within a secular worldview (Husain & Hodge, 2016). Within psychology today, there continues to be a skeptical attitude toward religion. Most mainstream North American psychologists describe themselves as materialists, with no belief or meaningful regard beyond this life (Hayes & Cowie, 2005), and negative attitudes toward religion are prevalent among North American mental health professionals. In a recent survey, Foskett, Marriott, and Wilson-Rudd (2004) found that 45% of mental health professionals felt that religion could lead to mental-health-related problems, while evidence suggests both positive and negative impacts of spiritual and religious beliefs and practices on people's physical and mental well-being. These attitudes toward spirituality and religious belief is problematic for effective mental health support. These attitudes contribute to a reluctance among Muslims to seek formal mental health services (Amri & Bemak, 2013) and, among those who seek and/or receive services, reduce the effectiveness of the care received.

There is evidence that patients benefit from a consideration of their spiritual needs by mental health professionals in the therapeutic relationship as well as in therapeutic approaches (Weatherhead & Daiches, 2010). It has been well documented that ideals relating to individualism have tended to dominate Western models of counseling, with therapists focusing on concepts such as self-esteem, self-actualization, and being able to communicate openly about one's opinions (Husain & Hodge, 2016). These ideals may be at odds with the basic tenets of Islamic teachings, which tend to emphasize interdependence, community actualization, self-control, delayed gratification, and implicit forms of communication that safeguard others' feelings (Williams, 2005). The misalignment of Eurocentric therapeutic approaches with Islamic beliefs and teachings can further inhibit the effectiveness of counseling with Muslim clients.

Therefore, the goals of this chapter are to understand the role of religion, particularly Islam, in the Western framework of mental health and recovery, as well as to describe the ways in which traditional Islamic teachings are being applied within informal mental health support systems, including the role of *Imams*, and how Islamic principles can be used to develop formal models of therapy. Finally, we will be exploring a peer support model for Muslim refugees, particularly in the Canadian context, and making recommendations drawing from the five pillars of Islam. Although the focus of this chapter will be on Canada and Canadian-Muslim communities, and the intervention we are proposing is one for Muslim refugees, we believe that there are common issues in this work that may be relevant to other Muslim communities around the world.

Fundamental Principles of Islamic Thought

Islam is the fastest growing religion in the world due to immigration, high fertility rates, and conversions (Nagra, 2011). There are about 940,000 Muslims living in Canada, and this number is estimated to rise to 2.7 million by 2030 (Hamdani, 2015). Muslim communities display a wide range of identities in terms of race, ethnicity, sectarian affiliation, class, gender, degree of religiosity, and generational experiences. The largest Muslim communities in Canada, by ethnicity, are South Asian (36%) and Arab (21%); however, there are also significant West Asian (e.g., Persian), Sub-Saharan African, and Southeast Asian Muslim communities (Rahnema, 2008). By no measure are Muslim Canadians a homogenous community, and any study focusing on religious identity must be mindful of the diversity and divisions among Muslims. Nonetheless, Islam has some core beliefs that are shared across communities.

Islam is a monotheistic religion, and is considered a way of life offering guidance within both the public and private spheres. Muslim children are taught from an early age about the five pillars of Islam (*arkan al-Islam)*, which are the foundation of Islamic ontology (Husain & Hodge, 2016). The pillars are categorized in the following *hadith*, or statement from the Prophet Muhammad: “Islam is built upon five [pillars]: testifying that there is none worthy of worship except Allah and that Muhammad is the Messenger of Allah, establishing the prayers, giving *zakat*, making pilgrimage to the House and fasting the month of Ramadan” (Oxford Dictionary of Islam). The five pillars outline a framework for daily worship, and are seen by Muslims as a sign of commitment to their faith (Oxford Dictionary of Islam, 2013).

The first pillar, the *shahadah*, is comprised of two declarations: (1) Stating that there is no God but Allah, and believing in God’s Oneness (*tawhid*) as well as relying on God’s help and decree, and (2) Declaring that Muhammad is the messenger of God, who embodied the message of the Qur’an and served as an example for humanity (Oxford Dictionary of Islam, 2013). This testimony of faith also signifies conversion, or entrance of a believer into the Muslim community (*ummah*) (Oxford Dictionary of Islam, 2013).

Following from the verbal statement of stating the Oneness of God, this testimony of faith is carried out in everyday life by the next four pillars. With regard to the five daily prayers, Muslims are commanded through the Qur’an (the most sacred text in Islam and believed to be the word of God) to establish the prayer at prescribed times, which includes before sunrise, at noon, in midafternoon, just after sunset, and in the late evening. The concept of *establishing* prayers also encompasses praying on time, being in a state of cleanliness (i.e., performing ritualistic washing before the prayer), praying in the direction of the *Kaabah* in Mecca, and being mindful of the physical actions and words that one is reciting throughout the prayer (Sheikh, 2018). The third pillar in Islam, *zakah* (alms tax), directs Muslims to donate 2.5% of their savings annually to those who are in need (Oxford Dictionary of Islam, 2013). The fourth pillar is fasting in Ramadan which corresponds to the ninth month of the lunar Islamic calendar. Muslims abstain from food, drink, and sexual activity from sunrise to sunset, in order to attain consciousness as well as to develop empathy for those less fortunate (Qur'an 2:183). The final pillar is the pilgrimage to Mecca during the first 10 days of the month of Dhu al-Hijjah. This trip is incumbent only upon those Muslims who are physically and financially capable.

The Qur'an and many of the Prophetic teachings also deal with and provide practical strategies for common psychosocial concerns and developmental milestones, such as marriage, legal rulings around divorce, financial transactions, taking care of elderly parents, child rearing, and adoption. Taking into account this Islamic framework, the daily and seasonal acts of worship serve as not only guidance but may also be helpful for personality adjustment and mental health (Baasher, 2001). For example, in the month of Ramadan Muslims are afforded the opportunity to develop good habits for the rest of the year and abstain from harmful ones, such as alcohol or drug addiction (Baasher, 2001). These Islamic directives also conceptualize hardships in life, such as illness or loss of a loved one, as trials from God through which a believer is purified and, if patient, will be rewarded in the Hereafter. Traumatic life events are not seen as a punishment necessarily, since the Qur'an recounts several stories of Prophets who were afflicted with extreme illnesses or family situations. Therefore, Muslims view life's struggles as opportunities to grow, and believe that daily Islamic practices such as the five prayers and reciting the Qur'an contribute to positive psychosocial health, both at the individual and at the community level (Baasher, 2001).

Theories of Islamic Psychology

Islamic psychology encompasses a framework regarding human thought, emotion, and behavior that originates from traditional Muslim thinkers, such as Abu Hamid Muhammad al-Ghazali and Abu Zayd al-Balkhi, and addresses how this knowledge interacts and even informs Western models of therapy (Al-Karam, 2018; Keshavarzi & Khan, 2018). Islamically integrated models of psychotherapy are embedded within this specific ontological and epistemological paradigm, which then guides practitioners' and researchers' understanding of health and pathology (Keshavarzi & Haque, 2013).

A number of Western therapeutic approaches are easily aligned with Islamic teachings and principles. Talk therapy, for example, has been a long part of the Islamic tradition (Badri, 2013, Trans.). In his book *Sustenance for Bodies and Souls*, Abu Zayd al-Balkhi, a prominent ninth century physician, described various forms of therapies in detail, including talk therapy, cognitive-based therapy, and psychodynamic approaches (Badri, 2013, Trans.). Al-Balkhi described that an external form of nourishment is that one can listen to the advice of another, "whose discussion would calm the agitated soul and treat its abnormality" (Badri, 2013, Trans.). In addition, he utilized many modern-day clinical terms when explaining behavioral phenomena, such as symptoms, endogenous vs. exogenous causes of depression, and personality styles (Badri, 2013, Trans.). Nonetheless, it is crucial to be sensitive to Muslim clients' faith-based worldviews, as well as their individual level of religiosity and spirituality. For example, in the case of practicing Muslims, one study found that there was greater receptivity to psychotherapy and an understanding that adverse emotions are not a sign of weak faith when narrations from the Qur'an and *Sunnah* (prophetic teachings) were used in the therapeutic process (Asamarai, 2018).

Traditional models of Islamic counseling are derived from the Qur'an, the Sunnah, and literatures of Muslim scholars. Al-Ghazali is one of the earliest and most prominent Islamic philosophers, describing human nature as an integration of bodily and spiritual forces. An individual's human nature is comprised of three elements, namely the *Ruh* (spirit), *Aql* (cognition), and *Nafs* (tendencies). All the three elements are an expression of the *Qalb* (heart) (Yaacob, 2013). He defined spiritual/psychological illness as distance from God and the degree of health as a function of the degree that one experiences proximity to God. This means that the ability to function positively in everyday life does not equate to sound mental health, but involves the development and presence of positive character traits, which is an important Islamic science called *tazkiyat-un-Nafs* (purification of the soul).

Al-Ghazali's approach has led to the creation of various models of Islamically integrated models of care, such as Islamic Cognitive Behaviour Therapy which includes cultivating close rapport with clients, identifying root causes of problems, combating desire, and exercising the soul (Zakaria & Mat Akhir, 2017). Several other concepts have also been translated from the ideas of Al-Ghazali such as opposite therapy, contemplation, prayer, and the power of suggestion. The underlying principles for many of these techniques involves asking the client to separate themselves from the materialistic world (*dunya*) and to contemplate their relationship with God. The process of contemplating is aimed at helping the individual to create a strong connection of the intellect (*aql*) with the heart (*qalb*) (Yaacob, 2013).

Similarly, Keshavarzi and Khan (2018) have described a model of Islamic psychotherapy that includes five components, including the *aql* (cognition), *nafs* (behavioral inclination), *ruh* (spirit), *ihsaas* (emotion), and *qalb* (heart). The *nafs*, in its uncontrolled state, is similar to the Freudian concept of the id, acting primarily on hedonistic desires. However, with refinement, the *nafs* can progress from a state of restlessness to being at peace, and find joy in virtuous behaviors such as praying (Keshavarzi & Khan, 2018). The *aql* is the likened to the brain, which is the rational faculty of a person. It possesses intelligence and acts from a place of logic (Keshavarzi & Khan, 2018). The *ruh* is the "spirit or life force of the human being, and has an affinity for the sacred, a thirst for meaning, and longing for the divine" (Keshavarzi & Khan, 2018). The *qalb* (heart) is at the center of this model, and it both receives and provides feedback to the other components of the psyche. In a *hadith* (statement of Prophet Muhammad), the heart is described as something that changes more frequently than boiling water. It is important to note the dynamic nature of this model, in that all components are interrelated (Keshavarzi & Khan, 2018). For example, a behavioral addiction, such as alcohol abuse, can lead to dysfunctional thinking, as well as incorrect beliefs about God's mercy, perhaps, leading to a decrease in spirituality (i.e., a prayer cannot be performed in a state of drunkenness) and then finally resulting in a “darkness” over the heart (Keshavarzi & Khan, 2018).

Mirdal (2012) shares the principles of mindfulness in the teachings of Jalal-ud-Din Muhammad Rumi. Analyzing Rumi’s works of the *Masanavi* gives insight into the journey of the human soul and its connection to a divine essence through freedom from the suffering of worldly vanity. For Rumi, the soul is like a pure child and society is seen as a destructive community that attacks through inductions, temptations, and suggestions, which the soul is compelled to yield to after resisting. The main cause of mental illness, in this framing, is moving away from the ego principle, which is divine and pure natured (Hakimi & Hakimi, 2018). It can be extracted from the works of Rumi that mental illness is also caused by cognitive distortions, which lead to a failure of stability, feelings of worthlessness, and symptoms of depression. Mirdal thus proposes an approach to mindfulness that entails acceptance and acknowledgement of both positive and negative experiences, unlearning of old habits and looking at the world with new eyes, and decentering—changing one’s focus from self to other. In this, we can see both traditional practices of mindfulness and also expressions of traditional Islamic beliefs about mental health.

Despite the several advances in Islamically informed therapies, to the best of our knowledge there is yet to be a single, unified Islamic model of psychology or a theory of Muslim mental health (Rothman & Coyle, 2018). There is consensus, however, on the following theoretical concepts: (1) The *fitrah* (human soul) is born pure, is innately good natured, and is inclined toward an upward trajectory of knowing God; (2) The *fitrah* becomes forgotten and “rusted” as part of a normal life course; (3) Remembering God and doing good works can help to align the soul with the *fitrah*, whereas negative characteristics and following undesirable impulses can result in a state of heedlessness of others and of God (Rothman & Coyle, 2018).

Thus, the goals of an Islamically informed model of mental healthcare would be to assist individuals in uncovering the *fitrah*, by using emotional, cognitive, and behavioral techniques from the Qur’an and *Sunnah* in order to achieve God’s pleasure in this world and the Hereafter. Because Islam views the self as a dynamic spiritual being within a collectivistic framework, Muslims may be influenced by their social support system which may then shape their attitudes toward mental health problems and recovery (Rassool, 2015; Rothman & Coyle, 2018).

Social Support in Faith-Based Communities

Social support can be separated into *perceived* social support and *received* social support (Cohen, 2004). Perceived social support is the extent to which individuals *perceive* that emotional, informational, or material support is available when needed. Received social support refers to the actual support enacted and received, such as financial assistance (Cohen, 2004). It is perceived support that appears to have the strongest links to psychological well-being (Lakey & Orehek, 2011). Several studies suggest that during stressful times, individuals tend to form social networks through which they are able to discuss challenges and receive and provide feedback, as well as material resources (Carver & Connor-Smith, 2010). There is also evidence to suggest that strengthening social support from network members without providing formal counseling may be sufficient to reduce the severity of postnatal depression, at least in some contexts (Hynie et al., 2015).

For many individuals, informal social networks include religious community leaders, who may be the first line responders for mental health care. This may be particularly true in the Muslim community. Rassool (2000) found that Muslims perceive their life stressors as a test of one's faith. Therefore, Muslims often seek guidance from Imams, who play a crucial role in shaping family and community attitudes regarding mental health (Padela, Gunter, Killawi, & Heisler, 2012). Imams also play a facilitator role by helping communities gain access to a larger network of mental health services (Ali & Milstein, 2012). We have found, in our work, that Imams are perceived to be very accessible by the community, as many Imams will hold office hours after specific prayers of the day, usually in the Mosque (Qasim & Hynie, 2018). Additionally, Imams do not charge a fee for these one-on-one consultations, thereby encouraging their congregation to approach them for faith-based counseling services (Qasim & Hynie, 2018). Among Muslims who do reach out for help to Imams, the majority seek counsel over marital and family issues (Ali et al., 2009; Qasim & Hynie, 2018; Rassool, 2015).

Abu-Ras, Gheith, and Cournos (2008) found that 94% of mosque attendees from 22 mosques in New York City perceived their Imam as a counselor, and 97% of participants found Imams to be a source of religious guidance. Moreover, studies suggest that Imams spend a significant amount of time "counseling" congregants. A study of 56 Imams reported that half of the Imams spent 1–5 h a week in counseling activities, and 30% of Imams spent 6–10 h a week (Ali, Milstein, & Marzuk, 2005). However, Khan (2006) reported that although more than half of the Muslims in the study had pro-counseling attitudes, 45.5% of the participants reported never seeking comfort from an Imam. Moreover, despite the Imams' commitment to social work activities and their acceptance as a source of guidance, many Muslims feel that Imams are lacking training to provide an adequate level of support (Ciftci, Jones, & Corrigan, 2012).

Despite being highly qualified in Islamic sciences and theology, Imams themselves have reported a lack of formal counseling training and tended to utilize a combination of informal psychotherapeutic techniques based on Islamic teachings (Abu-Ras et al., 2008; Khan, 2006; Qasim & Hynie, 2018; Sa'ad, Razali, Sanip, & Mohd Rani, 2017). Interestingly, Ali and Milstein (2012) reported that there was a positive correlation between an Imam's willingness to counsel an individual and collaborate with a clinician to the amount of training he's received. Imams who did not report any experience with pastoral counseling or Western psychotherapy also reported that they found great difficulties in differentiating signs of various mental illnesses (Abu-Ras et al., 2008).

There is very little psychological research addressing the attitudes and perceptions of Canadian-Muslims toward help-seeking behavior, and thus research on culturally relevant tools, resources, and practices in addressing mental health issues in the Canadian-Muslim community is scarce (Ali et al., 2009). Therefore, it is important to consider the role of faith in coping, especially in the rising Muslim refugee community both globally and in Canada (Latif, 2018).

The Role of Faith and Coping in Refugees

Refugees are individuals who have crossed international borders as a result of a "well-founded fear of being persecuted" on the basis of their religious, political, sexual, or other social identity, and whose country will not or cannot protect them or may in fact be placing them in danger of persecution (United Nations General Assembly, 1951). The number of refugees has been increasing in the last few decades, with 65.6 million people reported as living under forced displacement in 2016 (UNHCR, 2018; Latif, 2018). The resettlement and integration process is challenging for all newcomers, however refugees, as compared with voluntary migrants, experience several challenges such as undergoing or witnessing torture, poorer health outcomes, fewer economic prospects, and limited social networks, all of which create a unique sense of vulnerability (El-Khani, Ulph, Peters, & Calam, 2017; Hynie, 2018; Picot & Lu, 2017).

Prior to the revolution, Syria was the third largest refugee hosting country, accommodating refugees primarily from Palestine. However, with the recent conflict, it has turned into the largest refugee producing country (UNCHR, 2013). Before the conflict, Syria was home to 22 million people (IRCC, 2019). The Syrian population consists primarily of three religious groups: Muslims, Christians, and Druze, as well individuals from the Jewish faith (UNCHR, 2013). Since 2011, more than 12 million people from Syria have been impacted through forced migration and displacement, and represented in the media as the "Syrian Refugee Crisis." Canada has seen the arrival of more than 40,000 Syrian refugees, and as part of this Syrian experience (IRCC, 2019) it is particularly important to understand which coping mechanisms Syrian men and women are utilizing to navigate various financial, psychological, and cultural stressors, as they resettle into a new country (Alzoubi, Al-Smadi, & Gougazeh, 2019).

Pargament (1997) defined coping as a "search for significance in times of stress" (Xu, 2016). Faith-based coping mechanisms are "ways of understanding and dealing with negative life events that are related to the sacred" (Pargament, Koenig, & Perez, 2000). According to Pargament, religious coping serves several objectives, including to uncover meaning in a situation, to gain a sense of control, to achieve peace through feeling closeness to God, to develop connections with others, as well as to have a transformative life experience. According to this definition, religious-based coping provides a buffer against increasing stressors by placing trust in a higher power, as well as contributing to a more compassionate worldview especially in times of injustice and oppression, such as in the Syrian refugee experience (Ai, Peterson, & Huang, 2009). Religious belief systems play a crucial role in the coping process (Alzoubi et al., 2019). Several studies indicate that trusting and believing in a just and merciful God is a common religious coping strategy among Muslims (Alzoubi et al., 2019; El-Khani et al., 2017). Furthermore, refugees arriving from countries with higher levels of communal religiosity tended to adhere more strictly to religious rulings as a coping mechanism while adjusting to a new culture and self-identity (Buber-Ennser, Goujon, Kohlenberger, & Rengs, 2018). For example, within a Somalian and Ethiopian sample, upwards of 75% of refugees utilized prayer to cope with sadness (Khawaja et al., 2008). Faith was also used by Syrian parents residing in camps (El-Khani et al., 2017). The participants reported submission to God, and reciting the Qur'an as a mechanism to soothe themselves, as well as to provide hope and a forward-looking approach to the Hereafter (El-Khani et al., 2017). Finally, religion and faith-based institutions may also be a source of social support. El-Khani et al. (2017) also reported that social support for Syrian refugee parents allowed them to seek help from other parents on the various challenges of raising children while residing in camps by normalizing their thoughts and behaviors.

There is a tendency, however, to confound personal faith and religion. It is important to recognize that these can be separated into institutional religion, which includes the rituals, relationships, norms, beliefs, and structures of a particular religion, and personal beliefs. With this in mind, researchers have recently validated a scale of Spiritual Personality, which looks at two dimensions of individual differences, including how Muslims approach Islamic knowledge (experience vs. judgment) and disposition to behavior (action vs. restraint) (Abdul-Rahman & Khan, 2018). When working with Muslims who may be struggling with understanding their individual orientation to spirituality and their connection with God, encouragement from Qur'anic verses such as "Everyone behaves according to their nature (shākil)" may be an excellent starting point (*Surah Isra*, 111).

A faith-based approach would also take into account how individual differences can make certain Islamic moral (*akhlāq*) qualities easier or harder to obtain. For example, a person who is low on the personality trait of neuroticism, which is associated with higher levels of emotional stability, may find it easier to adopt an optimistic attitude, an *akhlāq* trait (Abdul-Rahman & Khan, 2018). Someone who is more introverted may find introspection and reflection (*murāqaba*) easier, whereas an extroverted individual may find it easier to maintain ties with family and friends (*silat ar-rahim*) as a way to offering and seeking social support (Abdul-Rahman & Khan, 2018).

In contrast to seeking social support, avoidant coping is defined as the cognitions and behaviors used to reduce the negative effects of a challenging situation, for example, by ignoring or deferring (Afshar et al., 2015). Within the avoidance coping style, studies indicate that refugees may turn to negative forms of coping, such as alcohol and drug abuse, smoking, and gender-based violence, especially as a means to cope with daily stressful conditions (Daud, 2009). Additionally, refugee participants have reported several ineffective coping strategies, such as sleeping, distraction, and social withdrawal (Finkelstein, Laufer, & Solomon, 2012). In terms of using religion in a negative context, evidence suggests that individuals may adopt "dooms-day" type beliefs about their life situation, take on a more literalist interpretation of sacred texts, as well as rely solely on prayer without receiving or providing any instrumental support (Ano & Vasconcelles, 2005). Harmful ways of coping have also been linked to several physical health conditions, including headache, fatigue, hypertension, and diabetes mellitus (Khawaja et al., 2008). For example, in one study, refugees residing in camps have reported adopting harmful and passive coping strategies, such as avoiding their present circumstances and cognitively framing their condition as out of their control (Alzoubi et al., 2019). Therefore, it is critical when working with individuals within a faith-based framework to assess any maladaptive forms of coping, such as avoiding and passivity, especially if it is emerging from a dogmatic belief system.

Overall, it may be beneficial for researchers, clinicians, and front-line workers to understand the pathways of developing social networks that are conducive to certain coping styles, and to provide therapeutic assistance to those individuals that are prone to using maladaptive coping mechanisms. Additionally, when working with faith-based communities, such as the Muslim community, that values interdependence and a religious worldview, it is crucial to utilize culturally appropriate models of care within an existing social support system (Keshavarzi & Khan, 2018).

Islamically Integrated Model of Peer Support

We have thus far outlined the various types of coping mechanisms that individuals utilize, including the role of faith, as well as the importance of social support in Muslim refugee communities. One promising community-based model of social support includes the use of peer support. Peer support is defined as social, emotional, and instrumental support that is provided in either a formal or informal setting (Solomon, 2004). The peers are individuals in the community that have lived experience of the target concern, and have also undergone the recovery process (Pound, Judd, & Gough, 2011; Solomon, 2004). Peer groups are not as formal as psychiatric care, nor are they just about being friends (Solomon, 2004). In a peer support model individuals apply a reciprocal, respectful, and non-linear approach of providing and receiving help, in order to change problematic thoughts and behaviors and come out of "stuck" places (Hurlock, 2010).

There are several features of peer support that make it a unique form of social support and therapy. This includes, for example, uniting members of a group together to discuss a common issue. Secondly, peer support groups are facilitated by another member of the community who has undergone a challenge as well as the recovery process, through which he/she can provide hope and motivation for others going through similar challenges. Additionally, it is theorized that social support could decrease the use of harmful coping strategies such as avoidance, as individuals believe their social network includes someone who will be available to listen (Tao et al., 2000).

Interestingly, the principles underlying peer support are similar to the ones taught in psychotherapy for individual counseling (Solomon, 2004). This includes empathy, creating a safe space, non-judgmental attitude, and use of validation. In contrast to the therapist–client relationship, peer support models utilize a facilitator who has undergone an experience related to mental health, as well as the recovery process; therefore, there are elements of hope, empowerment, and healing present in peer support groups (Solomon, 2004).

Researchers have identified that Islam plays a crucial role in the lives of Muslims, therefore it would be beneficial to not only include a component of spirituality but to frame a peer support model using an Islamic lens, depending on the facilitator's assessment of the group's level and connection of spirituality (Sheikh, 2018). The peer support model, based in the Muslim refugee community, can build upon community members' resiliency, and how "hope and trust are reconstructed through an increased awareness of how socio-political forces have created oppression, and this hope can then allow for the building of trust and connection between community members" (Hynie et al., 2015). In addition, when working within a peer support framework, clinicians have found it useful to share Prophet Muhammad's saying, "A believer is the mirror of a fellow believer" (Al-Adab Al-Mufrad 12:238). Through sharing this *hadith* at the outset of a session, clients and peers alike may be encouraged to take a non-judgmental position and reflect on the idea of a mirror, which by definition displays what it is shown (Asamarai, 2018). Taking the mirror analogy further, the peer group can organically allow for change without undue pressure, or harshness, by simply reflecting and drawing attention to processes as they happen (Asamarai, 2018).

The aforementioned pillars of Islam can also be drawn from to explore a faith-based model of peer support. For example, the first pillar represents a set of beliefs about one's relationship with God, and this would ideally be the starting point in an Islamically integrated peer support group. Qualitatively, everyone's relationship with God will look different; however, a safe group environment will allow participants to reflect on concepts integral to the Islamic creed, such as *tawhid* (Oneness of God), *tawakkul* (trusting in the plan and decisions of God), and the prohibition of *shirk* (associating anyone in the attributes of God). These conversations can be guided by the facilitator to understand how participants use their faith to navigate emotions in their everyday lives, as well as how they use their connection with God to cope with suffering and loss.

The mindful component of *salah* (prayer), the second pillar of Islam, can be translated into a peer support setting. Mindfulness practice is defined as "a mental state achieved by focusing one's awareness on the present moment, while calmly acknowledging and accepting one's feelings, thoughts, and bodily sensations" (Parrott, 2017). During prayer, Muslims are encouraged to envision their relationship with God, and to be in a state of heightened awareness that God is watching over them. For example, in one study, participants who were more knowledgeable about *Salah* tended to be more mindful in their prayer (Ijaz, Khalily, & Ahmad, 2017).

Studies have also indicated that offering the daily prayers regularly was associated with positive mental health outcomes (Ijaz et al., 2017). An Islamically integrated peer model can utilize this fundamental tenet of Islam, and perhaps utilize the various prayer positions (i.e., reflecting while in a state of prostration instead of sitting on chairs) and reflect on the verses in the Qur'an which highlight the benefits of prayer as "satisfaction for heart" (*Ar-Ra'd:*28) and a "source of keeping a person away from wrong behaviour" (*Al-'Ankabut*:45).

Additionally, the principles underlying *zakat*, or mandatory charity, can be utilized as a framework for community building as well as capacity building among peers. *Zakah*, in essence, serves as a reminder of one's broader social responsibilities to the community by helping those who are in need and strengthening the ties of brotherhood and sisterhood (Sheikh, 2018).

Conclusion

In summary, Islamic teachings highlight a collectivistic, community-based approach to health and spirituality, rather than an individualistic one (Husain & Ross-Sheriff, 2011). A statement by Ibn Khaldun, a North African historian and scholar from the fourteenth century, truly captured this ideology by stating that "compassion and affection for one's blood relations and relatives exist in human nature as a divine gift put into hearts of men. It makes for mutual support and aid" (Katsiaficas, 2014). Keeping this in mind, an Islamically integrated peer support group might be more beneficial than traditional therapy or counseling, as it utilizes natural social support already available at Mosques and Islamic classes for children, especially for Muslim refugee families. Furthermore, an Islamically integrated peer support model allows for reflections about the group's relationship with *Allah* (God), as well as an assessment of the aforementioned internal domains of each individual's psyche (*nafs, aql, ihsaas, ruh, and qalb*) as it relates to their narrative of displacement, resettlement, and forced migration.

Within Islamic law, Muslims are held responsible for maintaining respectful ties with their families, neighbors, and the community at large; therefore, an Islamically integrated model of peer support can be likened to worship (as well as create a buy-in from community leaders) in actualizing a commandment of God. Finally, the facilitator working from an Islamic paradigm would ideally hold a humble position, in that the individual will understand that he/she is simply an instrument of *Allah* (God) and a means to achieving recovery and healing, as is stated in the Qur'an: "And when I am ill, it is He (God) who cures me" [26,80] (Rüschoff & Kaplick, 2018).

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Chapter 9
The Impact of Cultural Beliefs on Mental Health Diagnosis and Treatment

Alean Al-Krenawi

Introduction

This chapter provides background information on cultural beliefs and their influence on behavior regarding mental illness. A number of studies have reported that cultural beliefs influence the experiences of illness and presentation of symptoms, leading to difficulty in making psychiatric diagnoses. To address this issue, I will mostly review case studies about the subject from the Arab Muslim world. Not much is known about the impact that diverse cultural-linguistic beliefs have on culture-specific diagnoses, traditional treatment, and management of mental illness in the Arab world. We do know however that people continue to use traditional treatments despite the introduction of Western health care services (Al-Krenawi, Graham, & Maoz, 1996; Lepowsky, 1990; Robbins & Dewar, 2011; Tabassum, Macaskill, & Ahmad, 2000).

Traditional treatment is usually sought based on cultural beliefs regarding the case of illness prior to utilization of western health care services. Medication is seen as a last resort and as a symptomatic treatment, while traditional treatment is seen as a cure for the cause of the illness (Decock, Hiawalyer, & Katz, 1997; Frankel, 1986; Hamnett & Connell, 1981; Macfarlane, 2009; Stavovy, 1996). Some people also use both types of treatment at some stage of their illness. The cultural issues already indicated are not adequately covered in predominantly western classification systems such as International Classification of Disease (ICD-10) and Diagnostic Statistical Manual for Psychiatric Disorders (DSM-IV). Thus, there is a clear need to improve general health workers' understanding of the cultural/western dichotomy, and the impact of such in the diagnosis and treatment of mental illness.

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Little is known about how confident general health workers are in dealing with the complex cultural issues among people with mental health problems. This chapter highlights the complex environment in which general health workers practice. It also shows why it is important to assess the general health worker's level of confidence in dealing with mental health issues in a dual system (traditional and western). The types of mental health problems that general health workers manage in the community and their need for adequate knowledge in both cultural and western mental health issues are necessary for the effective provision of mental health care.

Cultural Beliefs Regarding Causes of Mental Illness

Anthropological and psychological reports suggest that people's beliefs concerning causes of psychological and physical illness vary across cultures (Edman & Kameoka, 1997; Edman & Koon, 2000; Kleinman, 1980; Narikiyo & Kameoka, 1992). It is commonly believed in many cultures that some forms of supernatural agents are responsible for causing illness.

In Papua New Guinea, people believe that mental illness is caused by spirit possession/supernatural agents, sorcery, violation of social taboos, or envy of the achievements of others (Burton-Bradley, 1973, 1990; Burton-Bradley & Julius, 1965; Connell, 1997; Epstein, 1999; Frankel, 1986; Hamnett & Connell, 1981; Langness, 1965; Lepowsky, 1990; Lewis, 1975; Macfarlane, 2009; Pulsford & Cawte, 1972; Robin, 1979; Rodrigue, 1963; Salisbury, 1968; Schieffelin, 1996; Sharp, 1982; Stavovy, 1996). In Malaysia, people believe in black magic, spirit possession, supernatural agents, and religious causes (Chen, 1970; Edman & Koon, 2000; Kashim, 1997; Kinzie & Bolton, 1973; Knappert, 1980; Laderman, 1991; Massard, 1988; Osman, 1989a; Rahman, Azian, Sukardi, & Supyan, 2015). In Africa, the Malawi people believe in witchcraft and jealousy of achievements (Ashforth & Watkins, 2014; MacLachlan, Zimba, Bowa, & Carr, 1995). The Swahili people of Kenya believe in supernatural and spiritual causes (Beckerleg, 1994; Ndetei et al., 2015), while the Ulanga people in Southern Tanzania believe that illnesses are caused by social relationships with other people and spirits (Caplan, 1997; Feierman, 1985; Ngubane, 1977). Similar patterns exist among the Yoruba people of Nigeria (Adepoju, 2012; Jeiyeoba, 1988; Oyebola, 1980) and other parts of Africa (Roberts, 2001). In India, epilepsy, schizophrenia, and other forms of mental illness are perceived to be caused by Karma, demons, and spirits (Banerjee & Banerjee, 1995; Banerjee & Roy, 1998; Padmavati, Thara, & Corin, 2005). A similar pattern of causal beliefs exists in the Middle East, where mental illness is believed to be caused by spirits (Al-Krenawi & Graham, 2001; Tuncer, 1995).

It is not only in developing countries that different cultural and ethnic groups have diverse beliefs. This is also the case between ethnic migrant and native groups in developed countries. For example, in Australia, Vietnamese refugees have been found to have their own causal beliefs in supernatural agents (Phan & Silove, 1997; Steel et al., 2006). The Aborigines also believe that illnesses are caused by spirits

(Wake et al., 1999). In the USA, several studies of ethnic American students and other migrant ethnic groups (Japanese American, Filipino American, Caucasians, and Koreans) have demonstrated different cultural beliefs regarding the cause of mental illness (Edman, Danko, McArdle, Foster, & Glipa, 1999; Narikiyo & Kameoka, 1992; Otis & Kuo, 1984; Suan & Taylor, 1996; Urdaneta, Saldaña, & Winkler, 1995; Wong, Tran, Kim, Van Horn, & Calfa, 2010). In the UK, similar types of beliefs were described among other ethnic migrant groups (Dein & Stygall, 1997; Hussain & Gomersall, 1978; Tabassum et al., 2000). Ethiopian Jews in Israel view mental health from a perspective of a cosmological balance which needs to be maintained (Youngmann & Zilber, 2014).

In the Arab World, not everyone has a complete knowledge of infection, germ theory, or chemical imbalances in the brain or other scientific definitions and classifications of illness (Al-Wahbi, 2006; Polunin, 1976; Sweileh et al., 2014). People's beliefs of the causes of both psychological and physical illness are generally centered on spirit possession/supernatural agents, sorcery, and violation of social taboos or envy of the achievements of others (Al-Krenawi, 1999; Al-Krenawi et al., 1996; Tuncer, 1995). There are differences between different Arab societies, but there are also some general commonalities. In the entire Arab world, there are linguistic references to spirits that are believed to be the cause for mental illness.

Spirit Possession and Sorcery

Spirit possessions are a known part of Islamic tradition and are often perceived as the cause for hallucinations and other interferences of the senses. Spirits are called "Jinn," and while they are vaguely feared, they are not always malevolent (Watt & Montgomery, 1970, p. 153). They are therefore distinguished from other cultural concepts of a more pernicious possession by the devil (Al-Krenawi & Graham, 1997). Evil spirits can sometimes act alone, but most of the time it is believed that they are acting in according to God's orders. This can happen because the sick individual has sinned, and therefore God sent the spirits to possess him/her as punishment (Al-Issa, 1977; Al-Krenawi et al., 1996).

Let us take, for example, the case of patient M. He is a 31-year-old male, married, without children, and a life-long resident of the Negev (the southern part of Israel). He is diagnosed with paranoid schizophrenia and suffers from hallucinations. He perceives the images that haunt him as "Jinns." He believes that the root cause for his condition lies in the ways he disrespected his parents, especially his mother. This is, of course, a grave offense in Arab Bedouin tradition (Al-Krenawi & Graham, 1997).

Spirits can be healed by a "*Darvish*," a traditional healer that is versed in the holy text of the Koran and is able to communicate with, and overpower, the evil spirits. There are several schools of thought when it comes to the training of a "*Darvish*," and the result is a mixture of different kinds of therapeutic approaches. A "*Darvish*" can try to overpower the spirits and command them to leave, or it can try to communicate with them to understand the reason for the possession and then act accordingly (Al-Krenawi et al., 1996). In Egypt, and Qatar as well, traditional healers use herbal medicines in order to combat spirits. This is the preferred method among the majority of the population to treat mental illness (Fakhr El-Islam, 2008).

The influence of these cultural beliefs regarding the causes of mental health diseases is important to understand. They affect the way diagnosis and treatment should be performed. They also have a clear effect on the way the patient perceives his/her illness and how he/she will choose to seek medical assistance (if he/she seeks it at all).

The Influence of Cultural Beliefs on Help-Seeking Behavior

Cultural beliefs and perceptions related to causes of mental illness have been found to influence illness experiences, presentation of symptoms, help-seeking behavior, and the course of treatment approach used in many cultures (Abe-Kim et al., 2007; Kleinman, 1977, 1987; Lewis-Fernandez & Kleinman, 1995). For example, Indian patients with epilepsy, who believe in supernatural agents as the cause of their illness, tended to consult traditional healers prior to seeking western treatments. Others, who did not believe in supernatural causes, saw western treatment as the preferred method of treatment (Banerjee & Banerjee, 1995). Campion and Bhugra (1997) found that 48% of Indian patients sought alternative traditional treatment prior to seeking psychiatric help. Other studies among Indians with a diagnosis of schizophrenia also show similar patterns of seeking traditional treatment first (Banerjee & Roy, 1998; Chadda, Singh, Raheja, & Agarwal, 2001).

Studies in places such as Africa (Jeiyeoba, 1988; Oyebola, 1980; Roberts, 2001), Asia (Incayawar, Wintrob, Bouchard, & Bartocci, 2009; Kinzie & Bolton, 1973; Osman, 1989b; Razali & Najib, 2000), and the Middle East (Al-Krenawi & Graham, 2001) all describe similar patterns of consulting traditional healers and using traditional and alternative treatment prior to using western health services. Urdaneta et al. (1995) reported that in the USA, Mexican Americans' cultural beliefs about causes of illness also influenced their help-seeking behavior, which led them to consult traditional healers and use traditional treatment prior to consultation with health workers. Flaskerud (1986) and Abe-Kim, Takeuchi, and Hwang (2002) presented similar findings on other migrant groups seeking traditional and alternative treatments prior to western treatment. In Australia, a similar pattern was also reported for Vietnamese refugees (Phan & Silove, 1997). Jorm et al. (1997) reported that the general public in Australia preferred lifestyle changes and diets to professional treatment. The researchers reported that treatments overwhelmingly rated most helpful by mental health clinicians were rated as harmful by the public. Strongly held causal belief systems related to mental illness appear to dictate the seeking and use of treatment approaches.

The use of traditional treatment appears to be based on underlying cultural beliefs about the causes of mental illness (Kennedy & Olsson, 1995; MacLachlan, Nyirenda, & Nyando, 1995; Matoane, 2012). For example, Razali and Najib (2000) found that 69% of 134 Malay psychiatric patients consulted traditional healers prior to consulting psychiatrists for their present illness. Brodwin (1992) pointed out that both traditional and western methods of treatment can be used, either separately or in combination with medication. However, in several cultures, medication is seen and used as a symptomatic treatment, while traditional treatment is used as a cure for the cause of the illness (Banerjee & Banerjee, 1995; Edman & Koon, 2000; Wexler, 1976). Studies of different cultures across 26 countries found that rural communities in particular relied very little on psychotropic medication and regularly used alternative community healing techniques (Jablensky et al., 1992; Sartorius et al., 1996). This was especially the case in India and Africa (Sorsdahl, Stein, & Flisher, 2010).

In Israel, the Arab population underutilizes specialized mental health care services in comparison to the Jewish majority (Al-Krenawi, 2002). When a problem first appears, Arab patients usually turn to their families for support, and the families encourage the patient to rely on traditional cultural treatment if the western general practitioner failed to solve the problem (Al-Krenawi, 1999, 2002). There is great fear of stigmatization that can accompany a diagnosis of mental illness in Arab society. Traditional healers are able to treat individuals using non-stigmatizing modes of culturally acceptable rituals and practices, and are frequently preferred over modern mental health practitioners (Gorkin & Othman, 1994).

Main Types of Traditional Treatment Approaches Used

Traditional treatment in Arab Bedouin society is centered on the performance of healing rituals. The main ritual is called "*rijal Allah al-Salhin*" (invocation of saints, of God, and of the Prophet Muhammad). During the ritual, a special technique is deployed called "*Tazeem*." The "*Tazeem*" is a form of dialogue with the spirit. It enables the healer to understand the reason why the patient is being possessed and to resolve it, rather than through persuasion or confrontation with the spirit (Al-Krenawi et al., 1996). Music is always an important part of the ceremony, since it is believed that spirits are attracted to and affected by music. The sound of music can be used to allure the spirit and begin communication. Music can also be used to try and overpower the spirit and force it out. The "*Dg Altaar*" (drum) is used to drive the spirit away and release the patient from its harm. In some instances when the spirit is resisting the treatment and refuses to leave, the healer might try to "beat it out" of the patient, using a special stick for the task (Al-Krenawi et al., 1996; Berman, 2006). The rituals usually take place in the patient's house, and they involve close family members. Family's presence is an important part of the ritual, and the healer will often engage with them during the healing ceremony (Al-Krenawi & Graham, 1997).

The treatment however is not only short term and focuses on more than just the solution of the immediate problem. The "*Darvish*" is a religious authority, and just as western physicians try to instill healthy lifestyles in their patients for the prevention of illness, the "*Darvish*" does the same from his perspective. They are interested in promoting a heightened religiosity among patients, both as a mode of healing in the present and for better health further along in life (Al-Krenawi et al., 1996). The "*Darvish*" might assemble several different patients and perform a ceremony that is meant to tighten their relation to God. This ceremony is performed on a Thursday before the holy Sabbath and can be called a "*Hadrh*" (to invite a blessing from God) or a "*Dhikr*" (to remember or to invoke God's name), depending on the school of thought to which the "*Darvish*" prescribes (Al-Krenawi et al., 1996; Csordas & Lewton, 1998).

The Influence of Cultural Beliefs on Presentation of Bodily Symptoms

A number of investigations indicate that patients in many developing countries, and among ethnic migrant groups in developed countries, present with symptomatic complaints such as weakness/pain in parts of their body in a manner that is consistent with their cultural beliefs, perceptions, experiences, and cultural orientation toward illness (Lloyd, 1986; Mumford, Saeed, Ahmad, Latif, & Mubbashar, 1997; Rack, 1982). Some examples relating to the presentation of somatic complaints with underlying cultural beliefs are given in the following paragraphs. In some cultures, bodily complaints are descriptions that communicate distress and are related to conditions such as depression and anxiety rather than psychosis (Kleinman, 1980, 1988 in Stavovy, 1996; Keyes & Ryff, 2003). These somatic complaints are cultural points of reference for illness in different cultures, with underlying cultural causes (Tseng & McDermott, 1981; Ots, 1990 in Helman, 2000). Phan and Silove (1997) commented that psychiatric diagnosis is complicated by the presentation of somatic symptoms, which results in difficulty knowing the exact prevalence of mental illness in developing countries.

In the Arab Bedouin society in the Negev (the southern part of Israel), somatic symptoms tend to be the initial presenting complaints before any onset of psychological symptoms. In a study conducted on 60 Arab Bedouins who were referred to a psychiatrist (36 females, 24 males), all of them sought the help of a general physician for physical pains. It was only after no physical cause was found for their complaints that they were referred to see a psychiatrist (Al-Krenawi, 1999). In most cases, the patients themselves insisted that treatment in the western medical services will be limited to the physical realm only. Doctors often comply with the request and are not culturally sensitive to notice the underlying mental factors of the problem until many tests are performed to rule out physical causes (Al-Krenawi & Grahm, 1999).

Most of the somatic physical complaints among Arab Bedouins focus on headaches and heartaches. These are areas that are traditionally associated with the emotional state of a person (Al-Krenawi & Grahm, 1999; El-Islam & Abu-Dagga, 1992). There are gender differences in the type of somatic complaints presented. Males complained of fatigue and physical pain and weakness. Females, in contrast, described how pain traveled in their bodies, and often referred to the heart. The women also tended to rely more heavily than men on metaphorical language to describe subjective feelings; one patient, for example, explained that her affect was like the color of her clothes—black (Al-Krenawi & Grahm, 1999).

The cultural diagnoses may not be seen as diagnoses in the same way as those defined by western classification systems. In most instances with culture-specific mental illnesses, there is little distinction between causes and "diagnosis." Thus, the conceptualization and classification of culturally specific mental health problems in particular are greatly influenced by culture, language, and beliefs (Burton-Bradley, 1963, 1973, 1990; Burton-Bradley & Julius, 1965; Stavovy, 1996). The causal beliefs and the culture-specific diagnoses determine the type of traditional treatment to be applied. Therefore, beliefs regarding the cause of the illness, the presentation of somatic symptoms by the person with the illness, the establishment of a culture-specific diagnosis, and the type of traditional treatment prescribed either by a traditional healer or by a general health care worker are all entwined.

For general health workers dealing with mental health problems, an understanding of cultural norms, beliefs, and the presentation of somatic symptoms leading to culture-specific diagnoses is vital. The workers require both knowledge and clinical judgment to look beyond the presenting somatic complaints. The understanding of these cultural issues will assist in making an accurate diagnosis and appropriate treatment decisions. It is imperative that, in every clinical encounter, the patient's culture and perceptions be considered by the health workers (Jacobs & Giarelli, 2001). Failure to understand cultural issues may lead people with mental health problems to be treated for the physical complaints and not the underlying psychological problems. In other words, lack of cultural knowledge and understanding would lead to misdiagnosis and inappropriate treatment.

I will now present an actual case study taken from Papua New Guinea which demonstrates this point. For more than 6 months, a 35-year-old Papua New Guinean woman was treated on numerous occasions with painkillers for a complaint of breast pain. She even had a biopsy done to rule out breast cancer and had other pathology tests done as well to rule out other possible physical causes. The painkiller tablets did not improve her situation. She was eventually referred to a psychiatrist who prescribed a course of antidepressants. The woman told the female psychiatrist that she was the first doctor to have given her medication that cured her pain. The psychiatrist identified that the patient's symptoms had developed after her husband married a second wife, causing her to feel rejected and unloved. The breast was the site of a psychological pain and, as previously noted, is connected by the culture to feelings of love. The patient could not object to the second marriage of her husband or talk to anyone about her feelings, nor express her feelings freely, because her culture permits polygamy. To go against this tradition would alienate her from her community.

This case is an example of a patient who suffered a grief reaction or a reactive depressive illness or an unrecognized "cultural idiom of depression," as described by Stavovy (1996). The case was initially diagnosed and treated as a physical ailment, and only as a last resort referred to a psychiatrist when this approach did not succeed.

Other Cultural Phenomena That Are Likely to Complicate Psychiatric Diagnosis

There are certain cultural phenomena in different cultural groups that can sometimes be mistaken for symptoms of mental illness. These symptoms are sure to complicate psychiatric diagnosis if cultural norms and abnormalities regarding these symptoms and phenomenon are not understood. The normal becomes abnormal only when it exceeds the standard boundaries set by the concerned cultural-linguistic group. Given here are two common phenomena:

1. Treatment toward aggression and violent behavior
2. Attitude toward dreams and their interpretations

Aggression and violence can be interpreted in different ways, depending on the culture. Though most cultures would agree violent and aggressive behavior is wrong, determining what is considered "wrong" lies in the cultural norms and cultural context. This can often lead to problems when asking to diagnose a mental illness. For example, in Pakistani society, any type of aggressive behavior is considered rude and out of order. In that society, any individual who displays some sort of aggressive behavior, particularly in familial situations, could be branded as mentally ill and suffering from depression (Khalily, 2011; Tabassum et al., 2000). It is important for general physicians to be aware of this, since the testimonies of family members in regard to the patient's behavior carry a lot of weight during diagnosis.

Another important aspect is dreams, particularly recurring dreams. Dreams are often described in great detail to physicians as part of the symptoms that are troubling Arab patients. This is especially common among Arab women. However, physicians are often reluctant or unable to access the symbolic world of the patient due to cultural gaps in perception (Al-Krenawi & Grahm, 1999). This can also create a situation in which proper diagnosis and treatment options are hindered due to a lack of sufficient cultural training.

Language and Terminologies Describing Mental Illness

In Arabic, there are several terms often used to describe mental illness and its symptoms. However, these are vague or nonspecific, and therefore are not as precise as western medical terms. In many cases, people who demonstrate signs of mental illness will be described as suffering from *tisaramt* (mysterious disease) (Hassan Fadlalla, 2005). Anti-social behavior that can characterize mental illness, such as aggressiveness or diminished communicative skills, can be attributed to what is called *Sahir* (evil eye) (Abdullahi, 1994). Symptoms of anxiety or depression are generally called *Hariah*, and they do provide an adequate description for what a western psychiatrist would call displays of anxiety (Al-Krenawi & Grahm, 1999). Other general behaviors that are out of the ordinary can be described as *Amaal* (sorcery). Though the word itself describes the act of sorcery, it can also be used to describe behaviors that are attributed to sorcery (Al-Krenawi, 1999).

Since somatization is common among Arab people dealing with mental health issues, this trend is also reflected in the language. Often referring to troubles in the abdomen or the head region (particularly among men) and the chest area (particularly among women) should also trigger possible diagnosis of mental illness. It is common to describe these areas as "bad" when someone is feeling sadness or hopelessness (Hamdan, 2009).

The lack of specific terminology for mental health problems means cultural descriptions of mental illness often refer to the term itself to describe it and the explanations for the cause. From an Arab cultural perspective, mental health problems are often spiritual, social, or interpersonal problems. However, when the framework cannot define the problem, those who share these characteristics will tend to utilize general health services and do not see the need to use a specialized mental health service. In other words, the majority of the Arab population have not been exposed to, or introduced to, western terminologies such as depression, anxiety, schizophrenia, and other allied terms used to define a variety of mental health problems. Therefore, general health services are utilized rather than the limited social services.

Utilization of General Versus Specialist Health Services

Razali and Najib (2000) and Edman and Koon (2000) argued that the use of both traditional and western health care services and treatments indicates "deep seated" religious and cultural beliefs and practices concerning the cause of mental illness. These deep-seated cultural beliefs and values are likely to inhibit the utilization of western health services in both developed and developing countries. This underutilization of western health care services has been documented among the urban Pakistani community in the UK (Tabassum et al., 2000). Similar behaviors have been reported among Vietnamese refugees in Australia (Phan & Silove, 1997), amid Asian, and Mexican immigrants in the USA (Edman et al., 1999; Kuo, 1984; Narikiyo & Kameoka, 1992; Suan & Taylor, 1996; Urdaneta et al., 1995), and in developing countries such as Malaysia (Edman & Koon, 2000).

In developed countries, there is a gap in the need for specialized mental health services and the number of people utilizing them. For example, in the USA, 15% of the population was found to need specialist mental health services at any one time, but only 3% of Americans actually used specialist mental health services (President's Commission on Mental Health, 1978 in Stefl & Prosperi, 1985). Although no specific reference was made to the reason for underutilization, it is possible that it was due, in part, to the religious and cultural beliefs and values noted above. Many people with mental health problems in the general population are not accessing specialized mental health services (Mechanic, 1980; Regier, Goldberg, & Taube, 1978). Greenley and Mechanic (1976) found that only those with a high risk of mental health problems utilized specialized services, while most people were comfortable utilizing general services.

A large-scale research study conducted on people from Kuwait, Palestine, and the Arab population of Israel found a similar pattern in the Arab world. Even if a person was not inclined to have prejudice regarding mental health personally, there was still a high probability he would not utilize specialized health services (Al-Krenawi, Graham, Al-Bedah, Kadri, & Sehwail, 2009). The Arab population of Israel constitutes about 19% of the total population but consumes only about 2.8% of psychiatric services in clinics (Feinson, Popper, & Handelsman, 1992). There are various factors in Arab countries or Arab populations in non-Arab countries that cause this trend. Often, there are problems with accessibility to specialized health care, be it geographical or financial (Fishbein & Ajzen, 2000). In Arab culture, decisions concerning sickness and treatment are usually not taken by the individual alone. Instead, decisions are taken in a familial context, and the perceived opinion of the whole community is a large factor. Therefore, even in families who are more open toward specialized health services, a decision not to utilize them can be taken due to fears of stigma from the community (Al-Krenawi et al., 2009).

One must also take into consideration the larger historical aspect of colonial rule. For many years, the majority of the Arab population was under European colonial rule. This made their exposure to western medical services less than ideal, and to this day there is a general notion that western medical services are intrinsically incompatible with Arab and Muslim culture (Erickson & Al-Timimi, 2001). This historical context must contribute to the cultural climate concerning the utilization of specialized medical services.

The data clearly suggests that there is a general trend of underutilization of specialized health care services for the treatment of mental health problems in the Arab world. Like other indigenous and ethnic minority communities, cultural and social elements are a considerable factor. This is why cultural training and education for general health care providers are necessary. It will enable health care systems to deal more effectively with the Arab population and make sure people are directed toward the care they need.

Knowledge and Understanding of Mental Health Issues Is Necessary for General Health Workers

Global studies have reported that since general health workers are "gatekeepers" of mental health care, they are highly likely to provide the bulk of mental health care at the primary level, but they lack mental health knowledge (Alegria et al., 1991; Tobin & Norris, 1998). It is of utmost importance that they have a sound knowledge and understanding of mental health issues, including patients' cultural perceptions of illness (Jacobs & Giarelli, 2001; Tabassum et al., 2000).

It is difficult to diagnose mental health problems where cultural factors influence the clinical picture. Therefore, adequate understanding and knowledge of both cultural and western mental health issues can assist in accurate diagnosis and treatment decisions (Al-Krenawi & Graham, 2001; Burton-Bradley & Julius, 1965; Cormack & Furnham, 1998; Pulsford & Cawte, 1972; Ruiz, 1998; Stavovy, 1996). A lack of mental health knowledge can lead to misdiagnosis and inappropriate treatment. Hwang, Myers, Abe-Kim, and Ting (2008) report that, in developing countries, it is estimated that many men, women, and children suffer from serious mental illness due to misdiagnosis at general health care facilities. Even in developed countries such as the USA, mental health problems are more likely to go undetected and untreated in general health care facilities than in specialist services, according to Hough, Burnam, Karno, Escobar, and Telles (1987). Sartorius confirms this, and states that general health care workers in developed countries "who deal with large majority of the mentally ill are often poorly trained in psychiatry and do not recognize mental disorders when they see them. The treatment provided to those who are diagnosed is often not adequate, leading to outcomes that discredit psychiatry and its therapeutic armamentarium" (Sartorius, 1997, p. 70).

In context of the Arab population, the lack of proper identification of mental health problems and application of appropriate treatment may be partially explained by a lack of knowledge, skill, or sensitivity to signs and symptoms of mental illness. It may be also partially explained by the presentation of somatic symptoms with underlying cultural beliefs, which complicates appropriate diagnosis and treatment decisions.

There are several factors that are likely to impinge on what general health workers know about mental health issues and their ability to diagnose mental health problems. Perhaps foremost is the amount of training they receive. There is limited time devoted to mental health during basic and postgraduate training for general health workers. As a consequence, general health workers are likely to have limited knowledge of both western and cultural mental health issues.

If we wish to assure quality mental health care for indigenous and migrant communities, it is imperative that more culturally sensitive training be provided to general health care workers. As I have demonstrated with the case of PNG and other notable examples, the knowledge and data regarding the issue do exist and have existed for some time. What is necessary are models which could help improve accessibility of this knowledge to those who need it.

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Chapter 10
Depression, Cardiovascular Disease and Indigenous Australians

M. Le Grande, A. C. Jackson, C. F. Ski, D. R. Thompson, and A. Brown

Gaps in Cardiovascular Disease and Psychological Distress

In Australia, inequalities in health and well-being between Aboriginal and/or Torres Strait Islanders (hereafter referred to as Indigenous peoples) and non-Indigenous people have remained persistent and, in many instances, have worsened (Commonwealth of Australia, 2018; Holland, 2018), despite the adoption of an explicit health equality strategy in March 2008, with the signing of the *Indigenous health equality summit statement of intent* (Human Rights and Equal Opportunity Commission, 2008). Indigenous people live approximately 10–14 years less than their non-Indigenous counterparts (Brown, 2012) with much of this difference in life expectancy attributed to a failure to address the treatment gap in chronic diseases, particularly cardiovascular disease (CVD) (Vos, Barker, Begg, Stanley, & Lopez, 2009). Premature and preventable CVD deaths account for approximately

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one-quarter of the mortality gap between Indigenous and non-Indigenous people (Zhao & Dempsey, 2006). The impact of CVD on Indigenous Australians is felt more in the younger age groups, with the greatest disparity in rates in the 18–34 age group (Brown & Kritharides, 2017). At ages 35–44, the Indigenous rate for coronary heart disease (CHD) including heart attacks is 9–12 times higher than the rate for non-Indigenous Australians (Brown, 2012). Indigenous people also have higher prevalence of both biomedical (overweight and obese, hypertension, dyslipidaemia, impaired fasting glucose) and behavioural risk factors (tobacco smoking, insufficient physical activity, inadequate consumption of fruit and vegetables) than their non-Indigenous counterparts (Brown, 2012; Brown et al., 2014). Further, Indigenous people who are enrolled for cardiac surgery tend to have significantly more comorbidities such as diabetes, hypertension and renal impairment than non-Indigenous people and present for surgery, on average, 10 years younger (O'Brien et al., 2018) Significant disparities and barriers to cardiac care (Li, 2017; Walsh & Kangaharan, 2017), and higher levels of unmet needs during hospitalisation (Mbuzi, Fulbrook, & Jessup, 2017) compared with the non-Indigenous population, have also exacerbated the problem.

In parallel with these high CHD rates, Indigenous Australians also report disproportionally higher levels of psychological distress and associated conditions compared to non-Indigenous Australians. In the 2014–2015 ABS National Aboriginal and Torres Strait Islander Social Survey, almost a third of adult respondents reported high or very high levels of psychological distress, 2.6 times that of non-Indigenous adults (ABS, 2016). Further to this, 29% of respondents aged 15 years and over reported having a long-term mental health condition largely comprising depression (72%), anxiety (65%) and behavioural or emotional problems (25%) (ABS, 2016). A pertinent question, therefore, is to ask what the relationship might be, between the high prevalence of psychological disorders such as depression and CVD and associated conditions in Indigenous Australians.

The Complex Relationship Between Depression and Cardiovascular Disease: Evidence from the General Population

In recent years, significant attention and evidence relating to psychosocial risk factors as key determinants in both the aetiology of CVD and in the prognosis of patients recovering from adverse cardiac events have emerged (Benjamin et al., 2018; Bunker et al., 2003). Evidence from large longitudinal population studies indicates that depression is a key contributor to the development of CVD (Case, Sawhney, & Stewart, 2018; Hare, Toukhsati, Johansson, & Jaarsma, 2014; Rosengren et al., 2004). It is estimated that close to one in five people in the general population with chronic disease also have a diagnosis of comorbid major depression (Egede, 2007). The presence of depression approximately doubles the risk of first myocardial infarction or cardiac death (Nicholson, Kuper, & Hemingway, 2006).

Among patients with established CVD, the risk of a future serious cardiovascular event is increased three- to fourfold by comorbid depression (Flaherty, Wood, Cheng, & Khan, 2017). It is known that psychosocial risk factors such as anxiety and depression strongly influence levels of behavioural risk factors. For example, depressed patients are more likely than non-depressed patients to smoke (Gravely-Witte, Stewart, Suskin, & Grace, 2009) and to relapse after quitting (Perez, Nicolau, Romano, & Laranjeira, 2008). They consume higher levels of dietary fat (Murphy et al., 2012) and engage in less physical activity (Allan, Johnston, Johnston, & Mant, 2007) than those who are not depressed. Similarly, anxious patients have higher smoking rates (Kuhl, Fauerbach, Bush, & Ziegelstein, 2009) and dietary fat intake (Murphy et al., 2012). It is also known that depression significantly hampers rehabilitation efforts (Goldstein, Gathright, & Garcia, 2017) with depressed patients exhibiting lower treatment adherence and completion of rehabilitation programs (McGrady, McGinnis, Badenhop, Bentle, & Rajput, 2009).

The Complex Relationship Between Depression and Cardiovascular Disease: Evidence from Studies Comparing Indigenous and Non-indigenous People

Much of this evidence regarding the role of depression in the development of CVD and in the outcomes following a CVD event is based on research conducted with the general population. Very little research has been conducted in an effort to understand the role of depression in the development of CVD in Indigenous peoples. In Australia over recent years, the importance of assessing the burden and correlates of CVD, including culturally relevant assessment of depressive symptomatology, has become apparent in a small number of studies involving both Indigenous and non-Indigenous populations. A summary of a selection of these key studies is presented in Table 10.1. There are a number of common themes that emerge from this body of literature:

- The estimated prevalence of depression in Indigenous Australians is significantly higher than in non-Indigenous Australians
- Those Indigenous Australians who are assessed as having depressive symptomology tend to exhibit higher levels of both biomedical and behavioural risk factors for CVD
- Indigenous Australians who exhibit poorer health and CVD outcomes also exhibit higher levels of psychological distress or depression
- These depressed individuals also have significantly higher rates of heart disease compared to those who are not depressed
- Depression and heart disease in Indigenous Australians are also impacted by numerous other psychosocial, biological and environmental factors such as comorbidity, geographic location, socioeconomic disadvantage, inequality and barriers in access to care.

Table 10.1 Summary of selected studies exploring the relationship between depressive symptoms and cardiovascular disease in Indigenous Australians

Study	Sample	Methodology	Instruments	Aim	Results
Esler, Johnston, Thomas, and Davis (2008)	39 Indigenous Australians with verified ischaemic heart disease	Psychometric validation study. Semi-structured diagnostic clinical interview to determine DSM-IV criteria for depression compared with a depression screening tool	Modified PHQ-9 (depression screening tool); DSM-IV interview	Assess the reliability and validity of the modified PHQ-9 and determine the prevalence of depression in a sample of Indigenous people with ischaemic heart disease	The prevalence of either minor or major depression was 28.2% (15.4% major depression and 12.8% minor depression) which is much higher than the general population (6%). Modified PHQ-9 performed well, but the standard cut-off of 10 was not recommended for this population
Richmond et al. (2011)	Indigenous Australians ($n = 64$) and non-Indigenous Australians ($n = 361$) who are male, imprisoned and smoke	Cross-sectional questionnaire study to compare cardiovascular risk factors in the sample with the general population	Kessler Psychological Distress Scale 10	The aim was to compare cardiovascular risk factors among male smoking prisoners with males of similar age and socioeconomic background in the general population	Of the Indigenous prisoners, 55% had three or more CV risk factors compared to 36% for non-Indigenous. Current depression and anxiety symptoms were 47% for Indigenous men compared to 11% in the general population (matched on sex and age)

Schierhout et al. (2013)	1174 Indigenous Australian patients with type 2 diabetes	Clinical audit data from 44 health centres over 12 months	Standard screening tools included the K-5, K-6, K-10, PHQ-2+, PHQ-9 and Edinburgh Postnatal Depression Screening tool	To compare differences in depression screening, documentation and management between patients with different levels of disease severity, comorbidity and diabetes control	Low rates of depression screening (5%) were conducted in the 12 months. After adjustment for potential confounders, patients with more severe diabetes-related disease were less than half as likely to have been screened for depression using a formal tool
Brown et al. (2014)	436 Community dwelling Indigenous Australians	Cross-sectional study in four remote communities. Each participant was administered a structured questionnaire, clinical record review and comprehensive clinical examination	PHQ-9 depression screening tool	To assess cardiometabolic risk, geographic dispersion and correlates in Indigenous people	Those with elevated depressive symptoms were twice as likely to have heart disease or CVD independent of all other risk factors
McNamara et al. (2014)	1631 Indigenous and 231,774 non-Indigenous people aged 45 years or over	Population cohort study (from the 45 and up study) using postal questionnaires	Kessler psychological distress scales (K-10 and K-5)	To assess the cross-cultural validity of two Kessler psychological distress scales (K-10 and K-5)	Higher levels of missing data were recorded with Indigenous participants, e.g. proportion of missing/invalid responses for the K-10 item 7 (depressed) was 12% in Indigenous participants compared to 9% in non-Indigenous

(continued)

Table 10.1 (continued)

Study	Sample	Methodology	Instruments	Aim	Results
Almeida et al. (2014)	250 Indigenous Australians aged 45 years or over	Cross-sectional survey from six remote Indigenous communities; psychometric validation study	The Kimberley Indigenous Cognitive Assessment of Depression (KICA-dep) scale; DSM-IV interview	To determine the prevalence of depressive disorders among older Indigenous people living in the Kimberley, and investigate the sociodemographic, lifestyle and clinical factors associated with depression in this population	The point-prevalence of a depressive disorder in this population was 7.7%; Heart problems were more prevalent among participants with than without depression (OR = 3.3). There was also a non-significant excess of women, and people with diabetes and kidney diseases amongst those with compared with those without depression
Davis et al. (2015)	107 Indigenous and 793 non-Indigenous community dwelling diabetic patients	Longitudinal observational study	PHQ-9 depression screening tool; Brief Lifetime Depression Scale (BLDS)	To determine the prevalence and associates of depression in Indigenous and non-Indigenous Australians with type 2 diabetes	Depressive illness was more likely to be major and untreated in the Indigenous group. Lifetime depression was also more common in the Indigenous group. Increased alcohol intake was associated with current depression in the Indigenous group

Brown et al. (2016)	189 Community dwelling Indigenous Australians	Mixed methods community-based survey; psychometric validation study	Psychosocial questionnaire including modified PHQ-9, adapted K6 and 7-item culturally specific depression scale	To develop a comprehensive questionnaire, which could be used to delineate the intra-psychic and environmental factors contributing to psychological distress and depression in Indigenous Australians	13% of the cohort had possible major depressive disorder and 40% had elevated depressive symptoms. Depression scores were also higher among current smokers. Regression modelling indicated that the depressive symptoms expressed in this population are driven by a “sense of injury” and chronic stress
McNamara et al. (2018)	1631 Indigenous and 233,405 non-Indigenous aged 45 and over	Population cohort study (from the 45 and up study) using postal questionnaires	Kessler psychological distress scales K-10	To identify contributors to the difference in the observed prevalence of psychological distress between Indigenous and non-Indigenous people	High distress affected 43.8% of Indigenous and 20.9% of non-Indigenous participants. Rates of high psychological distress increased with the number of physical health conditions in a graded fashion

- Existing tools derived from non-Indigenous cultures are often inadequate in the assessment of depression in Indigenous people
- More promising results in validity of assessment have been found where efforts have been made to modify existing tools or design new tools to assess depression (e.g. modified Patient Health Questionnaire 9 [PHQ-9]) in order to take into account cultural differences in conceptualisation of depressive concepts.

Clearly, this body of literature points to factors specific to Indigenous people that may exacerbate the relationship between depression and CVD. To gain an understanding of this relationship requires a holistic framework that recognises the social determinants of health as the crucial influence on Indigenous social and emotional well-being (Dudgeon, 2017). These determinants include a range of current factors including social disadvantage, education and unemployment, as well as intergenerational legacies derived from colonisation such as trauma, grief, removal from family, racism and discrimination (Atkinson, Nelson, & Atkinson, 2014; Henderson et al., 2007). Further, it is known that Indigenous people qualitatively value factors that lie outside Westernised measures of health and well-being including cultural beliefs and connections to the land (Durie, 2006; Ganesharajah, 2009; Kral, Idlout, Minore, Dyck, & Kirmayer, 2011; Mark & Lyons, 2010). Some examples of how these social determinants of health and cultural beliefs may possibly impact upon the relationship between depression and CVD will now be elucidated upon.

Indigenous-Specific Factors That Affect the Relationship Between Depression and Cardiovascular Disease: The Role of Intergenerational Trauma

There is considerable evidence pointing towards the physiological impacts of earlier-life chronic stress, trauma and ongoing distress on the development of chronic conditions such as CVD. It is now widely acknowledged that intergenerational trauma in the form of cumulative cycles of adversity which promote morbidity and mortality (Prussing, 2014) has pronounced adverse impacts on current mental health and well-being. The ongoing effects of these historical disadvantages and intergenerational trauma on current health inequality between Indigenous and non-Indigenous peoples are observed internationally (Atkinson et al., 2014; Elias et al., 2012; Evans-Campbell, Walters, Pearson, & Campbell, 2012; Heart, Chase, Elkins, & Altschul, 2011; Millender & Lowe, 2017; Walters et al., 2011).

One specific example of how intergenerational trauma has adversely impacted on current risk factors for CVD is in the issues associated with cigarette smoking. Smoking is the single most important risk factor for heart disease in Indigenous Australians (Gray, Brown, & Thomson, 2012). Prior to European settlement some Indigenous people chewed native tobacco such as *pituri* (Ratsch, Steadman, &

Bogossian, 2010), and consumption was moderated by a number of social control mechanisms in traditional communities (Brady, 2002). It is apparent from the historical records that obtaining modern forms of tobacco, as well as other resources such as food, from Europeans was viewed as a rightful exchange for the loss of land (Brady, 2002). Thus, the early roots of Indigenous smoking addiction may have come about as a cultural shift which indirectly resulted from the loss of land and resources, an important stressor for Indigenous people (Kingsley, Townsend, Henderson-Wilson, & Bolam, 2013). More disturbing is the evidence that Europeans deliberately exploited Indigenous people's addiction to nicotine. Many Indigenous workers were paid with tobacco rations, instead of money, until the 1960s (Calma, 2009) and predatory tobacco companies continued to promote Indigenous smoking well into the 1990s (Brady, 2002).

There is also evidence that higher levels of stress experienced by Indigenous people was and continues to be associated with higher tobacco use (Passey, Gale, & Sanson-Fisher, 2011). For example, a study located in Central Australia found that Indigenous male current smokers reported significantly higher PHQ-9 depression scores than non-smokers (Brown et al., 2016). Importantly, it has been shown that members of the "stolen generation"—children of Indigenous descent who were removed from their families by government agencies and church missions, exhibit a higher prevalence of tobacco use than others (Briggs, Lindorff, & Ivers, 2003). Evidence from qualitative studies also highlights the perception of smoking as a form of stress relief and a source of calm in response to life stressors (Yuke et al., 2018). More recently, culturally meaningful approaches to smoking cessation based on "trauma-informed" principles have been advocated, rather than conventional individualistic "blame and shame" approaches (Wyndow, Walker, & Reibel, 2018).

Indigenous-Specific Factors That Affect the Relationship Between Depression and Cardiovascular Disease: Discrimination and Intergenerational Transmission

Given the high levels of self-reported racism and consequential stress encountered by Indigenous Australians (Larson, Gillies, Howard, & Coffin, 2007), it is possible that racial discrimination is also a key Indigenous-specific determinant of the gap in CVD levels experienced between Indigenous and non-Indigenous people. Evidence from systematic reviews have concluded that discrimination, whether internalised, interpersonal or institutional, acts as an important stressor that in turn negatively affects both physical and mental health (Heard-Garris, Cale, Camaj, Hamati, & Dominguez, 2018; Paradies, 2006; Paradies et al., 2015; Pascoe & Smart Richman, 2009). For example, the prospective Aboriginal Birth Cohort Study found that self-reported racism in young Indigenous Australians was associated with anxiety, depression and suicide risk (Priest, Paradies, Gunthorpe, Cairney, & Sayers, 2011). In another study conducted in rural Australia, Indigenous people who reported negative treatment based on race were more likely to report significantly poorer mental and physical health-related quality of life (Larson et al., 2007). In addition, other systematic reviews of epidemiological studies have specifically reported linear relationships between levels of self-reported discrimination and important CVD risk factors such as weight and body mass index (Bernardo, Bastos, Gonzalez-Chica, Peres, & Paradies, 2017; Spahlholz, Baer, Konig, Riedel-Heller, & Luck-Sikorski, 2016). Qualitative research with urban Indigenous Australians has found that unhealthy eating behaviour, alcohol usage and smoking are among the unhealthy strategies used to counter negative emotions such as anxiety or depression brought about by racial discrimination (Ziersch, Gallaher, Baum, & Bentley, 2011).

It is also known that stress itself affects cortisol secretion (Richman & Jonassaint, 2008) which in turn activates lipoprotein lipase, a fat storing enzyme primarily responsible for the accumulation of body fat and can also lower insulin sensitivity (Mead, Irvine, & Ramji, 2002). An Australian study comparing Indigenous and non-Indigenous young adults demonstrated a blunted cortisol awakening response which was differentially associated with chronic experience of stress (Berger et al., 2017). This type of cortisol response is commonly observed in patients with severe mental disorders including depression (Dedovic & Ngiam, 2015). It has also been shown that chronic stress resulting from frequent racist encounters is associated with chronic low-grade inflammation in the form of elevated levels of pro-inflammatory biomarkers (Nuru-Jeter et al., 2013). In another study conducted with African Americans, pathological blood pressure regulation in the form of blunted β-adrenergic receptor responsiveness was associated with racial discrimination assessed using the Perceived Racism Scale (Hill et al., 2018). Evidence from both animal and human studies has led some researchers to speculate that early life stressors actually cause structural remodelling of the brain, in the form of dendritic remodelling in the hippocampus, basal amygdala and prefrontal cortex (McEwen, Nasca, & Gray, 2016), changes which can adversely impact upon physical and mental health through the life course. Preliminary evidence also suggests that adverse stress, brought about by discrimination at any stage of the life course, can potentially causes adverse alterations in cellular mitochondria, which in turn can induce inflammation responsible for CVD (Picard & McEwen, 2018). It is certainly possible that biological embedding of early life traumatic experiences can influence health and well-being throughout the life course and via epigenetics can be transmitted over generations (Anda et al., 2006; Brockie, Heinzelmann, & Gill, 2013; Chief Moon-Riley, 2017; Heard-Garris et al., 2018). Indeed, twin studies have provided evidence that important reactions to chronic stress such as the cortisol awakening response are highly heritable (Franz et al., 2010).

Indigenous-Specific Barriers to Secondary Prevention of Cardiovascular Disease

The adverse impact of chronic stress and depression on the prognosis and management of CVD (Flaherty et al., 2017) is well known in the general population. Significant disparities and barriers to cardiac care, compared with the non-Indigenous population, have also exacerbated the problem in Indigenous people. A recent systematic review examining the association between self-reported racism and various measures of healthcare service utilisation found that racism was associated with more negative patient experiences of health services, lower levels of healthcare-related trust, satisfaction and communication (Ben, Cormack, Harris, & Paradies, 2017). Reported barriers to health care utilisation in Indigenous Australians include lack of culturally competent healthcare practitioners, high staff turnover which breaks trust, which meant that participants only engaged in the system if they were physically very unwell (Jobling et al., 2016). When Indigenous people do engage with cardiac care at metropolitan hospitals, they report a sense of dislocation and disorientation, particularly as they are dislocated from both their home land and their community (Worrall-Carter et al., 2016). Further, many Indigenous cardiac patients do not fully comprehend their treatments or the western biomedical model, and this contributes to mistrust in the health system (Artuso, Cargo, Brown, & Daniel, 2013). The availability of Indigenous staff such as Indigenous Hospital Liaison Officers in hospitals and health care centres is seen as vital for Indigenous cardiac patients since they provide crucial links to cultural security (Mbuzi et al., 2017). It is not surprising, therefore, that a study that introduced Indigenous Health Workers into a cardiac inpatient care team significantly improved patient follow-up and increased participation in cardiac rehabilitation by Indigenous patients (Taylor et al., 2009).

Appropriate Assessment of Social and Emotional Well-Being in Indigenous People

It is increasingly apparent that existing Western-developed health and well-being frameworks, perhaps even the concept of ‘depression’ itself often fail to address issues relating to connectedness, grief, trauma, resilience, empowerment and control, so crucial to Indigenous health and wellbeing. Arising from the recognition that stress and emotional well-being in Indigenous peoples worldwide are strong determinants of physical health (Drew, 2015), the concept of social and emotional well-being (SEWB) has been put forward as a more culturally appropriate construct of ‘wellbeing’ (Day et al., 2015; Gee et al., 2014; Social Health Reference Group, 2004). SEWB is defined as “a multidimensional concept of health that includes mental health, but which also encompasses domains of health and wellbeing such as connection to land or ‘country’, culture, spirituality, ancestry, family, and community" (Gee et al., 2014, p. 55). This approach acknowledges that well-being can be influenced by a wide range of external stressors including cultural dislocation, family breakdowns, discrimination and social disadvantage (Gee et al., 2014), but can, conversely, be supported and preserved by a range of socially and culturally constructed features of individual and collective life. Three major categories of SEWB instruments have been identified in the literature: unmodified standard instruments (e.g. Kessler K-10), cross-culturally adapted standard instruments (e.g. Adapted Patient Health Questionnaire (Brown et al., 2013)) and Indigenous developed measures (e.g. Strong Souls Inventory (Thomas, Cairney, Gunthorpe, Paradies, & Sayers, 2010)). A recent review advised that standard instruments should only be used if they have been subject to a formal cross-cultural adaptation process (Le Grande et al., 2017).

Conclusion: A Bidirectional Relationship Between Depression and Cardiovascular Disease in Indigenous People?

The association between depression and CVD in Indigenous people, as in the general population (Lippi, Montagnana, Favaloro, & Franchini, 2009), is likely to be bidirectional with depression directly responsible for CVD and vice versa—a vicious cycle. Effect modifiers in the context of this relationship include harmful behaviours such as smoking and, importantly, underlying and ongoing intergenerational trauma and discrimination, key determinants and mediators of social and emotional well-being. If the relationship is indeed bidirectional, then an argument can be put forward for interventions that directly target cardiovascular risk factors or interventions focused on improving social and emotional well-being, which in turn will lower the risk of CVD. In the general population the traditional approach to lowering CVD rates has been the former. Could it be that interventions aimed to negate the effects of intergenerational trauma and discrimination experienced by Indigenous people, factors that are central to their social and emotional well-being, will ultimately be more successful in closing the gap than efforts to directly lower cholesterol, decrease smoking rates, improve exercise and so forth? Would efforts to assess true progress in the achievement of health equity be better addressed by instruments that are closer to the Indigenous conception of social and emotional well-being than the current Western-derived measures representing depression?

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Chapter 11
Culture Through a Clinical Lens

Cynthia C. Wesley-Esquimaux and Steven Koptie

Many of us grew up as direct recipients of the policies and practices that brought us The Royal Proclamation, the Indian Act, Indian Agents, Indian Residential Schools, and the "Violence of Benevolence" (Wesley-Esquimaux, 2011, unpublished paper). Not the kind of benevolence that is gentle and caring, but the kind that is judgmental and jarring, painful in its application, disruptive and lingering. We watched the children turned adults in our world bend to its tenants, bend to its demands, and then bend to the personal violence left in its wake. Too many of us live with memories of the fighting, drinking, physical and sexual pain we were subjected to… the result of our parents and grandparents' childhoods being ripped asunder by the "care and benevolence" of those who ran the circus called "Indian Affairs and Northern Development" through the 50s on up to present day.

Today, we encounter a federal government who has said yes to change, to nation recognition, and to addressing and correcting past infractions. What do we have to do to ensure this government keeps its word, and delivers this renewed vision? More importantly, what is our renewed vision, and how will this vision contribute to the very important work of not only documenting and discussing but also living the promise of our ancestors?

What will it take to make those changes, and who will be responsible to ensure they actually happen and are sustainable? We can continue to look to the government of Canada as the primary culprit when it comes to how to we got to where we presently are, or we can look to ourselves as catalysts to the kind of change only we

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can generate. The preference is that we take the ‘I am a catalyst’ approach because we have been in the place of loss for far too long. Recognition of historic wrongdoing is slowly beginning to deliver dividends, but it hasn’t always been proactive enough to hold the interest or aspirations of young people. Today, the movement is toward taking responsibility for living better, being stronger, and building the kind of nationhood that holds deep meaning. We want to give and receive the kind of respect that can’t be eroded, tossed carelessly aside, or dismissed by perceived higher powers. We understand reciprocity, as it is a powerful tenant of Indigenous values. We want our children and grandchildren to live forward with a different reality, and to know a power and purpose of their own.

We will move forward, because we have already learned to assess the damages, write our pain, challenge our keepers, and reclaim our lives and hopes. We are stepping up to multiple tables and declaring our intention to take sole responsibility for reconstituting our nations, reframing our health and educational needs, reclaiming our spiritual practices, and rematriating our children back into the circle of our nations. Our children became and have remained the primary pawns in the colonial game of removal, relocation, and the cultural genocide of the First Peoples of this land. Our spiritual practices are directly tied to the reconstitution and reclamation of our health and well-being, and the proper nurturing of our children. We will not, cannot, have one without the other. Our children will not be safe, will not be assured physical and mental well-being and cultural safety, without the full reclamation and reconstitution of Indigenous spiritual understanding and practice. We must be guided by spirit, not by wealth, not by individuation, not by policy and practice, but by a larger understanding of who we truly are, and the reclaiming of our ability to walk confidently in that knowledge.

When we focus in on the children, what do we see? In November 2016, one of the authors had the privilege of speaking to a group of youth “aged out” from foster care. They asked for rematriation, not repatriation to their homes and communities, because it has been seemingly eternal and unrelenting “paternal” policy and practice generated by government and western society that took them away from their mothers and the care and connection they knew they needed to be healthy emotionally, mentally, spiritually, and even physically. Perhaps with influences from their own worldview they might not be driven so hard into more loss and addiction. Why a reference to rematriation? It has been said that “nothing is over until our women’s hearts are on the ground” (Cheyenne Proverb).[1] And Indigenous peoples have observed the women of our nations standing firm in the face of alienation and hurt to bring us home to ourselves. They have held tightly to the cultures of their nations and have done their best to ensure the continuance of Indigenous knowledge, passing what they could to the children they have been allowed to raise. Allowed, because the imposition of ‘Child Welfare’ after the insult of Indian Residential Schools has torn thousands of children from their arms and from our nations. This is where calls to action on healing have been generated. This is where utilizing a

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[1] https://www.goodreads.com/quotes/857542

clinical lens becomes the challenge. The backdrop to change, to embedding cultural safety, to healing, means endorsing a feminine paradigm.

Today, Indigenous peoples are slowly relearning how to “lift the people up” and protect them from the violence that has run rampant through the story of their lives, while our men do their part to call out the violence and heal their own pain. The lens we are gazing through today was put forward by an Indigenous woman seeking to protect an Indigenous boy from this fate. Irihapeti Ramsden (2003), Ngai Tahupotiki and Rangitane of Aotearoa identified a possibility, clinical practice viewed through a cultural lens. A lens which challenged the imposition of racialized care and an indifferent approach to Indigenous health care in New Zealand, cultural safety, now a globalized requirement.

Koptie's (2009a) reflection on chapter 9 of Ramsden’s Ph.D. thesis, “the Public Narrative on Cultural Safety,” reviewed the difficult “melancholic journey of self-discovery” Ramsden advocated for Indigenous change agents to gain a perspective on colonial inertia as an ongoing challenge. Her frequent challenge to her nursing students was, “There are three types of people in the world: those who make things happen, those who watch things happen and do nothing and finally those who never knew what hit them. Let nurses be of the first group” (Ramsden, 2003).

Cultural Safety (Koptie, 2009a) is the neutral space between divergent internal states which develop according to lived experience and a sense of security with the world in which we are living and externally impacted by. Anxiety and depression develop when there is an inability to locate certainty, security, and consistency in our internal and external environments. We live in a country with “Indian Reserves,” and as long as this circumstance in our collective present and future remains under the control of the federal government, cultural sensitivity and safety will remain elusive. The first step for Canadian social service workers toward making cultural sensitivity and ultimately cultural safety real is having the uncomfortable conversations that will dismantle colonial approaches to Indigenous victims of the “intent to destroy” (Tatz, 2003). As Dr. Lisa Wexler has noted,

> Linking colonialism – historical and ongoing – to the health disparities experienced by Indigenous people is an important step in understanding how to begin to promote health and wellness in Native communities (Wexler, 2009, p. 1).

Today we must go back before we go forward; we have to re-examine the process that brought us to this question of culture as healing and where it intersects with clinical care. In the 1990s, Cynthia Wesley-Esquimaux was tasked with working through a communal conversation on trauma; this work came out of an intensive engagement designed to frame community-driven self-government. People expressed concern that the process of self-government was being pushed forward before the necessary work of healing and reconnecting to culture and spiritual practices was done. What was standing in the way of bringing the tenants of Indigenous knowledge and health back into community, back into the heart of our homes and cultural expression? What would a healthy and inclusive approach mean to those delivering services to Indigenous peoples, both on and off reserve? Was there anything healthy about the way the health care system delivered services to Indigenous peoples? Was there any understanding of what might constitute trauma, historic or contemporary, in a population that had yet to identify its own cultural markers for well-being? We had not yet examined our own need for cultural safety, or the value of cultural practice in healing historic trauma and the contemporary effects of Indian Residential Schools, foster and adoptive care, or for addressing the horrifying facts of missing and murdered Indigenous women and men. We had not addressed how culture could be viewed through a clinical lens and be used to blend healing modalities. In those earlier days, we were decades away from trauma informed practices in health, education, and mental well-being. We had to look in several places for inclusive policy and practice, and models that might influence the trajectory of health care in Canada.

In Australia, Westerman (2010) argued that the inaccessibility of mental health services developed and delivered to Indigenous Australians was rooted in both lack of cultural competence and need for clinical competencies:

> Few individuals or services are able to integrate clinical and cultural elements of service delivery. For example, accurate diagnostic formulation can only occur if practitioners have a clear understanding of the cultural and clinical manifestations of mental illness to be able to determine the most likely cause of client distress (clinical or cultural) (Westerman, 2010).

Cultural competence for clinical practice requires an education inclusive of the lessons from the worst crimes against humanity over the colonization period post 1500 AD. Our hearts ache for Syria and Yemen. Tatz (2003) calls for teaching:

> Racism is destructive, irrational behavior rather than a mere mindset of prejudice. It is often translated into vicious practice and often enough, into genocide. It is finally come to be seen for what it has long been, namely, the most important single cause of conflict in the modern era (p. 172).

Witnessing an adult review an anxiety activating memory of being severely punished by a cruel father for going to the window during the war in Germany, and the struggle to reframe the event to a parent scared of what a bomb might do if exploded near the family home contributed to our understanding of the adaptability of Indigenous social work across cultural domains (Koptie, 2017–18).

> One of the ultimate goals of REBT is to encourage a client to serve as [her] own therapist as soon as [she] can during therapy and after formal therapy has come to an end. Unless a client has internalized a set of self-helping strategies and techniques, [she] may well fail to deal with any new aversive activating events that [she] might encounter in therapy and once therapy has come to an end. (Dryden, 2009, p. 209).

Colin Tatz made efforts in 2003 to solve the "riddle of the soul of suicide" in Indigenous Australian and New Zealand communities. His important contribution on studies on genocide in his book "With Intent to Destroy: Reflecting on Genocide" told us that Indigenous mental health was different, that Indigenous suicide was different, that how we dealt with Indigenous peoples must also be different if we were to provide the kind of supports and assistance that would address the underlying pain of marginalization and the kind of isolation that numbs the soul.

We know that the underdevelopment of vast regions of Canada has been effectively linked to the process of colonialism and the impacts of profound loss and forced acculturation. Wexler (2009) examined the colonial discourses that Alaskan Native Youth internalize to attempt to make sense of their overwhelming sense of powerlessness and rationale for self-destructive behaviors.

> Linking colonialism-historical and ongoing-to the health disparities experienced by Indigenous people is an important step in understanding how to begin to promote health and wellness in Native communities…Highlighting the link between colonialism and self-destruction among Inupiaq young people challenges the common characterization of suicide as mainly a biomedical issue, and repositions it as a political problem stemming from colonization. (Wexler, 2009).

Graduate degrees created opportunity for the authors to return to rural and remote social work in northern Ontario and university administration. Northern practice created an opportunity to demonstrate the utility of Cultural Safety in social work and education. There, Steve Koptie saw the necessity for clinical competency to reduce suicide, family violence, and child apprehensions, major indicators of the failed "Reservationization of Canada" (Koptie, 2009a). Both authors have demonstrated, through applied research practices and Indigenized treatment approaches, that Indigenous research and writing are crucial contributions to restoring mental well-being to neglected regions of Canada. They observed that most of remote Northern Ontario does not reflect a space that is "Yours to Discover," as our Ontario license plates invite, but rather a deplorable and shameful existence to uncover.

Koptie also discovered remarkable resilience and self-determination in women in remote First Nations, who assumed roles in suboxone treatment programs to address community emergencies where over 60% of their members, including youth, were receiving harm reduction services for opiate pain medication abuse. Ten plus years of family and community turmoil where every family had been tragically altered by overdose deaths and suicides related to brutal drug withdrawal episodes and a loss of basic community safety had led to pervasive hopelessness and despair. These conditions in rural and remote Ontario demand deep reflections on how denial, complacency, and historic amnesia of the truth of brutal colonial intentional actions to remove, displace, and destroy have left a legacy of health challenges that even Indigenous women have a difficult time mitigating. First Peoples across Canada find themselves living in a new kind of war zone, a zone that has been creating intergenerational violence and hurt generation after generation through constant cultural incompetence delivered through external interference and violence of benevolence (Wesley-Esquimaux, 2011, unpublished paper).

Acting as a Registered Social Worker in a remote fly-in reserve in Northwestern Ontario addressing suicide and opiate addiction, and consulting on the delivery of tested elements of practice, Koptie also looked at several potential models. His focus culminated in wise practice concepts, blending the best of identified best practices (Wesley-Esquimaux & Calliou, 2010) from Historic Intergeneration Trauma Transmission (Wesley-Esquimaux & Smolowski, 2004), the Strengths Model (1992), Rational Emotive Behavior Therapy (Ellis, 2005), Cognitive Behavioral Therapy together with Motivational Interviewing (Randall & McNeil, 2017), Adverse Childhood Experiences theory (ACE's) (1985), and Stages of Change training (Prochaska, Norcross, & DiClemente, 2013).

For example, the strengths model focuses on what abilities the person possesses rather than labeling weaknesses, problems, or deficits that need fixing. Dr. Alicia Dunlop held that most youth find ways to survive even though they may be labeled dysfunctional. The problem is that social workers all too often operate from the paradigms learned from white middle-class constructs. Most social workers have little exposure to cross-cultural Indigenous historic realities, and the curriculums at all levels of academia are lacking guidance on how to mitigate stigma, stereotypes, and early childhood traumas, especially in Indigenous populations.

Through the Strengths Model, we observed how we can help vulnerable youth strengthen their roots and grow up to be capable and productive citizens. This model requires assertive outreach, engaging Indigenous youth in their own environments and not merely waiting for them to attend what are often culturally unsafe adult-based agency spaces. Equally important is provision of a wholistic education of community social service providers on the complex needs of special needs clientele.

Each of these models were used to facilitate delivery of Suboxone Programs for on-reserve First Nations men, women, and youth battling opiate addictions. Key community workers were and remain essential for the success of these culturally informed clinical addiction treatments. The failure to deliver viable health, social services, and, more troubling, basic community safety for rural and remote Indigenous citizens of Ontario challenges Canada's claim of being a modern state. We question the right of Canada to claim jurisdiction over rural and remote territories when the truth of their lived experience remains fragile and uncontested. If we are truly moving to reconciliation of our mutual histories and experiences of colonial experimentation, then we all have work to do.

Several group sessions were conducted on the Stages of Change cycle to help identify where people were struggling. Self-identification of adverse childhood experiences and personal loss experiences is a vital component of overcoming addiction. People require non-judgmental support utilizing the Stages of Change Circle Teachings, which readily complimented Indigenous Wholistic Medicine Wheel Teachings.

Koptie was able to elicit a deep sense of pride from the key workers and suboxone program participants who then designed their own poster-sized wall chart of the Stages of Change/Medicine Wheel Teachings to guide their work. On a note posted at the dispensing site, "Unconditional Positive Regard" represented a transfer of social work knowledge and non-judgmental orientation as vital in providing harm reduction and allowing relapse to not only represent failure, but a step toward healing. Relapse became an opportunity for unified efforts to share strategies on how to mitigate common stresses related to living in isolated communities. The program became a launch pad to explore and express the intergenerational impacts of dislocation, residential schools, and child welfare's apprehension of children. It also made it possible to discuss the devastation of alcohol abuse and family violence.

After completing two graduate programs in community development and Indigenous Social Work, Koptie advocated for the Centre of Addiction and Mental Health (CAMH) to deliver a Suboxone Program training course through videoconferencing. This has yet to be delivered due to unresolved colonial debates on who funds Health and Wellness training for Indigenous peoples in Ontario, the provincial or the federal government. The provincial government claims constitutional rights to the mineral resources in Northern Ontario, but for the most part remains uninterested in the human development of the people who inhabit two-thirds of Ontario. This stalemate costs lives and more than likely prevents Canada from ever becoming a peaceful nation. This leads us to the current conversation on Truth and Reconciliation being promoted across Canada.

Truth and Reconciliation conversations are very recent intrusions in Canada's institutions of higher learning. They are intrusive by their long absence in the consciousness of Canadian teachers and students. Cultural knowledge exchange requires a wholistic understanding of how what "we did not know" has had serious implications on how we practice community service to peoples excluded by Canadian society and deliberately robbed of their cultural identities. It will be impossible to alter the sad trajectory of many rural and remote First Nation peoples until professional schools of training adapt and adjust their evidence-based healing models to include cultural safety and wise practices. Wise Practice frameworks can be developed by balancing the uniqueness of place and culture with clinical diagnosis and intervention, while being inclusive of mainstream and Indigenous worldviews. As a First Nation social worker with clinical skills tested and informed by teachers, mentors, and role models from Canada's Southern Ontario community of practice, Steve found that his own knowledge base was frequently inappropriate for providing clinical services in the vast region where the pavement ends in Northern Ontario, the Nishnawbe Aski Nation, a territory of the size of France.

Steve met with a group of youth in Cat Lake First Nation for a conversation on how binge drinking patterns in Northern Ontario become normalized. The youth were forthcoming in sharing how the opening of winter ice roads creates opportunities to access Ontario Liquor Control Board Alcohol, for what they term "good alcohol" (Koptie, 2017, unpublished conversations). The main form of alcohol in many Northern communities is called Home Brew, unsafe, secret concoctions of fermentation recipes passed down in families over generations. Some of those secret ingredients could include rubbing alcohol for added "kick" (Mushquash, Stewart, Comeau, & McGrath, 2008). Social Workers in rural and remote Canada recognize the negative Public Health consequences of these intoxicants on large numbers of Northern citizens. The majority of harmful impacts on community safety are unfortunately monitored through the local justice system and frequently result in over-incarceration. Alcohol-related incarceration is an under researched topic in Canada's north (Mushquash, Stewart, Comeau, & McGrath, 2008). Research on drinking motivation in Nova Scotia First Nation adolescents suggests "drinking to party" is a way to gain social affiliation, as in many cultures, but the quest for intoxication rules. Heavy alcohol use for "intoxication-rather than social affiliation-appeared to be the desired outcome of drinking" (Mushquash, 2008). Mushquash also suggests that promoting responsible social drinking as a strategy to reduce harm from alcohol abuse may not serve First Nation communities. Indigenous youth who consume alcohol mainly to achieve the highest level of intoxication will not respond well to abstinence programs for treatment and prevention. What is happening behind the drinking to intoxication is what needs further research and targeted attention.

The youth claimed that unless they binge drank the "good alcohol" (store bought) to the "point of getting totally 'F'D up' it was a waste of good money," as bootlegged good alcohol is apparently more expensive than illegal opiate drugs (Mushquash, Stewart, Comeau, & McGrath, 2008). The drinking patterns in these communities are carried over lifetimes and migrate to urban centers where good alcohol is readily accessible. Alcohol poisoning is an all too frequent outcome, as is undiagnosed alcohol withdrawal, which is more problematic and can be fatal. This destructive cycle was highlighted in the 2017 Coroner's Inquest into the death of an Indigenous man, Romeo Wesley, who died in the Cat Lake First Nation nursing station after an altercation with police (Cameron, 2017). The need for better training for police and health providers to recognize and respond appropriately to drug and alcohol withdrawal was one of the Coroner's recommendations in order to avoid unnecessary deaths for intoxicated Indigenous people (Verdict Coroners Report, 2017).

These harsh complexities were demonstrated in a counseling session in Fort Severn, Ontario, the most northern community in Ontario and on the Hudson Bay. A mother who lived with her grown sons sought support for family violence. Her sons were physically abusive toward her when they wanted to obtain money to buy drugs. She had approached the nurses provided by Health Canada at the community health clinic for help to manage the everyday anxiety of her home life. She indicated that, "the nurses were dismissive of her situation and told her she was always complaining about her children" (Fort Severn, 2006). Their clinical advice was for her to request the doctor to increase the dose of her mood management medication. Instead, she chose to suffer in silence. When the doctor was approached about how the nurses engaged community members and the nature of cultural competence training that remote nurses undergo, the response was "Steve, people receive compassionate care at this clinic" (Koptie, 2017, unpublished conversations).

Many of these stories happen every day in under-resourced centers of mental and general wellness clinics in the north, and highlight the presumptive idea of the inclusion of cultural safety in Canada. Having researched Ramsden's work on Cultural Safety in health care in New Zealand where she offers a step-by-step progression toward culturally safe engagement, I am aware of the deficits here in Canada. Moving from cultural sensitivity, to awareness of cultural difference, to wholistic training, to operationalizing wise practices, requires fully untangling what is happening in clinical practice. This will require the creation and use of a clinical lens that actually sees the value and utility of cultural practices as effective tools for healing. It is essential to address the disturbances of mental well-being and offer appropriate cultural and sustainable emotional, social, and spiritual interventions.

Steve assisted in the delivery of the northern suboxone program, a Community-Based Taper-to-Low-Dose-Maintenance Suboxone Treatment Program for

Prescription Opioid Dependence in Remote First Nations in Northern Ontario. It is opioid substitution therapy based on a model developed by Mae Katt, a remarkable Indigenous community development nurse out of Thunder Bay, Ontario. Mae Katt's (Katt et al., 2012) approach generates community well-being by promoting community ownership and self-determination. Before this program was initiated, outside interventions came through visiting experts who sporadically flew in to remote communities to "bring healing" to the community. However, as already noted, external intervention creates inconsistencies in treatment planning and case management, which in turn limit continuity of care. Continuity of care is key to lasting wellness, and not just care, but culturally informed care. Another other common external approach in the north is sending Indigenous people to distant treatment centers where clinical services are meant for southern Canadian health consumers. There continues to be critical disconnects between Indigenous service users from rural and remote realities and clinically trained social workers in developed urban centers.

Making things happen in rural and remote communities requires a practice orientation borrowed from Carl Roger's, "Unconditional Positive Regard." While observing the dispensing of suboxone to over 80 community members over a 2-h period (10 AM–12 PM) and providing structured counseling sessions (1–8 PM) 1 week/month to high risk for relapse participants, it became clear that the community was able to demonstrate the value of self-determination for this community well-being programing. There were opportunities to debrief key community workers (not always formally educated with graduate degrees) to endorse and encourage their ability to provide services, which in urban centers are the responsibility of highly trained health care workers or social workers. They were able to demonstrate a respectful, caring, and tolerant approach to family and friends who had extensive histories of opiate misuse.

When Indigenous people are integrated into non-threatening therapeutic work, play, and living environments, resilience factors develop to balance out maladaptive behaviors. Change then flows from an ecological perspective at the individual, family, and social levels. Rapp (1998) states that the concept of hope derives from the totality of "willpower and waypower" toward goal achievement. The community benefits from inclusive connectedness, role-modeling, and peer support as a shared struggle, as opposed to isolation and marginalization. He advocates a case management model based on engagement and relationship maintenance, with the focus on strengths as opposed to pointing out weaknesses. This includes teaching ownership of personal recovery or goal achievement, learning to approach resources as needed, and always renewing collaborative opportunities. This allows gradual disengagement from resources that have limitations on the services they can provide. Rapp (1998) holds that diminished progress to follow a healing plan often comes from a failure of services to hold parallel visions, philosophies, and action plans which can result in participants falling through gaps or lapses in accountability for the provision of necessary interventions.

In 2018, returning to social work in southern Ontario as a Rationale Emotive Behavioral Therapist (REBT), Koptie was surprised by the level of opiate abuse in the Barrie, Ontario, a region of Central Ontario. Having lived in Thunder Bay, Ontario, for 5 years and having faced the challenges of the opiate crisis there, and the opiate epidemic in several rural and remote First Nations in Northwestern Ontario, it was discouraging to be confronted with the tragic impacts of opiate abuse on families and youth in a place where there was an abundance of social service agencies and clinical options. After working in communities "under serviced" by provincial and federal health services, and the poor funding of human needs in Ontario's north, to experience the disarray of mental well-being support systems in the south was disconcerting. The lack of strategies to collaborate and coordinate addiction services in developed regions of Ontario leaves one with a sense of deep concern for the nations in rural and remote regions where access is even more challenging.

Decades of social work in urban, rural, and remote communities becomes puzzling when the required infrastructure to link expertise and workforce training to on-the-ground key workers is so slow to happen. These writers have witnessed the successes of mental well-being consults through videoconferencing as well as multiple communities learning and sharing wisdom in joint training sessions. Canada could become a global leader on knowledge transfer and workforce development by more effectively utilizing the wide range of this country's centers of learning and research and sharing concrete ideas with First Nations in the north. Addressing knowledge exchanges and transfers could contribute to the well-being of rural and remote regions. Canada could become a nation of equality for all and promote the exclusion of none.

In the north, the authors encountered mining prospectors from all directions of Mother Earth who were struck by the neglect of Canada's northern communities. The longer we stayed in the north, the clearer it became that Canada's international reputation is facing long overdue scrutiny. A mining engineer from South Africa once asked, "What is wrong with Canada?" and "Why has Canada not reached agreements with Indigenous peoples in the James Bay region?" He spoke of the huge economic potential of mining strategic minerals within Northern Ontario (Koptie, 2018, unpublished conversation). To allow mining in one of the world's most resource-rich sites, the Ring of Fire would generate trillions of dollars. This development impasse mirrors the uncertainty across Canada where unresolved historical wrongs have made Canada a hard place to do business. Every professionally trained Canadian engineer, doctor, nurse, social worker, and teacher suffers from the exclusion of Indigenous ways of being, seeing, and doing in advancing Canada, and creating "A Fair Country" (Saul, 2008). As an Indigenous person writing on the Oka Crisis of the early 1990s, Koptie postulatesd that Canada in many regions is a failed state. "Are we unable to develop pipelines and mining properties on Treaty lands for the same reasons we cannot develop a National Suicide Prevention Strategy, a Safe Alcohol Retail Strategy, and Opioid Dependence Treatment programs which would benefit all Canadians? Are profits more valuable than Wholistic Well-Being on a sustainable planet? How will Canadians Seven Generations ahead view our inactions now? Indigenous peoples everywhere on Mother Earth are witnesses to the aftermath of the intent to destroy and are pleading for change" (Koptie, 2010a, 2010b).

Koptie incorporated the clinical structure of Albert Ellis's Rational Emotive Behavior Therapy (REBT) into his social work practice in northern Ontario. Albert Ellis's Rational aspect of the evolving Cognitive Behavioral Therapy model resonated with his on-the-ground experiences in rural and remote social work. Finding a context for Ellis's "Thinking about our Thinking" became an inspiration for researching and critically reviewing every idea learned and practiced in wellness promotion community work. Ellis's focus on how irrational beliefs activated by life stresses lead to unwanted actions/behaviors fits the colonial circus metaphor for colonization, and how it has contributed to suicide and family crisis (Koptie, 2009b). The MSW program at Laurier had provided understanding for the utility of culturally safe social work practice, and the University of Toronto had highlighted effective community engagement in community service. A self-reflective journey was facilitated by the completion of a Master's of Indigenous Social Work program at Wilfred Laurier University. This program is based on Indigenous ways of knowing, seeing, and doing, and provided a clinical lens that embraced cultural imperatives.

Having a foot in two divergent worlds, one where a mainstream concept of healing is promoted and where one is told what is wrong and offered designated treatment, and one where a wholistic assessment is made before healing even begins, has a significant impact. For Indigenous peoples, being told what is wrong before any lived experience is assessed minimizes the potential experience of well-being. This is because Indigenous peoples' wholistic well-being cannot be solely tied to acculturation and assimilation, as it has been in the past. There must be a global challenge to decolonized humanity and ensure the entire person is received not only for treatment but also for culturally informed care and support.

The transfer back to social work in southern Ontario confirmed the utility of blending Indigenous ways of doing with mainstream concepts which Duran termed a Hybrid Model of healing. Koptie incorporated lessons learned in REBT with Residential School survivors when serving two clients in Central Ontario raised by parents who were children in Germany during the Second World War. By developing the four important connections in solution focused therapy as advocated in the REBT approach: an interpersonal connection, an educational connection, an outcome connection, and an enlivened involved connection (Dryden, 2009, p. 2), he was able to serve these clients in a way that resonated with their lived experience, and utilized Indigenous wise practices.

Blending historic intergenerational trauma teachings from Indian Residential School survivors, adverse childhood experiences (ACE's), and "speaking" unspoken mental distress provided a launch pad for exploring and expressing how irrational beliefs dominate decisions made in life. Mental well-being begins with questioning the source of those thoughts and automatic behaviors activated by the "common experiences" we all have. Associated trauma, neglect, and maltreatment, especially for children, has a long reach into adult lives. As a society, we are gaining powerful insight into the neurological manifestations of excessive fear and toxic stress reactions on the developing brains of infants and children. Adult lives are not immune; the pain generated in childhood often manifests in poor mental and physical health, and frequently in early death. When the authors were being raised in the

50s and 60s, they could see it and feel it. Trauma and an imbalance of the Indigenous psyche was all around those who were raised in the 1950s through the 1980s, the drowning of identities and pride in alcohol and dysfunctional, crisis-filled family circles.

Through these conversations and lived experiences, a model using the medicine wheel was developed by Dr. Wesley-Esquimaux in the 1990s to help Indigenous people locate the adverse events that had sent them reeling, as well as the positive events that sent them healing. On the wheel, the impacts of trauma and adverse childhood experiences are illustrated as internalized impacts, which manifested in inner pain, leading to addictions and the numbness that follows, and finally manifest through the outward expression of inner pain through systemic diseases and physical pain. The events that send people healing can include the birth of a child or grandchild, a marriage, even a death of a loved one that pushes one to question their own lifestyle and make positive changes. (Figure 11.1 The "Circle of Trauma" was conceived by Dr. Wesley-Esquimaux in the mid-1990s to visually illustrate why it is important to do the 'inner work' of identifying critical life events blocking healing and holistic well-being.)

The wheel speaks to the "lostness" of children, now grown, but raised away from cultural practices and ancestral languages, with broken connections to family, community, nations, and the Great Mystery. It expresses how we lost so much when we lost each other. How we lost the ability to know we had a larger purpose and that our children were sacred gifts to be protected from conception through adulthood. We visited upon them the hurt experienced generation after generation. Today, we are still there in a hurt place in so many ways and we continue to find ourselves struggling against the effects of intergenerational trauma. We are healing, but many are not yet strong enough to say no, and not yet strong enough to stop domestic violence, sexual violence, or community and family divisions. Indigenous peoples are moving forward, but are stuck in so many ways because of what has gone on before.

As an entire society, we need to address the state of cultural shock that followed unrelenting historic trauma; a legacy of warfare, disease, poverty, dislocation, oppression, and forced assimilation since contact. Healing strategies for the Indigenous people of Canada must promote the transformation of victimization to survival to "victorization" (Wesley-Esquimaux, 2007) by reconciling multigenerational traumas into a strong, fully indigenized model of healing. A paradigm shift is required to challenge the over-reliance on outside explanations for the supposed cultural and racial inferiority of Indigenous peoples across Canada. More attention to highlighting the inherent strengths that served historical resistance of what was for the most part a one-sided Canadian colonization experiment is required, by non-Indigenous as well as Indigenous scholars. The role of contemporary Indigenous scholars will then become the restoration of the true identity and cultural humanity of their ancestors. The moral and ethical obligations of society demand multiple curative options and reframing of the colonial interpretation of Indigenous health and well-being. We must make room for Indigenous worldviews because they are essential to the building of mutual good will. Re-framing the research will challenge the mythology of the settlement of Canada and truthfully represent Aboriginal voice and place in colonial history.

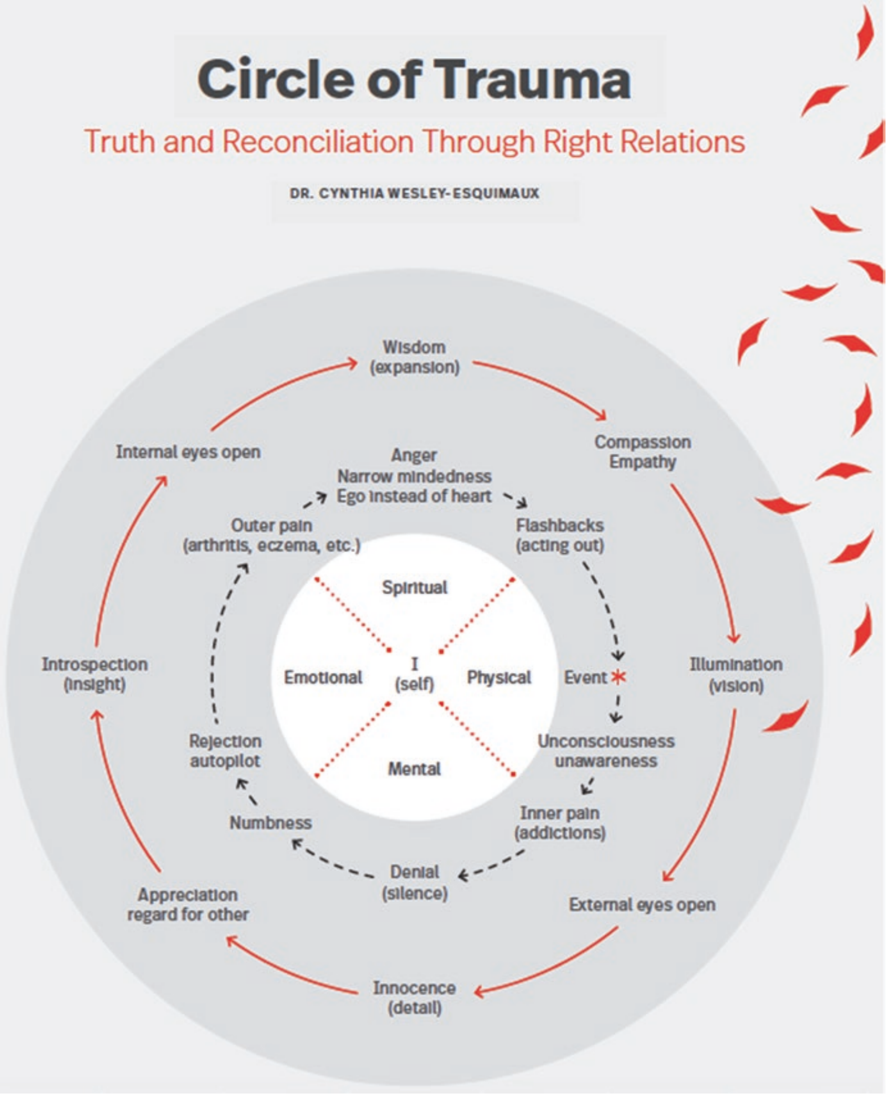

Fig. 11.1 Circle of Trauma

The sharing of successful healing narratives will assist in the restoration of well-being, and contribute to holistic wellness "on the ground" and correction of the health disparities which Smith (2006) referenced. Equally transformative will be our mutual realization that the historical upheavals and injustices that led to internalized self-hatred and ultimately became interwoven in many generations of First Peoples families were, in fact, an external onslaught (Duran & Duran, 1995).

Post-colonial Indigenous scholars must locate and include direct narratives in their published interpretations of the social/political upheavals in their traditional territories. These narratives will guide healing journeys from despair, hopelessness, helplessness, and oppressive dependency that continue to impact physical, social, mental, and spiritual wellness to the vision our ancestors intended for our survival. This is the Spirit and Intent of the Treaty relationship which framed Canada's true identity.

We have work to do, in our own mind, heart, and body, and in our own family and community. We have healing to address, and the rebuilding of compassion and support for those who continue to struggle. We have to take responsibility for each other, for the hungry or hurt children who live down the road, for the woman being beaten next door, and for the elder who has not completely awakened from a long dark night of the soul, beaten down and confused by an unrevealed, unhealed past. And, for those of us who have managed to heal those hurts, we have to step up and help those who have not.

We must enliven the seven teachings and find a way to embrace the *courage* to live through spirit, to effectively *respect* ourselves and each other, to be *humble* enough to know we need help to get where we want to go as nations, to be *honest* with ourselves so we can better assess where we are as a people and not only as individuals, and to tell the *truth* even though it hurts, so we can see our truth is not the only truth, and humanity in its entirety needs to heal. It is these teachings that bring us through to the challenge and grace of *love* and how we live and share it, and will help us master the gift of *ancestral wisdom*. We know we cannot get to wisdom without mastery of the first six, so let us begin the journey today, and walk together in collective strength.

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Chapter 12
Trauma and Its Impacts

Stewart Sutherland

Introduction

This chapter discusses trauma-informed anxiety disorders and their symptoms, as outlined by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) (American Psychiatric Association, 2013). It will also investigate research regarding disorders not covered under formal diagnostic guidelines, including the impacts of trauma on children, adolescents, and adults. Understanding trauma will help bring into perspective why Indigenous individuals and communities harbor feelings of mistrust and anger toward governments and authorities, such as the police.

Working through the many layers of trauma is complex, as communities and individuals have suffered extensive global trauma under removal policies. From the outset, Indigenous peoples suffered under assimilation policies (Canada, 2012). While in care, many suffered physical and emotional abuse. I argue that many have been traumatized by the knowledge and the aims of the policies. For example, the BTH Report states that Aboriginal and Torres Strait Islander people were aware of the government intention of genocide (HREOC, 1997). This is emotional trauma and has affected the emotional stability of the wider Indigenous community, not just those removed from their families. This is an important consideration for reconciliation, as the majority of Indigenous peoples will see efforts through a lens of trauma and mistrust.

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Defining Trauma

Figley (1985) and Atkinson (2007) define two areas of trauma that are different but related:

1. Psychological trauma is an emotional state of discomfort and stress resulting in memories of an extraordinarily catastrophic experience, which shattered the survival centers of invulnerability to harm.
2. Trauma behaviors are a set of conscious or unconscious actions and behaviors associated with dealing with the stresses of catastrophic trauma. This includes the period immediately after the event.

Theories in Framing Trauma

Derrick Silove is a key writer in the field of trauma analysis. His work on post conflict trauma and mental health treatment models also form the basis for my thinking regarding the consequences for people affected by assimilation.

Building his work around healing following trauma in the mid-1990s (Silove et al., 1995), Silove (2005) developed the *Survival and Adaptational* framework. The framework hinges on the concept of five things that need to be addressed in order for a person or a community of people to heal following a traumatic experience. These are as follows: (1) safety, (2) attachment, (3) identity and role, (4) justice, and (5) existential meaning. With high rates of community and institutionalized racism, and without true self-determination, these elements are not being addressed and Indigenous people are experiencing isolation.

Betrayal Trauma Theory

Betrayal trauma theory, as theorized by Freyd (1994, 1998) and Freyd, Deprince, and Gleaves (2007), builds on Silvove's trauma analysis. However, it places the importance of the child/caregiver relationship over other psychological responses to trauma. Betrayal trauma theory deals with the practical matters of forgetting (a type of amnesia) over the more cognitive principles of memory retention (DePrince et al., 2012). Forgetting allows the victim to remain attached to the caregiver who is vital to the child's development, ability to thrive, and ultimately its survival (Becker et al., 2003). An example of this theory would be a person who breaks a leg while hunting with friends. They will lay and wait for help, as the pain tells the body not to move and therefore do more damage. But if the same break occurs while alone, the body would override the pain to allow the person to move in order to seek help. The need to survive overrides the pain intended to limit further damage.

Fraser's (1997) work agrees with Silvove's in terms of safety, justice, and identity. In order for a child that has been removed under welfare policies to fit back into society and operate as a whole person, the safety, justice, and identity issues of that child must be addressed.

Litz, Orsillo, Friedman, Ehlich, and Batres (1997) and Roathbrum (2001) investigated how patterns of betrayal lead to the development of persistent negative behavior. They suggest that the trauma of betrayal as experienced through forced removal cannot be looked at on a plane with a single axis as outlined in the DSM-V (American Psychiatric Association, 2000). Freyd et al. (2007) explains that the relationship between a child and their care giver(s) is critical to that child's capacity to maintain an inherent trust in their safety and security within the broader society, and for Indigenous people this pertains to non-Indigenous people. If there is a significant breach in this trust, the child will withdraw to protect its survival goals, which is the basic mechanism of human survival. This is an emotional survival mechanism in children, which will cause them to withdraw and retreat from society in order to maintain life. These works have common themes of safety and the assumption that when individuals cannot physically protect themselves, they do so through a psychological method.

Becker et al. (2003), p. 185, describes this as follows:

> Analysis of the evolutionary pressures, mental models, social cognition and developmental needs suggest that the degree to which the most fundamental human ethics of violating can influence the nature, form, and process of trauma and responses to trauma.

Becker et al. (2003) worked on the premise that betrayal trauma theory is logical, as the issue of memory is a fundamental question when relating to child trauma. What would we expect to happen to information about child trauma? (Becker et al., 2003). To be highly motivated by trauma and betrayal when we have the option to choose who to further interact or socialize with is a positive psychological motivator. When an individual does not have that choice and needs to engage with the perpetrator in order to survive, forgetting[1] then becomes the mechanism for survival (Becker et al., 2003).

Betrayal trauma theory assumes that when trauma is inflicted by the child's caregiver, it is much more likely to create environments which are conducive to memory recovery. This means that the victim may relive the trauma or induced memory loss, or forget when trauma is inflicted by a stranger (DePrince et al., 2012). This forgetting is reasonably common. It explains why victims of assimilation policies either forget or recall vividly their experiences depending on which response was conducive to survival, and if the perpetrator was the primary caregiver who inflicted the trauma.

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[1] I use the word forgetting instead of amnesia throughout this chapter. This is because both words have different meanings within psychology. For further reading on this, you may choose to look to Larry Squire's 1981, Two forms of Human Amnesia: An Analysis of Forgetting; or, RD McKee & LR Squire's 1992 works in the *Journal of Neuroscience*, Equivalent forgetting Rates in Long Term Memory for Diencephalic and Medial Temporal Lobe.

Kestenberg and Brenner's (1996) work on child and adolescent trauma found that infants suffer more devastating effects due to trauma than do their older adolescent counterparts. This is due to the separation of the child from the primary caregiver. Adolescents and older children have experienced a longer period of healthy development before they went into care, which provides a protective quality. Adolescents also have a greater sense of invulnerability, rebelliousness, and willingness to explore, thereby making them more resourceful.

Post-traumatic Stress Disorder

Generalized anxiety disorders are a group of disorders that are common and often diagnosed among trauma victims (Burton, Westen, & Kowalski, 2012). Perhaps the most well-known disorder under anxiety is post-traumatic stress disorder (PTSD). PTSD is a potentially debilitating anxiety disorder triggered by exposure to a traumatic experience such as an interpersonal event of physical or sexual assault, or finding a body of someone who has committed suicide. It has also been described as occurring among individuals from foster homes and residential institutions.

PTSD is commonly diagnosed among trauma victims, due to its definition. According to the American Psychiatric Association, PTSD develops after someone is exposed to an extremely traumatic event, and they react to the event with intense fear, horror, or hopelessness (American Psychiatric Association, 2000).

People who were placed into institutional care, such as survivors of the Stolen Generations, residential schools, and institutionalized Māori, are often given a diagnosis of PTSD; this diagnosis is similarly given to Vietnam Veterans (Brasfield, 2001). The available literature informs us that the rates of PTSD among Vietnam survivors were 15% for males and 12% for females (Douglas, 1993; King, King, Fairbank, Keane, & Adams, 1998). Very little information on the rates of diagnosis for the Stolen Generations or residential school survivors is available. There is data on PTSD and childhood sexual assault, single event trauma, and general population data that could be used to apply a comparison. Within the general child population, Cohen (2010) argues that at any time, 9.2% of children (0–18 years) would meet the criteria for PTSD. McCloskey and Walker (2000) reported that 24.6% of children who suffered a single event trauma meet the criteria for PTSD. Wolfe, Sas and Wekerle (1994) found that 48.9% of children had been sexually assaulted and met the criteria of PTSD.

Intrusive symptoms of people with PTSD include distressing thoughts or images; nightmares about the event; acting as if the traumatic event is re-occurring; intense psychological distress; and physical symptoms such as sweating, muscle tension, and rapid heartbeat when exposed to things that trigger memories of the traumatic event (Jones et al., 2003). PTSD sufferers may resort to alcohol or illicit drugs to block out unwanted memories and feelings associated with the trauma (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995; Oakley Browne, Wells, Scott, McGee, & New Zealand Mental Health Survey Research Team, 2010).

There are several other symptoms and behavioral patterns of PTSD that are worth noting. People may lose interest in the everyday activities of life such as employment and/or leisure activities (Perry, 2001). These feelings may also extend to future events (Dominquex, Nelke, & Perry, 2002). This detachment may also affect feelings of joy, love, and other feelings of happiness, leading to withdrawal from society and other people (Cohen, 2010; Dominquex et al., 2002; Perry, 2000). PTSD sufferers may not see themselves getting married or having a family, or living into old age, and these feelings of hopelessness may become overwhelming (Vorvick & Rogge, 2012). The symptoms also extend to the physical realm, as many sufferers are unable to sleep well, are angry, have impaired concentration, are always on the lookout and/or often easily startled (Cohen, 2010; Dominquex et al., 2002; Perry, 2001; Pham, Weinstein, & Longman, 2004). Changes in mood and feelings, as well as altered states of thinking and behavior, may also occur due to the traumatic event (Perry, 2000; Perry & Azad, 1999). There is also evidence that sufferers of PTSD may be sexually dysfunctional on both physical and emotional levels (Cosgrove et al., 2002; Kotler et al., 2000), and that men, more often, may commit domestic violence (Cloitre et al., 2009).

It is common for people with trauma to have other psychological disorders. The most common psychological disorders that accompany PTSD are as follows: drug and alcohol issues, depression, panic disorders, bipolar mood disorder, and generalized anxiety disorder (Brady, Killeen, Brewerton, & Lucerini, 2000; Saladin, Brady, Dansky, & Kilpatrick, 1995).

Developmental Trauma

The traumatic stress field has adopted the term *complex trauma* to describe the experience of multiple and/or chronic developmental and first-time traumatic events, most often of an interpersonal nature, for example sexual or physical abuse (Teplin, Abram, McClelland, Dulcan, & Mericle, 2002).

These associated disorders must be viewed as part of a scale of diffuse psychological changes brought on by dramatic events and associated initially with PTSD. In real life, expression of trauma is not rigidly set but can comprise a continuum based on the type and severity of the trauma, past experiences of the victim, the prevalence of this association, age, gender, and many other factors (Moroz, 2005).

Atkinson (2002) and O'Shane (1993) argue that anxiety disorders such as PTSD and acute stress disorder are unable to accurately capture the levels of chronic ongoing stress that Indigenous people experience in their everyday lives. Nor do these diagnoses take into consideration trans-generational trauma, racism, or the ongoing stresses that continue as part of the effects of colonization.

Developmental trauma disorder is based on the belief that multiple exposures to interpersonal trauma, such as abandonment, betrayal, and physical or sexual assaults, have predictable outcomes that affect many areas of functioning. A diagnosis of developmental disorder is given when symptoms do not meet the DSM-V diagnostic criteria (Acton, 2012; Stein, Hollander, & Rothbaum, 2009).

Developmental trauma disorder may cause many of the same symptoms as PTSD but cannot be diagnosed under the DSM-V (American Psychiatric Association, 2000), as it does not meet the criteria (Van der Kolk, 1985, 2003). While there are many reasons why a PTSD diagnosis may not be given, one is cultural. That is, the DSM-V does not take into account cultural backgrounds or practices and treats everyone from a western (American) viewpoint, which is one of the reasons Social and Emotional Wellbeing frameworks were established (Social Health Reference Group for, National Aboriginal and Torres Strait Islander Health Council, and National Mental Health Working Group, 2004).

Even so, many of the symptoms are the same: complex distributions of affect regulation; an inability to form personal attachments; rapid behavioral regression; mood swings; little to no admissions; aggressive behavior against oneself and others; poor sleep, eating habits, self-care, and poor world view; physical responses from gastrointestinal distress to headaches; self-endangering behaviors; self-hatred and self-blame; and chronic feelings of ineffectiveness (Van der Kolk, 1985, 2003).

Developmental trauma sets the stage for unfocused responses to subsequent stresses leading to a dramatic increase in the use of medical, social, and mental health services, as well as the criminal justice system (Teplin et al., 2002; Van der Kolk, 1985).

Impacts of Trauma

Impact of Trauma in Children

The ground-breaking work of Terr et al. (1999) regarding child trauma has determined that more than 30% of children exposed to traumatic events will develop serious and chronic psychotic problems. Babies are particularly attuned to their primary caregiver and can sense their fear and traumatic stresses (Victoria Department of Human Services, 2014).

Van der Kolk (2003, 2005) explains that children learn to regulate their behavior in anticipation of their caregiver's responses to them. This interaction allows them to construct a profile of the world around them. As a child, the internal working model is defined as the internalization of the effect and cognitive characteristics of their primary relationships. Early experiences occur in the context of the developing brain, and so their development and social interactions are excessively intertwined. In the human brain, the most important information for successful development is conveyed by the social rather than the physical environment (Perry, 2000). When repeated trauma occurs in the presence of a supportive, if helpless, caregiver, the child is likely to respond by withdrawing from the parent. The more disorganized the caregiver, the more disorganized the child (Bernstein et al., 1994; Herman, Christopher Perry, & Van der Kolk, 1989).

Histories of childhood physical and sexual assault are associated with a host of other psychiatric diagnoses in adolescents and adulthood, including: substance abuse; borderline and antisocial personality disorder; and eating, associative, effective, cardiovascular, metabolic, immunological, and sexual disorders (Van der Kolk, 2003).

Emotional to Physical

Apart from psychiatric diagnoses, individuals exposed to emotional, physical, and sexual traumas are at an increased risk of developing physical health difficulties (Chartier, Walker, & Naimark, 2007; Edmonds, Hampson, Côté, Hill, & Klest, 2016; Goldsmith, Freyd, & Deprince, 2012; López-Martínez et al., 2016).

Felitti et al. (1998) found that children who had experienced sexual, physical, or psychological abuse, or had been exposed to interparental violence, were more likely to report chronic bronchitis or emphysema, stroke, cancer, ischemic heart disease, skeletal fractures, hepatitis, a greater number of sexual partners, increased smoking and drug abuse, and to rate their health status as fair or poor.

Edmonds et al. (2016) found that women who had been exposed to betrayal trauma were more likely to experience chronic fatigue, bladder problems, pelvic pain, headaches, chronic pain, asthma, diabetes, and heart problems. The links among HB trauma include anxiety, depression, and compromised immune function, suggesting that HB trauma may influence immune function via psychological symptoms (Reiche, Morimoto, & Nunes, 2005).

While there is little evidence of work comparing Indigenous trauma and its effects on physical health, it is a common experience throughout the world that Indigenous people experience disproportionate levels of social, economic, physical, emotional, and psychological issues (Adelson, 2005; Anderson et al., 2006). There is evidence contained within Australia, Canada, and New Zealand's national health statistics as to what these are. For each, the health disparities between Indigenous and non-Indigenous people are large across a number of health issues such as drug use, obesity, type 2 diabetes, sexual dysfunction, and hospitalization (Anderson et al., 2006; Canadian Government, 2011; Government of Canada, Health Canada, 2007; Government of Canada, Statistics Canada, 2013; Krynen, Osborne, Duck, Houkamau, & Sibley, 2013; Statistics, 2015).

The disparity has largely gone unexplained; however, one explanation that has been proposed is trauma. Sutherland (2017) found high rates of anger and resentment (59%), grief and loss (13.9%), contact with the criminal justice system (33%), shame of Indigeneity (11%), and emotional distress (9%) among First Nations Canadians, Māori, and Aboriginal and Torres Strait Islander people who had suffered trauma. It is noted that these are psychological issues, though depression may transform into many of the physical issues listed.

Adolescent Trauma and Its Effects

The development of a child between 12 and 18 years is significant, both physically and psychologically, as the body undertakes significant changes in growth, motor function skills, puberty, and sexuality. During this stage, psychological growth is also occurring. The child begins to develop a sense of self, acquires relationship skills, develops an understanding of their own sexuality, and develops their identity based on gender and culture norms.

In adolescents who have been removed from their original culture and language environment, these interpersonal functions become blurred as adolescents have conflicting cultural norms on which to base development. At the same time, there are a number of social and emotional factors that are also developing, such as empathy, morality, an understanding of peers in social groups, boundaries, reciprocity, and appropriate behavior; as such, they may lack the insight and control to act appropriately. The adolescent will explore sexuality and intimate relationships, develop wider interests in society, become responsible for themselves and independent from family, have mood swings, and develop cognitive and creative skills (Victoria department of Human Services, 2014).

The quote below has been pulled from my research and demonstrates this point on how a disruption in psychological and social development in adolescents can continue into adult life.

> It was a terrible thing and my wife and I had trouble with the sex part. I had to go to counselling for sex, to really have this feeling…It took a long time to get back. I got three kids and they seem to be all right but they suffered on account of my illness because one of the things I went through is I started drinking. But I want to finish this story about…Him knowing all about me, my medical records and saying that I was a schizophrenic (First Nations Male, Winnipeg Canada).

In the last decade, neuroscientists have learned how fear and trauma influence the mature brain. Recently, scientists have been investigating the effects of trauma on the developing brain. It is increasingly clear that experiences in childhood have relatively more impact on the developing child than experiences later in life. This is because the brain is designed to change through brain plasticity in response to parent receptive stimuli. When the parent or caregiver is responsible for trauma, forgetting information associated with this trauma changes the brain, allowing for the child to remain close to the caregiver (Kolb & Gibb, 2011).

As stated above, cultural norms are important to the developing brain. An individual's brain develops for the type of environment they are raised in. If that world is categorized by threats, chaos, unpredictability, fear, or sexual or physical abuse, such as the environments described by participants, the brain will reflect that by altering the development of the neural systems involved in stress and fear responses. When a child is threatened, various brain responses are inherent.

Trauma and Adolescence

Trauma may affect development during adolescence by creating tension, irritability, reactivity, and the inability to relax. These patterns can include sleep disturbance, distancing from family, development of eating disorders, substance abuse, becoming aggressive and violent, self-harming, or thoughts around suicide. These patterns also prevent normal physical and emotional growth in the adolescent. They may lead to feelings of shame and humiliation, loss of self-esteem and self-confidence, increased self-focusing and withdrawal from society, personality changes, and relationship impairments. Feelings of revenge, sexual promiscuity, reduced capacity to feel, and numbness are common, as is a need to grow up faster. Other common effects include poor peer-group relationships, teenage pregnancy, and dropping out of school (Cook et al., 2005; Saltzman, Pynoos, Layne, Steinberg, & Aisenberg, 2001).

To understand how adolescents are affected by and cope with trauma, an understanding of what constitutes normal adolescent development is needed. This age group has three stages: early adolescence (11–13 years); middle adolescence (14–18 years); and late adolescence (19–21 years). The American Academy of Child and Adolescent Development ("Normal Adolescent Development Part I," n.d.) has listed a number of other sub-stages across the three developmental areas: physical, cognitive, and social-emotional (Cole, Martin, & Dennis, 2004; Headspace, 2014; Howes, Phillips, & Whitebook, 1992). Howes et al. (1992) created a nine-stage model of adolescent development, focusing across the three stages of development. These are as follows:

1. Coping with the physical changes of puberty
2. Mastering an upsurge of sexual and aggressive impulses
3. Developing autonomy from parents
4. Forging sustaining ties with peers and adults outside the family
5. Developing the capacity for intimacy with romantic others
6. Establishing a desirable sense of personal values
7. Consolidating a coherent identity (including gender, vocational, and ethnic roles)
8. Achieving a sense of competency and industry in work or school
9. Planning realistically for eventual economic self-sufficiency

These developmental processes help adolescents make sense of the world in which they live (Cole et al., 2004; Howes et al., 1992). While the adolescent is moving from the paradigm of parental care to that of independence, any physical, sexual, and/or emotional trauma they experience or witness can have profound consequences on the developing mind (Cole et al., 2004; Headspace, 2014).

Emotional or physical trauma may cause a number of reactions within the adolescent, including feelings of self-doubt, shame, anxiety, mistrust, and poor self-esteem. These may lead to problems with assertiveness, anger, sexual arousal, or poor social skills, along with poor academic and/or vocational outcomes and mistrust in people. All of these factors contribute to a deficit in identity (Kidron, 2003; Williams, 1994).

Adolescents may re-experience, rethink, or experience for the first-time trauma which occurred earlier in their lives. This is due to the development of cognitive/mental processes, leading to organized thought and abstract thinking (Headspace, 2014). This advanced cognitive and emotional development gives the adolescent a new sense of understanding and perception, allowing them to understand the trauma that they have experienced in a different way (Steinberg, 2005).

Range of Responses to Trauma

Van der Kolk (1985) was one of the first to study PTSD in adolescents, and found that adolescent soldiers in the Vietnam War suffered PTSD at greater rates than older solders. It was hypothesized that this was due to the intensity of their bonds with peers.

A study by Terr et al. (1999), involving adolescents who witnessed the explosion of the Challenger spacecraft, found that only 5.4% of participants developed PTSD relative to this event. However, approximately half developed the psychological disorders of anxiety and depression. Both conditions are overlaying symptoms of PTSD.

The work of Brent (1995) and Brent, Bridge, Johnson, and Connolly (1996) suggests that most adolescents who experience trauma do not go on to develop PTSD, which would seem to reflect the work of Terr et al. (1999). Of the adolescents that do develop the disorder, the symptoms are the same as those in adults. While most adolescents that experience trauma do not go on to develop PTSD, most will still experience substantial distress and long-term impairment. The effect of this can present as a lack of respect for, or insolence toward, authority, and the adolescent will see their outlook for their future as bleak. It is common for adolescents to have multiple disorders at the same time such as depression, substance abuse, and conduct disorders (Brent, 1995; Brent et al., 1996).

Trauma, Removal and the Community

The assimilation policies and resulting institutionalization of children has caused trauma to the immediate and extended family and community, due to a compounding effect of the trauma (HREOC, 1997). This is primarily due to a forced and often traumatic removal method of child from their parents and community. This diminishes the role of parents and community as the child's protectors, in turn causing psychological trauma (Miller, 1996). As a result, parents and community members remain hyper-vigilant and guard their children from this threat. While the Bringing Them Home (BTH) Report (HREOC, 1997) details the Australian experience, Miller (1996), Fontaine (2011), and Consedine and Consedine (2012) identify similar experiences reported by the First Nations of Canada and the Māori of New Zealand.

Physical and emotional trauma, as suffered by individuals while in care, can only be described as systematic torture by the state (HREOC, 1997; Libesman, 2004). The BTH Report (1997) as well as Miller (1996) and Milloy (1999) argue that the unjust treatment of children while in these institutions constitutes cultural genocide and ethnocide, as they meet a number of articles under the United Nation's Convention on the Prevention and Punishment of the Crime of Genocide:

> In the present convention, genocide means any of the following acts committed with the intent to destroy, in whole or in part, a national, ethnical, racial or religious group: (a) Killing members of the group; (b) Causing serious bodily or mental harm to members of the group; (c) Deliberately inflicting on the group conditions of life calculated to bring about its physical destruction in whole or in part; (d) Imposing measures intended to prevent births within the group; (e) Forcibly transferring children of the group to another group (United Nations and Schabas, 1948)

As discussed earlier in this chapter, knowledge of the intent of these policies created its own trauma and compounded other traumatic events. This builds on the complexity of the diagnosis, as the DSM-V does not take this into account.

Recommended Treatments as Supported by Research

Trauma-Focused Psychotherapies

Trauma-focused psychotherapies are the most recommended type of treatment for trauma associated with traumatic events. "Trauma-focused" means that the treatment focuses on the memory of the traumatic event or its meaning. Treatments use different techniques to help the client process the traumatic experience. This may involve visualizing, talking, or thinking about the traumatic memory, or changing unhelpful beliefs about the trauma.

The number of sessions needed is still debated, though a general concession suggests 8–16 sessions (Hembree, Rauch, & Foa, 2003). There are many trauma-focused psychotherapies, the following of which have the strongest evidence base.

Prolonged Exposure

Prolonged exposure (PE) has strong empirical support for its efficacy in reducing trauma-related psychopathology (Foa & Rothbaum, 1989; Rothbaum, Hodges, Ready, Graap, & Alarcon, 2001). Prolonged Exposure therapy helps teach the patient to gain control by focusing on negative feelings (Foa, Zinbarg, & Rothbaum, 1992). Prolonged Exposure therapy is a cognitive behavioral therapy (CBT) based on the integration of exposure therapy principles with the framework of emotional processing theory, and is designed specifically to ameliorate post-traumatic stress disorder (PTSD) and related problems. Research supports the efficacy of exposure therapy with patients who suffer from PTSD. The published research has found large effect sizes, and the majority of individuals either achieve remission or exhibit clinically significant symptom reduction. Most randomized clinical trials (RCTs) have been conducted with civilian populations who have experienced civilian-type traumas such as sexual assault, physical assault, and motor vehicle accidents (Peterson, Foa, & Riggs, 2011).

Cognitive Behavioral Therapy

Cognitive behavioral therapy teaches the patent to change their thoughts, mental images, self-talk, core beliefs, and behaviors about themselves, other people, and the world around them (McEvoy, n.d.; Ruwaard et al., 2009).

The way we think is guided by what we pay attention to, the way we interpret what is happening around us, and the experiences we are most likely to remember. Sometimes we tend to focus too heavily on the negative or maintain a strong belief that things should be different, both of which contribute to the development and maintenance of the problem. CBT allows the client to assess the negative thoughts about themselves or their view of the world and replace them with positive ones. Through behavioral change, CBT seeks to offer a holistic approach to mental health care (McEvoy, n.d.; Rahman, Malik, Sikander, Roberts, & Creed, 2008; Ruwaard et al., 2009).

The client will also learn coping skills and techniques that pertain to their health issue, as well as more general life skills. This knowledge will then equip the client to actively change their behaviors (McEvoy, n.d.). They will be able to deal with circumstances that they were formerly powerless to handle. CBT seeks to implement this relationship between information and activity, in order for a person to improve their symptoms (McEvoy, n.d.; Rahman et al., 2008; Ruwaard et al., 2009).

Cognitive Processing Therapy (CPT)

Cognitive processing therapy (CPT) is an evidence-based, cognitive behavioral treatment designed specifically to treat post-traumatic stress disorder (PTSD) in association with comorbid symptoms (Galovski, Wachen, Chard, Monson, & Resick, 2015; Williams et al., 2011).

CPT helps patients learn how to challenge and even modify unhelpful, negative beliefs related to the trauma they were exposed to (Peterson et al., 2011). This creates a new understanding, which in turn forms a conceptualization that reduces the ongoing negative effects of the trauma (Cohen, 2010; Foa & Rothbaum, 1989;

Vorvick & Rogge, 2012). While created for PTSD, CPT has been demonstrated across a variety of types of trauma, including sexual assault (Galovski et al., 2015; Williams, Galovski, Kattar, & Resick, 2011).

Eye Movement Desensitization and Reprocessing (EMDR)

Eye Movement Desensitization and Reprocessing (EMDR) is a relatively new psychotherapy treatment ("EMDR: Eye Movement Desensitization and Reprocessing," n.d.; Litz et al., 1997). EMDR was originally designed to alleviate the distress associated with memories of traumatic events (Shapiro, 2001). It is growing in popularity, particularly for the treatment of post-traumatic stress disorder and other trauma-associated disorders ("EMDR: Eye Movement Desensitization and Reprocessing," n.d.).

Like all psychotherapies, EMDR helps the victim process and make sense of their trauma. It does this by focusing on the emotionally disturbing material in brief sequential doses, while paying attention to a back-and-forth movement (e.g., a light) or sound (e.g., a tone) (Rothbaum, Astin, & Marsteller, 2005; "What Is EMDR?|EMDR Institute," n.d.).

Medications

Medications that have been shown to be helpful in treating symptoms of depression and anxiety are selective serotonin reuptake inhibitors (SSRIs) and serotonin-norepinephrine reuptake inhibitors (SNRIs). SSRIs and SNRIs affect the levels of naturally occurring chemicals in the brain called serotonin and/or norepinephrine. These chemicals play a role in brain cell communication and affect how one feels. There are also other medications that may be helpful, although the evidence behind them is not as strong as for SSRIs and SNRIs.

Selective Serotonin Reuptake Inhibitors (SSRIs)

Selective serotonin reuptake inhibitors is the collective name given to the most common antidepressants. SSRIs offer a different chemical structure than cyclic antidepressants and deliver different effects on the brain ("Selective Serotonin Reuptake Inhibitors (SSRIs)," n.d.); for this reason, they are considered relatively safe. SSRIs work by enhancing the function of nerve cells within the brain that regulate emotion by increasing levels of the neurotransmitter serotonin, which influences mood, emotion, and sleep (Stahl, 1998).

SSRIs primarily assist the brain in sustaining enough serotonin. SSRIs help make more serotonin available by blocking the reuptake process. It is incorrect to say that depression and related mental health conditions are caused by low serotonin levels, but a rise in serotonin levels can improve symptoms and make people more responsive to other types of treatment, such as CBT ("Selective Serotonin Reuptake Inhibitors (SSRIs)," n.d.; "What Are SSRIs?" n.d.).

Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs)

Serotonin-norepinephrine reuptake inhibitors are a class of antidepressants used in psychiatric treatment, primarily clinical depression, though they have also been used in the treatment of other anxiety disorders such as obsessive-compulsive disorder and attention deficit hyperactivity disorder ("Serotonin-Norepinephrine Reuptake Inhibitors," n.d.). SNRIs affect two important brain chemicals—serotonin and norepinephrine ("Serotonin-Norepinephrine Reuptake Inhibitors," n.d.; "Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs)," 2013). SNRIs are different than SSRIs, as they work specifically with the neurotransmitters serotonin and norepinephrine ("Serotonin-Norepinephrine Reuptake Inhibitors," n.d.).

As previously discussed, serotonin is often referred to as a "feel-good" chemical because it is associated with positive feelings of well-being. Combined with norepinephrine, which is related to readiness and energy within the body, SNRIs help treat depression. They do this by stopping neurotransmitters from going back into the cells that released them, therefore keeping higher levels of serotonin and norepinephrine in the brain ("Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs)," 2013). SNRIs are often an effective form of treatment for patients who have unsuccessful treatment with SSRIs, as these only work on one chemical messenger (Hajós, Fleishaker, Filipiak-Reisner, Brown, & Wong, 2004).

Seeking Treatment

It is commonly excepted that some people are hesitant to seek treatment because of their concern with stigma or a reluctance to relive certain life experiences (Briere & Scott, 2014; Saltzman et al., 2001). What has not been fully explored are the issues regarding Indigenous people not seeking treatment due to their distrust of mainstream service. For many Indigenous people, the trauma was caused by institutions and people of authority; for example, the forceful removal of newborn babies by medical staff. While mainstream media sees this as a part of history, it is still current for Indigenous people as stories are passed from one generation to the next. In Australia, it was only in 1973 that such policies and practices ended (HREOC, 1997; Sutherland, 2017). Canada seceded their policies in 1996 with the closing of the last Residential School (Canada, 2012; Sutherland, 2017). Sutherland (2017) found that 59% of people removed from their families and placed into care still harbored anger and resentment toward the government, institutions, and non-indigenous people for the mental, emotional, physical, and sexual trauma inflicted.

No one treatment is right for everyone, which stands true for Indigenous people and is compounded by their reluctance to seek help from non-Indigenous people and providers. Working on a client-centered approach, there is need for a discussion about treatment options to determine which therapies should be applied. This will also help the client to relax and build the relationship with the therapist/practitioner and help prevent mistrust.

Conclusion: Relevance to Indigenous People Forcibly Removed

Freyd et al. (2007), in a rebuttal to McNally (2007), state that people never truly forget a traumatic experience, and argue that sexual abuse is one of the more common forms of betrayal trauma, in that “knowledge isolation about the event” needs to occur so that attachment to the primary caregiver can continue. This means that the event in the mind of the victim becomes separated from the emotional responses to the caregiver, in order for the relationship to continue.

Since invasion, Indigenous peoples have faced a range of traumatic events, such as enslavement, being forced off their land, and the policies and practices of assimilation. The effects of this trauma continue long after the traumatic events subside. The 2010 Health and Welfare of Australia’s Aboriginal and Torres Strait Islander Peoples Report found that 31% of Aboriginal people reported psychological distress at high or very high levels in everyday life. The rate of reported psychological distress within Māori (26%) (Krynen et al., 2013) and First Nations (30%) (Caron & Liu, 2010) mirrors the Australian results. This means that between 26% and 31% of the Indigenous population will display symptoms as listed under the DSM-V or other emerging theories of trauma.

Physical and emotional states can prohibit people from positively engaging outside of the community in which they feel safe (Dyregrov, Nordanger, & Dyregrov, 2003), which in turn limits their interactions with people that they do not know. In many cases, people can summon the ability to interact and be pleasant for a brief period of time, but then retreat within themselves. This may be one reason why Indigenous people find it hard to move forward in the healing and reconciliation processes.

According to some Indigenous people, there is a predisposition that drives them to this contact. The trauma of colonization, the establishment and forced relocation onto missions, and past forced removal policies account for the over-representation of Indigenous people in the criminal justice system across the three jurisdictions within the study. The two major contributors of people facing the courts today are drug use and mental health issues. The following chapter has presented misuse of alcohol and other drugs as being the result or symptom of trauma.

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Part III
Culture and Mental Health

Chapter 13
Supporting Post-secondary Youth Mental Health Through Inclusive Practices Attuned to Culture

Rani Srivastava and Raman Srivastava

Mental Health and Post-secondary Youth

In Canada, it is estimated that in any given year, one in five individuals will experience a mental health problem (Mental Health Commission of Canada, 2018). Mental illness is recognized as the single most disabling disorder worldwide, and impacts Canadian youth at a rate of 10–20%. Mental health disorders are the second highest source of hospital care expenditures in Canada, and suicide is the second highest cause of death for youth aged 15–24. The statistics and the associated economic and social impact are staggering.

The challenges are even greater for youth pursuing post-secondary studies. Young adulthood is a time when mental illness first starts to emerge (Dagani et al., 2017; de Lijster et al., 2017) and is often not recognized. Survey data from Ontario university students notes that university students were twice as likely as non-university youth to report symptoms of mental illness, with over 50% of students reporting feeling hopeless, 33–43% feeling so depressed they were unable to function, and 6–9% seriously considering suicide in the 12 months prior to the questionnaire (OCHA, 2009).

Post-secondary education is also a significant milestone in the lives of young people. It is a time of excitement, challenge, and significant transition as youth experience people, issues, and circumstances that are new and potentially very different than that of their home. It is also a time when youth expand their thinking

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academically and socially, take on more responsibility for self-management, develop an identity, and form new relationships. Some youth come to this stage with unrecognized and untreated symptoms of mental illness, while others experience the emergence of such symptoms during post-secondary education, making the transition even harder.

Unrecognized and untreated mental illnesses in this population can have devastating long-term impacts. Symptoms can interfere with psychological and social development, academic success, educational and career goals and trajectories, as well as establishing senses of self, belonging, and relationships (Patten, 2017; Srivastava & Srivastava, 2019). Students are also at risk for increased loneliness and isolation, along with sleep difficulties, somatic symptoms, and physical health challenges (Chang, Jetten, Cruwys, & Haslam, 2017; Keenan-Miller, Hammen, & Brennan, 2007). The result is a cycle where symptoms interfere with daily functioning, which in turn can further compound the distress and illness burden.

Given the economic and social impact of mental illness in post-secondary youth, early recognition and intervention is critical. Mental illness *can* be treated effectively. Early recognition and intervention of mental illness can mitigate its burden and the long-term sequelae, allowing youth to return to their regular activities and more easily pursue their life goals (Mental Health Commission of Canada, 2018; Pedrelli, Nyer, Yeung, Zulauf, & Wilens, 2015).

Fortunately, this need for intervention has been recognized by Canadian post-secondary institutions and they are attempting to address it. A national survey of student mental health services at Canadian post-secondary institutions noted that 73% of the 168 institutions surveyed had a variety of on-campus programs addressing mental health (Jaworska, De Somma, Fonseka, Emma Heck, & MacQueen, 2016). The range of services offered included mental health promotion targeted to specific mental illnesses as well as to general issues such as stress, anxiety, substance abuse, depression, and suicide; support services through orientation, peer tutors, mentors, and community services; screening services for early identification; and counseling and academic accommodations (Cribb, Ovid, Lao, & Bigham, 2017; Jaworska et al., 2016).

Unfortunately, the effectiveness of the services remains unclear, and in fact research suggests that, despite implemented initiatives, poor mental health among post-secondary students remains a significant issue (Dunn, 2014; Jaworska et al., 2016; Kirsh et al., 2016). Through a national survey, Jaworska et al. (2016) note that fewer than 50% of 274 surveyed health professionals who worked directly with students felt their institution's programs were effective. Research has also noted a general lack of culturally sensitive and culturally appropriate services. International students and others who identify themselves as having a minority group status based on culture, race, sexual orientation, and other identities are particularly vulnerable, given their risk of additional stressors such as discrimination, ridicule, and even violence (CACUSS & CMHA, 2013; Clement et al., 2015; Dunbar, Sontag-Padilla, Ramchand, et al., 2017; Dunn, 2014; Giamos, Lee, Suleiman, Stuart, & Chen, 2017; Ruzek, Nguyen, & Herzog, 2011).

In recognition of the significant mental health challenges for post-secondary youth and a need for a more systemic response, a number of national and provincial guidance documents have emerged over the past 5 years (CACUSS & CMHA, 2013; Council of Ontario Universities, 2017). The guidelines argue for a systems-wide approach that engages the entire campus; recognizes the significant impact of cultural, spiritual, and socioeconomic factors on learning, well-being, and mental health; identifies a need to address discrimination and inequities; and calls for the creation of a supportive and inclusive campus environment (Srivastava & Srivastava, 2019). Although these guidance documents identify culture as an important consideration within their advocacy for systemic approaches, the associated recommendations are limited to funding community-based (i.e., external) mental health providers for providing culturally relevant counseling on campuses. The action plans fall short of providing effective guidance on how to understand or address the impact of culture on student mental health. There is no discussion of how culture is understood, how it can be leveraged by individual staff or institutions to support a diverse student population, or how to create culturally appropriate programs and inclusive campus environments.

Culture: A Determinant of Mental Health

There is little doubt that health and illness are impacted by factors beyond the biomedical realm. These determinants of health are defined by the Public Health Agency of Canada (2018) as “the broad range of personal, social, economic and environmental factors that determine individual and population health”. Among these, “culture” and experiences of discrimination and historical trauma are recognized as important determinants for many groups. Culture influences every aspect of health and illness—from how health is maintained, to explanatory models of causation, to how illness is perceived, as well as what symptoms are deemed worthy of help seeking, what remedies are sought, and who is consulted in the help-seeking process (Srivastava, 2007). For some cultural groups, illness, particularly mental illness, is attributed to spiritual causes, and therefore traditional healers and religious leaders may be the preferred practitioners for help seeking. Because of this relevance to multiple domains of an individual’s illness experience, culture has a particularly significant influence on mental health.

Despite culture’s significance, the term itself is difficult to define. While some equate culture solely with ethnicity, race, gender, or religion, this is an incomplete oversimplification (Srivastava, 2014). Such narrow perspectives can be problematic as they conceptualize culture as static, reinforce stereotypes, and fail to recognize the diversity that exists within groups. More comprehensive theories and frameworks recognize culture as a broader and more dynamic phenomenon that includes multiple dimensions, such as age/generation (e.g., “millennial culture”), class (e.g., "middle class culture"), sexual orientation (e.g., "gay culture"), socioeconomic status (e.g., "inner city culture" or culture of poverty), and citizenship (e.g., "American culture") (Srivastava & Srivastava, 2019). Culture can therefore be more ideally defined as **c**ommonly **u**nderstood **l**earned **t**raditions, and **u**nconscious **r**ules of **e**ngagement (Srivastava, 2007). This view highlights that culture consists of patterns, explicit and implicit, of and for behavior, based on traditional (i.e., historically derived and selected) ideas and attached values, and that it provides mental models to experience and navigate the world (Adams & Markus, 2001, p. 287; Srivastava & Srivastava, 2019).

Despite shared values and patterns of behavior, diversity and individual variation undoubtedly exist within cultural groups. *Cultural identity* is a reflection of how one's cultural patterns manifest within them, and what that manifestation means to them (Berry, Phinney, Sam, & Vedder, 2006; Bhui et al., 2012; Rogers-Sirin & Gupta, 2012). It is important to note that one's subjective experience (i.e., manifestation and meaning) is significantly modulated by interactions, by how one is viewed and treated by others. This consideration is often made with negative associations; for example, experiences of being "different" than the norm or of marginalization can negatively modulate cultural identity. Marginalization is the experience of exclusion, powerlessness, and limited access to rights and resources, based on social identities such as gender, race, sexual orientation, religion, socioeconomic status, or other minority identities (Srivastava, 2007; Zangeneh, 2008). It often results in discrimination and a potential lack of psychological and physical safety. On the other hand, circumstances can facilitate positive experiences as well, such as inclusion, privilege, and power, which can *positively* modulate one's cultural identity. Interestingly, experiences of prejudice and discrimination can result in both positive and negative modulations—they lead to a denial or silencing of aspects of one's cultural identity, but they can also lead to a stronger identification with their cultural group, perhaps to create and draw power from a sense of belonging and solidarity (Khanlou, Koh, & Mill, 2008).

As individuals belong to multiple cultures, they accordingly have multiple cultural identities that—when combined with other identities such as those related to personality, social roles, relationships, and employment—interact to form an overall identity or sense of self (Srivastava, 2008; Whannell & Whannell, 2015). Just as one's experiences modulate the identities themselves, one's multiple cultural and social identities interact in ways that can accentuate, mitigate, or even create entirely new patterns of experiences, including inclusion, exclusion, privilege, and/or marginalization (Srivastava, 2014). Thus, experiencing multiple marginalized identities can lead to unique challenges, while having multiple points of privilege can, in some instances, mitigate the impact of marginalization. Fundamentally, this concept relates to intersectionality.

In summary, culture is about patterns as well as power, and both contribute to (or threaten) belonging, resilience, inclusion, and exclusion. It should also be noted that culture exists at the level of the individual, the group (family/team/department), as well as the broader organization/institution (Fung, Lo, Srivastava, & Andermann, 2012; Srivastava, 2007).

Cultural Competence and Cultural Safety

Cultural competence is frequently noted to be an essential component of effective mental health care (Fung et al., 2012; Sue, Zane, Nagayama Hall, & Berger, 2009). Being competent involves having “suitable or sufficient skill, knowledge, [or] experience for some purpose” (Dictionary.com, n.d). As a collective term, cultural competence thus refers to the ability to work effectively with diverse cultural groups or in cross-cultural interactions. It should not be mistaken as being or becoming a knowledge “expert” in a culture or cultures. Given the dynamic and intersectional nature of culture, such expertise is neither possible nor sufficient. Knowledge of cultural patterns is helpful in generating possible insights and hypotheses, but does not necessarily lead to effective interactions in itself. Cultural competence is about the *application* of nuanced knowledge with skill and sensitivity, with the understanding that culture is about patterns versus universal truths, and that ultimately one must tailor their work to the individual’s unique and specific cultural identities.

Cultural safety is another term commonly cited in the literature as providing guidance for inclusivity. Initially developed in New Zealand to draw attention to the effect of colonization on the health of the Indigenous Maori people, cultural safety is based on the notion of biculturalism (Racine, 2014). Cultural safety situates health inequities within the context and legacies of colonialism, historical trauma, and ongoing treaty and political issues (Aboriginal Nurses Association of Canada, 2009; Gerlach, 2012). However, the clarity and generality of cultural safety is unclear, particularly with respect to its applicability toward immigrant, refugee, ethnic, and other racialized populations (Gerlach, 2012; Srivastava, 2014). We see the relationship between cultural competence and cultural safety as synergistic. Both frameworks articulate the need for inclusivity; respect for unique history, traditions, and beliefs of individuals and groups; communicating in culturally appropriate ways; self-awareness, particularly with respect to one’s own privilege and biases; and a recognition of the broader social determinants of the impact of health on individuals, families, and communities (Srivastava, 2014). Cultural competence encompasses the minimal requisites of safety and humility, but extends beyond this to compel the system and service providers to proactively and appropriately address the needs of diverse vulnerable populations (Fung et al., 2012)

The Relationship Between Culture and Post-secondary Youth Mental Health Challenges

In this section, we begin with a brief examination of the underlying tenets of inclusive practice. This is followed by a discussion of the identified barriers to mental wellness for post-secondary youth, along with potential strategies that reflect cultural competency and inclusive practices.

To create inclusive campus environments that support mental wellness, it is necessary to understand the principles underlying inclusive practices. These principles include respect for differences; embracing and recognizing diversity as a source of strength and competitive advantage; and both understanding and adhering to principles of equity and commitment (RNAO, 2007). In education literature, "inclusive education" largely refers to creating inclusive schools for children with special needs; however, the characteristics and attributes can certainly be extended to post-secondary institutions. Characteristics of effective inclusive schools include positive relationships; supportive environments; opportunities for vulnerable students to show areas of strength and thus develop feelings of competence; and opportunities for students to participate in, better understand, and navigate broader social expectations (Canadian Research Centre on Inclusive Education, n.d.). These tenets of inclusivity can be applied at both the individual as well as the institutional level.

There is considerable literature identifying barriers to wellness and accessing mental health services for post-secondary students. While stigma continues to be a significant barrier, literature indicates that the barriers to help-seeking extend beyond stigma and a lack of knowledge (Eisenberg, Hunt, & Speer, 2012). Barriers can be grouped into three intersecting levels: intrapersonal (the self, individual), interpersonal (relational, interactions with others), and systems (campus climate). Most barriers, if not all, are further accentuated when cultural issues also exist (Clement et al., 2015; Dunn, 2014; Kirsh et al., 2016).

Intrapersonal

At the intrapersonal or individual level, barriers to mental wellness and accessing services in post-secondary youth can be related to a general preference for self-reliance, a desire to fit in and succeed at this life phase, self- and peer-stigma, a lack of knowledge and awareness of mental health issues and services, a lack of perceived need for help, difficulties with accessing appropriate services when the need is recognized, a lack of time, and unrecognized and untreated mental illness within their family (Czyz, Horwitz, Eisenberg, Kramer, & King, 2013; Dunn, 2014; Eisenberg et al., 2012; Islam, Multani, Hynie, Shakya, & Mckenzie, 2017; Kirsh et al., 2016; Ruzek et al., 2011).

It is also recognized that, for multiple reasons, these barriers can be accentuated for students with non-dominant cultural identities. Consider the role of stigma associated with mental illness, something that exists in all cultures but can be particularly challenging in cultures with certain characteristics. Certain cultures may attach the etiology of mental illness to religious or supernatural causes, or may have little social acknowledgement. Consequently, mental illness can be viewed as punishment or weakness, which is then associated with shame or guilt for the individual and family, and will therefore be considerably minimized and remain unaddressed. As specific examples, being Black, East Asian, South Asian, religious, male, and growing up in a poor family have been previously associated with high personal stigma and a significant negative association with professional help seeking (Eisenberg et al., 2012; Giamos et al., 2017).

Other cultural characteristics also play a role in modulating the impact of mental illness on the individual. In some cultures, concepts of depression and anxiety are not understood, and the associated symptoms may be regarded as experiences that are minor or common and not something for which help is sought or available. Additionally, for many international students and some cultural groups, the negative impact of mental illness on academic success is equated with a failure in one's duty or bringing shame to the family, thus further compounding stress, hopelessness, and contemplation of suicide (Li, Tse, & Chong, 2014). Some cultures (e.g., Asian and African) express mental health symptoms in physical terms or through somatization (Olawo, 2018; Ruzek et al., 2011). This can also occur in other groups where being strong is an important value, people are uncomfortable acknowledging emotions, and/or mental illness is not seen as a “real” illness; thus, symptoms become expressed in alternate, more culturally acceptable ways. A lack of recognition or exploration of such symptoms as potential mental health issues can lead to ineffective care and poor outcomes.

Interpersonal

Transitions and changing relationships are key characteristics associated with post-secondary education. As youth engage with post-secondary institutions, they need to develop new relationships with peers and faculty as well as re-define existing relationships with family and friends who are part of their home culture. Positive relationships and a sense of belonging are essential components of inclusive environments and play an important role in the mental health and well-being of youth (Public Health Agency of Canada, 2018); accordingly, factors compromising their development represent barriers to wellness. Such factors include marginalization, exclusion, and overt discrimination, are due to both conscious and unconscious biases of peers and professors; and can in turn lead to increased social isolation and withdrawal, which further exacerbate challenges in recognizing illness and seeking treatment. As a specific example, an increasing body of literature notes that students who identify as a sexual minority (lesbian, bi-sexual, gay, transgendered) are more likely to experience harassment, discrimination, and even physical violence. This leads to more psychological distress, mental health-related academic challenges, lower mental health-related service utilization, and a stronger likelihood of disengagement from the campus community (Dunbar, Sontag-Padilla, Ramchand, Seelam, & Sttein, 2017; Oswalt & Wyatt, 2011; Woodford & Kulick, 2015). The challenges are likely to be even greater for LGBTQ students who are racial minorities (Bouris & Hill, 2017).

For many post-secondary youth, interpersonal family-related issues—such as acculturation, intergenerational conflict, and parental views on mental illness—are significant factors that either add additional stress, impact help-seeking, or both (Knis-Matthews et al., 2012; Olawo, 2018). Olawo (2018) notes that in Africa, both mental health challenges themselves as well as the associated help-seeking pursuits are stigmatized experiences and hidden within the family for fear of social discrimination. A 2017 study of South Asian youth identified conflict with parents as a major stressor impacting their mental health (Islam et al., 2017). The nature of the conflict was related to high expectations for academic and career success, and also largely related to cultural incongruence with the culture of origin and the Canadian culture, leading to increased pressure on youth to have to reconcile and embody a "dual culture."

Interpersonal barriers also extend to mental health services themselves. A commonly identified barrier is a lack of culturally competent services. A lack of cultural competence can be seen in providers who are unaware of cultural expressions of mental illness or preferred ways of healing, who feel ill-equipped to treat certain cultures or provide certain necessary interventions (e.g., family meetings), or who have unconscious biases. For students, encountering such providers can lead to mistrust, less effective treatment, and early disengagement from care (Dunn, 2014; Knaak et al., 2017; Vukic et al., 2011).

System

For the purposes of this chapter, we are focusing the system-level discussion to the institution and not the broader level of society. Institutional-level system barriers include a competitive culture with expectations of coping, stigma of mental illness, inadequate communication regarding available supports and services, a lack of coordination among services, and a lack of diversity in the kinds of services offered (Dunn, 2014; Giamos et al., 2017; Kirsh et al., 2016). These barriers are all things within the institution's sphere of control.

Strategies for Culturally Inclusive Practices That Address Barriers to Mental Health

Overall, the call to action is a need to create more inclusive campuses that consider the nuanced interactions between culture and mental health services. This section begins with considerations on reaching individual students, and then evolves to more thematic strategies. Strategies can apply to all key roles within the post-secondary structure, including administrators, faculty, staff, or student leaders.

Integrated Psychoeducation Opportunities

Post-secondary institutions host many information/orientation sessions for students and families about campus services, issues that can be expected, how to seek out support (for students), and how to support their children (for parents) during the transition to, and participation in, post-secondary studies. These are valuable opportunities for key messages about mental health and inclusivity to be delivered in a non-stigmatized context together with other post-secondary topics. Specific recommended messaging includes the following: (1) conversations about mental wellness and illness in a way that acknowledges differing beliefs and attitudes; (2) highlighting different ways that mental illness can present (e.g., somatic symptoms) and explicating the links between physical health and mental health; and (3) connecting mental wellness to academic performance. Overall, the objective is to both educate and normalize the variety of ways in which symptoms may surface, and link the desired behavior of help seeking to the shared purpose of academic success. While thoroughly addressing stigma and mental health literacy of families is not within the scope of such sessions, important family-directed topics should be discussed, such as the role family can play in not just accepting illness but also drawing on cultural strengths to promote recovery and well-being.

Self-reliance

Building on values of self-reliance, preferences for online information, and interactions and activities that are linked with academic success, students could be encouraged to take advantage of online programs such as Mental Health First Aid (www.mhfa.ca) or Mental Health 101 (www.camh.ca/en/health-info/mental-health-101; jack.org/Resources/Mental-Health-101). A possible motivator could be to link the completion of such courses to extracurricular credits or other incentives. Students should also be made aware of screening and support programs that can provide them with anonymous, confidential self-assessments, as well as guide them to resources within the campus or the community. Some examples include “Check up from the Neck up” (www.mooddisorders.ca/program/check-up-from-the-neck-up) and Big White Wall (www.bigwhitewall.ca).

Cultural Identity

Post-secondary studies are a time where identity exploration and development are significant issues for youth, and institutions should intentionally support such reflection and dialogue through how services are structured and recognized. Specifically, leaders and initiatives promoting mental wellness should encourage students to connect with their cultural identities, both home and local.

A strong sense of cultural identity has been associated with enhanced mental health, specifically with improved self-esteem, resilience, coping styles, general life satisfaction, performance under threat, and protection against distress from discrimination and mental health symptoms (Chang et al., 2017; Rogers-Sirin & Gupta, 2012; Shepherd, Delgado, & Paradies, 2018; Weber, Appel, & Kronberger, 2015). Literature on Indigenous mental health is even more explicit, where mental health problems are attributed (at least partly) to a disconnection from Indigenous culture, while a strong connection to Indigenous culture and community has been identified as a significant support for mental health and healing (Vukic et al., 2011). Notably, while cultural connectedness can enhance agency and resiliency, students also need to be mindful of how protective factors can also potentially hinder them. In a study of African youth, Olawo identified internal strength and religious beliefs as supports which helped youth overcome life challenges and also as factors that increased expectations of self and led to delays in help seeking.

Most campuses have a variety of groups that students can join on the basis of their identities and interests; however, it is important to build bridges and linkages among the groups themselves to acknowledge the intersectional nature of identity. Cultural integration has been associated with more positive mental health than remaining solely tied to a home culture (Bhui et al., 2012), and cultural familiarity and meaningful cross-cultural engagement have been specifically recognized as attributes of Culturally Engaging Campus Environments (CECE) (McShay, 2017). Promoting integration and intersectionality is important, as research indicates that while segregation can lead to a sense of solidarity within a group, it can also serve to create barriers with respect to integration across groups (Burkhardt & Bennett, 2015).

Coordination

Inclusive spaces require more than effective communication. The overall campus climate is created by the cumulative attitudes, behaviors, and standards for faculty, staff, and students concerning access, inclusion, and respect for individual and group needs, abilities, and potentials (Rankin, 2005). There is general agreement that organizational-level cultural competence must address key areas such as leadership, commitment, and infrastructure to support workforce development, enhanced physical environments, abilities to tailor services to specific group needs, and integration of diversity initiatives within measures of success (Fung et al., 2012).

Leadership: Organizational and Student

It is our view and experience that leadership is perhaps the most critical ingredient for creating organizational culture change toward a more inclusive climate. Literature on the success of diversity initiatives has indeed identified senior leadership as a critical factor, crucial element, pre-requisite, and key enabler (Ainscow &

Sandill, 2010; Dreacjhslin, 2007; Essandoh & Suflas, 2016). Leaders must commit to use their mandate, privilege, and authority to signal that these topics matter, not just by talking openly about mental health in general, but about inclusion as well. The Association of American Colleges and Universities' (2015) guide for committing to equity calls for "frank, hard dialogues about the climate for underserved students with a goal for effecting a shift in language and actions" (p. 5) and these require leadership endorsement and support.

Leaders do not necessarily need to be experts on mental health, cultural competence, or inclusion. For example, organizational leadership simply needs to value these principles, engage in learning, challenge stigma and discrimination, and commit to being an ally, i.e., someone who recognizes that although they may not share the marginalized identity of a group, they can make efforts to better understand the struggle and commit to actions for a more inclusive environment. A key function of leadership is to support initiatives through resources and encouragement, and promote the adoption and enactment of desired behaviors. However, leaders involved in activities closer to direct student interaction—i.e., those on the "front lines," such as student mentors or club leaders, and the associated leadership of these activities—must understand these principles and develop abilities to productively incorporate them into initiatives.

Workforce Development

To create and sustain inclusive practices, structural and procedural changes are also needed at the institutional, departmental, and interpersonal levels. Workforce development is thus perhaps the second most important factor in creating an inclusive campus environment that supports mental health. As referred to above, staff, faculty, and student leaders are on the "front lines," interacting with students every day. Development workshops are thus critical for these groups, as they are uniquely positioned for impacting the student experience. These impacts are numerous: they serve as role models whose perspectives and behaviors students may replicate; as representatives of the institution, their interactions can make students feel included or excluded to the campus community overall; and they have frequent opportunities to identify students who would benefit from additional supports.

This training can take many forms, but considering certain elements is important. General courses, such as mental health first aid, are as important for these groups as they are for students themselves. Group-specific training should be *targeted and relevant* to the given group's activities to best facilitate buy-in and practical changes. Involving individuals with lived experiences and members of minority communities in the development and delivery of such workshops can also be particularly effective. Invariably, an important first step in training around inclusivity is having these front-line individuals acknowledge and address stigma and bias toward mental illness and minority identities, within themselves as individuals and within their greater community. Only then can they best support vulnerable students proactively as well as in confronting and challenging peer-based discrimination. An easily accessible step toward assessing bias could be to take anonymous implicit bias tests such as those offered through Harvard University (implicit.harvard.edu/implicit/education.html). Without engagement, training rigor and availability are less relevant, and so just as incentives such as recognition, awards, or others are provided to complete training in other topics, they should also be directed for completing training around these principles.

Together, these training efforts are likely to create both champions and allies for mental health. Ultimately, they will better equip these service groups to teach and support all students in ways that foster inclusivity (Association of American Colleges and Universities, 2015).

Partnerships

Partnerships are another critical area to both model and further strengthen inclusivity. Intra-institution partnerships, particularly between faculty and students, can foster integration. As an example, most departmental structures have committees with mandated or optional student representation. It is important these existing structures be optimized for meaningful engagement, which entails diversity in the students who are represented and support for representatives to have views heard and respected. Extra-institutional partnering, such as with community, cultural, and mental health groups, allows the institution to expand its own learning as well as the options available for support.

Thoughtful partnership should be considered by leaders of student groups as well. Intentional partnerships between groups, whether between dominant cultures and non-dominant cultures (“reaching out”) or between minority cultures (“standing together”), afford strong opportunities for promoting intersectionality and inclusivity. Furthermore, promoting mental health within minority groups can help reduce stigma commonly associated with that culture, if relevant.

Particularly valuable partnerships can be found with formal and informal leaders with lived experience from within or around the campus community. These should be leveraged by student groups and the institution as a whole. These connections can highlight the importance of help-seeking and early intervention to future academic and goals. Studies have also shown that personal experience and interactions with individuals with a mental illness (past or present) has been shown to effectively challenge negative views and stigma (Olawo, 2018).

Environment: Visibility and Events

In creating an inclusive campus, attention needs to be paid to the multiple dimensions of the campus environment—physical, digital, and social. Students engage with the physical and/or digital campus environment on a regular basis. Posters, LCD displays, and learning/course management systems offer significant opportunities to display key symbols, messages, and information about mental wellness, as well as supports and services available to students. Making these messages visible in the environment can reinforce information as well as validate and normalize help-seeking. The "significance of everyday" can be very powerful (Burkhardt & Bennett, 2015). Like with health promotion and psychoeducational materials, these messages need to include diverse faces and voices and be adapted for cultural congruence, as appropriate. To understand examples of cultural congruence, consider how different cultures may respond differently to messages connecting mental health to "improving general health" versus "improving academic success," or linking mental wellness to "reaching one's dreams" versus "facilitating one's ability to provide for family," or contextualizing help-seeking as "being important" versus "a sign of strength." Otherwise, without diverse representation, materials and messages can in fact negatively impact belonging and help-seeking. A particularly poignant quote in a qualitative study of South Asian youth sums up the experience:

> …I am not targeted for suffering from mental health. I am really not targeted for anything except racism … I feel like people see a poster and feel like they are not, they don't see themselves in it and feel like they are not included. They will think like oh, only white people suffer from mental health, I am fine, they might think something like that (Islam et al., 2017, p. 6).

The social environment offers significant opportunity for inclusive practices. Burkhardt and Bennett (2015) note that cultural events on campus can be an effective and engaging way of establishing a cultural presence and making campus diversity visible. The researchers also found that "in addition to being afforded opportunities to cross-culturally interact at the events, participants contended that feeling valued on campus translated into increased pride and confidence, which, in turn, was found to make them more open to intercultural interactions outside the context of the event" (Burkhardt & Bennett, 2015, p. 173). Certainly, cultural events can come with their own challenges; however, these should be weighed against the benefits, as they serve as opportunities for students who may be at risk of isolation and marginalization to engage in identity-related interactions that lead to enhanced community affiliation and mental health. Noteworthy is that even students who do not engage directly with such events derive benefits from them, by seeing that diversity and inclusion are valued within their campus community.

It should also be noted that considerations to increase social inclusivity should not be limited to visible cultural differences such as ethnicity. An inclusive social climate has events that are accessible to, relevant to, and connect those with diverse sexual orientations, academic interests, political ideologies, personalities and personal interests, economic backgrounds, and other identities.

The partnerships previously discussed—intra-institutional, extra-institutional, between faculty and students, etc.—can play key roles in enhancing the social environment, tangibly via direct involvement, and more intangibly via supportive micro-interactions.

Clinical Providers

Related to a number of the strategies discussed above is the strengthening of the cultural competence of the health care providers who design and provide services. At the most basic level, this involves assessing cultural identity and cultural explanations before determining the most appropriate mental health interventions, a step previously recognized as "critical" (Fung et al., 2012). This also involves counseling and health services incorporating the broad view of culture as patterns and power. Furthermore, services should recognize the importance of family for many cultures, and thus prioritize and undertake family interventions as feasible and appropriate. Similarly, services should recognize the importance of strengthening students' cultural identities, and thus, as a part of routine management, connect students to relevant campus and community groups. The physical environment plays a role here as well—an inclusive, culturally informed mental health service would be attuned to stigma and privacy. Examples of this would be having a physical location or space that is incorporated into less-stigmatized services (e.g., mental health services delivered in the same space as physical health or other services), or having sufficient individual services (for privacy) rather than relying on delivery to groups. These recommendations can be accomplished via training, partnerships with community groups with specific cultural expertise, and offering mental health and physical health services that lead to more holistic care.

Conclusion

This chapter discusses how inclusivity and cultural competence are key enablers of success in supporting the mental health of post-secondary youth. Culture is a key determinant of mental health and influences identity and behavior through shared patterns and traditions as well as experiences of marginalization, exclusion, and racism. Cultural identity can impact mental health positively and negatively, and thus is an important concept to keep in mind for service design. Barriers to mental wellness and help-seeking at post-secondary institutions can be grouped into three broad categories: individual or intrapersonal; relational or interpersonal; and organizational or system level. Strategies for culturally inclusive practices that address barriers to mental health include integrated psychoeducation, supporting development of cultural identity, workforce development for faculty, staff, and student leaders, leadership at multiple levels of the institution, partnerships, environment (including digital and social), and culturally competent services and service providers.

The key themes for inclusive mental health promotion include normalization of challenges, validation of differences, aligning efforts and goals, and engaging all stakeholders within and surrounding the post-secondary campus communities. The strategies presented are not exhaustive and not all are supported by empirical evidence. It is our hope that the exploration and discussion will lead to further refinement and testing of these and other strategies in order to mitigate the risk and burden of mental health challenges among post-secondary youth.

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Chapter 14
A Cross-Cultural Study on the Experience of Shame and Guilt

Chang Su and Michaela Hynie

Shame and guilt are painful, self-conscious emotions that have pervasive effects on our daily lives. They are universally among the most painful of human experiences (Ho, Fu, & Ng, 2004). Both of these emotions frequently result from moral transgressions or the violation of social norms or rules (Fischer & Tangney, 1995). Shame and guilt function as mechanisms of social control by helping to regulate and subtly shape people's social behavior to adapt to the moral standard of their society. Thus, these negative, self-conscious emotions may strengthen social relations and reduce the likelihood of rejection by others (Hynie et al., 2006).

The difference between shame and guilt puzzles most North Americans, since the terms "shame" and "guilt" have often been used interchangeably, and theorists have disagreed about whether they are actually distinct emotions (Hynie et al., 2006). In fact, experiences of shame and guilt can be both intertwined (Harper & Hoopes, 1990) and distinct (Schmader & Lickel, 2006; Tangney & Dearing, 2002). Research within U.S. contexts suggests that experiencing guilt leads to higher self-esteem and increases empathy and perspective taking, and is associated with variables related to maintaining strong interpersonal bonds (Tangney, 1998). Guilt is generally a less painful or devastating experience than shame (Kubany & Watson, 2003), and is often related to healthier social and emotional functioning in Western cultures (Tangney & Dearing, 2002).

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In contrast, shame is more self-focused than guilt and pertains to a belief that one would be evaluated negatively by others in response to a transgression (Tangney & Dearing, 2002). It involves strong self-deprecating evaluations of the entire self that are associated with a feeling of helplessness, worthlessness, and powerlessness (Anolli & Pascucci, 2005). People's reactions to shame are more intense than their reactions to guilt. They feel lonely and angry with themselves (Xie & Qian, 2000), and fear being humiliated, ridiculed, or laughed at (Li, Wang, & Fischer, 2004). Shame therefore motivates an individual to withdraw from contact with others (Tangney, 1995). Experiences of shame in Western cultures are related to many negative psychological symptoms including depression, somatization, pessimism, suicide attempts, social anxiety, and social avoidance (Anolli & Pascucci, 2005; Lutwak & Ferrari, 1996; Tangney & Dearing, 2002).

Different Types of Guilt and Shame in China

Bedford (2004) conducted an ethnographic study to identify the Mandarin terms for guilt and shame, and to clearly establish dimensions of the experiences of guilt and shame, including characteristic patterns of behavior, transformation of self, and values highlighted by these emotional experiences for Chinese people. Three main types of guilt were identified (*nei jiu, zui e gan*, and *fan zui gan*) along with four types of shame (*diu lian, can kui, xiu kui*, and *xiu chi*). These are described in Table 14.1.

In a subsequent study, Bedford (2004) asked 34 women (aged 24–31) from middle-class families in Taiwan to answer two questions, "What do you think of when I say the word shame?" and "What do you think of when I say the word guilt?", and then they freely talked about their feelings. Three main types of subjective guilt emerged: *nei jiu* (failed personal responsibility), *zui e gan* (moral transgression), and *fan zui gan* (law/rules transgression); and four main types of subjective shame emerged: *diu lian* (loss of face), *can kui* (failure to obtain ideal), *xiu kui* (personal failure), and *xiu chi* (social failure). For each type of guilt and shame, many aspects of the concept were touched upon, such as the definition, ways to cause the emotion, whether an audience was required, whether it was personal or universal, and the target of the emotion (of self/for other). The results showed that all three types of guilt contained the notion of different types of responsibility, and the common aspects of the different types of shame experiences included exposure, inadequacy, and concern about identity.

While the different types of shame and guilt are associated with distinct terms in Chinese, there is evidence to suggest that North Americans also distinguish between different types of shame and guilt. Frank, Harvey, and Verdun (2000) developed a study based on Bedford's characterizations of the five forms of shame. They drafted scenarios intended to evoke *diu lian, can kui, xiu chi, xiu kui*, and *nan wei qing* shame feelings, and also added scenarios for two guilt factors. These two guilt concepts were *shang hai ta ren* (harm to another person) and *wei bei xin ren* (trust violation), which were derived from a study by Gore and Harvey (1995). Their American

Table 14.1 Linguistic terms and definitions of shame and guilt in Mandarin and English

Linguistic term	Definition	Present in mainland Mandarin	Present in English
General guilt	Moderately painful, a sense of remorse after violating standards	Yes	Yes
Nei jiu-1—harm another person—shang hai ta ren	Painful feelings due to a failure to uphold an obligation/responsibility to another; hurting someone; feeling sorry and feeling indebted to others	Yes	No
Nei jiu-2—trust violation—wei bei xin ren	Painful feelings due to a failure to uphold the trust of others. It is related to internal feelings of obligation	Yes	No
Zui e Gan	Painful feelings due to a moral transgression. It is connected to moral responsibility and obligation to others. It can be a much stronger feeling of guilt than the two kinds of *nei jiu*, but it is not the same as breaking a law	Yes	No
Fan zui gan	Painful feelings due to a legal transgression (i.e., committing a crime or breaking a rule that all society members must obey). It is felt more strongly than *zui e gan*	Yes	No
General shame	Acutely painful emotion, due to violating standards	Yes	Yes
Xiu chi	The strongest negative emotions due to a perceived social failure (i.e., an act that easily receives universal condemnation)	Yes	No
Can kui	A mild negative feeling due to failure to obtain an ideal or meeting another person's ideal; having let down another person	Yes	No
Diu lian	Strong negative emotion due to loss of reputation; caused by transgression of public identity	Yes	No
Xiu kui	Negative emotion due to personal failure/inadequacy or violation of a self-expectation; due to a threat to one's private identity	Yes	No
Nan wei qing	Embarrassment due to social impropriety. It is mild, situation-specific, and transient	Yes	Yes—Embarrassment

participants responded differently to the different types of shame and guilt. Thus, shame and guilt appear to be multidimensional constructs in both China and North America, although the exact number of subcategories varies between studies.

Based on these earlier studies with Chinese and American participants, we identified and generalized nine categories of self-conscious emotions, four types of guilt (*nei jiu-1—guilt about harming another person, nei jiu-2—guilt about a trust violation*, *zui e gan—moral transgression*, and *fan zui gan—law/rule transgression*), and five types of shame (*xiu chi—social failure, can kui—failure to obtain an ideal, diu lian—loss of reputation, xiu kui—personal failure*, and *nan wei qing—embarrassment*).

Shame and Guilt-Eliciting Situations

One way that researchers have explored the experience of shame and guilt is by asking participants to recall situations that had elicited shame and guilt and write descriptions of these situations (Dahl, Honea, & Manchanda, 2003; Etxebarria, Isasi, & Pérez, 2002; Henkin, 2004; Tangney, 1992). For example, Tangney (1992) studied the situational determinants of shame and guilt in young adulthood, and has developed scenarios for shame and guilt based on the themes that emerged in participants' personal reports. Tangney (1992) asked her participants to describe in writing "three situations in which you are most likely to feel shame or guilt". The descriptions were coded by the length, degree of specificity, types of grammatical subject (whether it was written in first person, second person, or third person), performance type, interpersonal content, types of interpersonal concern, and types of violations described (omission versus commission). Guilt was typically induced by specific moral transgressions and involved harm to others. Shame descriptions were longer and overall less specific than guilt descriptions. Shame was induced by specific moral transgressions as well as non-moral situations, and issues such as failure in performance situations and socially inappropriate behavior.

Other researchers focused only on guilt-producing events. For instance, Etxebarria et al. (2002) asked respondents from two age groups (one with ages 15–19 and another with ages 25–48) to report their most recent experience of guilt and three things that usually made them feel guilty, and then analyzed the nature of the events that caused guilt. Most of the reported events were interpersonal, with many of them involving close relationships. Thus, having participants generate examples of their own experiences has been found to be a useful way of examining the nature of shame and guilt experiences, and will therefore be the method used in this study.

The Purpose of This Study

Empirical studies on shame and guilt are now quite numerous (Etxebarria, 2000; Tangney, 1995), but studies directly aimed at analyzing the types of events that elicit shame and guilt are still scarce. Moreover, although some previous studies found differences between events eliciting shame and guilt, all but one were conducted only in Western countries or in mainland China, not allowing for a cross-cultural comparison (Qian & Qi, 2002; Tangney, 1992; Xie & Qian, 2000). Furthermore, the concepts of shame and guilt in these studies (Etxebarria et al., 2002; Henkin, 2004; Tangney, 1992) did not provide a full range of shame and guilt concepts to their participants. Past research has suggested that European Americans may also experience the nine Chinese concepts of emotion, even though the distinct terms are lacking in everyday life and are not reflected in ordinary English usage (Bedford, 2004; Frank et al., 2000). Depending on which type of shame and guilt that participants choose to describe, one might get very different results. Thus, a more thorough comparison of shame and guilt between North Americans and Chinese participants requires examining differences across these nine different concepts.

The main aim of this study was thus to explore the prevalent themes in Chinese and European Canadian descriptions of situations that elicit each of the different types of shame and guilt, and to focus on within-culture and between-culture differences in particular. These will be examined in an exploratory way, in terms of higher order themes that emerge to distinguish shame from guilt in Western cultures.

Methods

Participants

Thirty-nine native mainland Chinese Mandarin speakers, ranging in age from 20 to 45 years (18 women, $M = 26.4$, $SD = 6.5$; 18 men, $M = 27.8$, $SD = 8.4$; three respondents did not report their gender), were recruited via email using snowball sampling by the author, whereby additional participants were recruited through a university teacher living in North-Eastern China who passed the request along to her networks. All of the participants were living in North-Eastern China, were raised in mainland China, and had never traveled abroad.

Thirty-four European adults living in Canada, ranging in age from 19 to 44 years (19 women, $M = 25.6$, $SD = 8.7$; 15 men, $M = 31.0$, $SD = 10.2$), were also recruited. Twenty-two European Canadian participants (15 females and 7 males) were recruited through the Undergraduate Research Participant Pool (URPP) at York University, and completed the survey online. Twelve participants (four females and eight males) were recruited through random approach in the author's neighborhood in a northern suburb of Toronto. Participants completed a brief demographic questionnaire asking about age, gender, and cultural background. Chinese participants were given all the materials in Mandarin, and European Canadians were given the same surveys in English (see Appendix).

The procedure was approved by the University ethics committee. Participants in mainland China were contacted by email and directed to a website for the study. Participants were asked to read a consent form and type "I agree" on the consent form on the web site, and then completed the demographic questions. After answering all the questions, participants returned the package to the researcher by email and received a written debriefing by email. Chinese participants completed all materials in Mandarin. The survey was translated into Mandarin by the first author, and then translated back by a second bilingual Mandarin speaker.

Canadian URPP participants completed the survey online after being directed to the survey website. Participants were asked to read a form and type "I agree" on the consent form before proceeding. They completed all materials in English. Once completed, participants pressed the "submit" button and then received a written debriefing and a thank you letter.

For the community sample, the author approached adults on the street who appeared to be of European origin, and briefly explained the aim of this study. Five people who were approached declined to participate, but 13 agreed. After they finished the survey at home, the author picked it up from their house or they dropped it off at the author's home.

Data Analysis

There were a total of 343 stories (192 shame scenarios; 151 guilt scenarios) from Chinese participants and a total of 289 stories (157 shame scenarios; 132 guilt scenarios) from European participants. There were also a few participants who wrote more than one scenario for one of the concepts (Chinese: $N = 4$; European Canadian: $N = 1$). Two pairs of coders identified the common themes among these different concepts of shame and guilt within the two groups of participants. The author organized all of the scenarios from the same concept together. The coders discussed any disagreements in the main themes.

Cohen's kappa coefficient was computed for each condition separately. The inter-rater reliability for the five shame themes in the Chinese data was 0.88, and for the four guilt themes, the mean of *kappa* was 0.90. The inter-rater reliability for the five shame themes in the European Canadian data was 0.89 and 0.92 for the four guilt themes.

The main themes were then analyzed to look for higher order categories. Two bilingual female coders were asked to sort the scenarios into these categories. There were eight higher order categories. The inter-rater reliability for doing the higher order categories was 0.88. The data was analyzed using Chi-square statistics to examine differences in higher order categories of shame and guilt within and between cultures.

Results

The Length of the Description of Types of Emotions (Overall Shame and Guilt) by Gender (Male and Female) Within Each Cultural Group

Because the two samples responded in a different language, comparison between cultural groups would be meaningless. A 2 (type of emotion) by 2 (gender) mixed design analysis of variance (ANOVA), with type of emotion as the repeated measures factor, was therefore conducted on the length of the descriptions separately within each culture. There was no significant main effect of either emotion or gender on the length of description of guilt and shame in the two cultural groups, and also no significant interaction effects within cultural groups.

Themes Between Cultures

The main themes of all the categories of guilt in Chinese participants and Euro-Canadian participants were examined. Only the themes that emerged for more than one participant in each concept are reported in these and subsequent analyses. All four types of guilt, *nei jiu-1* (*guilt 1*)*—shang hai ta ren (harm to another person)*, *nei jiu-2* (*guilt 2*)*—wei bei xin ren (trust violation)*, *zui e gan* (*guilt 3*)*—moral transgression*, and *fan zui gan* (*guilt 4*)*—law/rules transgression*, were related to responsibility. From the scenarios of *nei jiu-1 (guilt 1)—harm to another person* that were written by the Chinese participants, we identified several lower level themes. The most prevalent themes were as follows: intentionally said something that hurt someone ($n = 14$); accidentally/thoughtlessly said something that hurt someone ($n = 11$); behaved aggressively ($n = 5$); failed expectations (other's expectation: $n = 4$); cheated ($n = 2$); and failed responsibility/duties of their social role ($n = 2$).

From the scenarios of *nei jiu-1 (guilt 1)—harm to another person* that were written by the Euro-Canadian participants, the most prevalent themes were as follows: intentionally did/said something that hurt someone ($n = 14$); accidentally/thoughtlessly said something that hurt someone ($n = 7$); failed one's expectations (own: $n = 2$; other's: $n = 6$); failed responsibilities/duties of their social role ($n = 3$); and lied ($n = 2$).

For *nei jiu-2 (guilt 2)—trust violation* in Chinese participants, we obtained the following themes: failed other's expectations ($n = 10$); broke a promise ($n = 7$); broke a confidence ($n = 4$); failed responsibilities of their social role ($n = 3$); said/did something mean ($n = 2$); cheated ($n = 2$); and lied ($n = 2$).

For *nei jiu-2 (guilt 2)—trust violation* in European Canadian participants, we obtained the following themes: broke a confidence ($n = 8$); failed expectations of relationship (own: $n = 3$; other's: $n = 3$); broke a promise ($n = 6$); cheated ($n = 4$); said/did something mean ($n = 4$); failed responsibilities of their social role ($n = 3$); and intentionally hurt someone ($n = 2$).

For *zui e gan (guilt 3)—breaks a moral rule* in Chinese participants, we observed the following themes: behaved aggressively ($n = 15$); stole ($n = 6$); did not engage in studies ($n = 4$); cheated ($n = 3$); and failed expectations (own: $n = 3$; other's: $n = 2$).

For *zui e gan (guilt 3)—breaks a moral rule* in European Canadian participants, we observed the following themes: cheated ($n = 5$); said/did something mean ($n = 3$); acted selfishly/did not help others ($n = 3$); lied ($n = 2$); disobeyed a traffic law ($n = 2$); was rude ($n = 2$); and was not faithful in religion ($n = 2$).

For *fan zui gan (guilt 4)—breaking the law and rules* in Chinese participants, we observed the following themes: stole ($n = 13$); behaved aggressively or had aggressive thoughts ($n = 9$); played a prank with negative consequences for others ($n = 3$); and failed expectations (own expectation: $n = 2$; other's: $n = 2$).

For *fan zui gan (guilt 4)—breaking the law and rules* in European Canadian participants, we observed the following themes: disobeyed a traffic law ($n = 10$); stole ($n = 9$); said/did something mean ($n = 6$); felt guilt about feeling no shame ($n = 4$); failed responsibility ($n = 2$); and lied ($n = 2$).

The main themes of all the categories of shame in Chinese and European Canadian participants were identified. Based on the descriptions of each category of shame in Study 1 (*xiu chi*, *can kui*, *diu lian*, *xiu kui*, *nan wei qing*), we identified the following themes for each shame concept. For *xiu chi (shame 1)—very deep shame* in Chinese participants, we observed the following themes: stole ($n = 6$); did badly in an exam or a job ($n = 6$); persevered in an argument when they knew they were wrong ($n = 3$); criticized/blamed ($n = 3$); said/did something mean ($n = 2$); was caught doing something wrong ($n = 2$); and was caught spitting ($n = 2$).

For *xiu chi (shame 1)—very deep shame* in European Canadian participants, we observed the following themes: said/did something mean ($n = 9$); did badly in an exam or a job ($n = 6$); showed something private in public unexpectedly ($n = 3$); engaged in bad parenting ($n = 3$); cheated ($n = 3$); lied ($n = 2$); acted selfishly/did not help others ($n = 2$); and mistreated/rejected others ($n = 2$).

For *can kui (shame 2)—failure to attain a personal ideal* in Chinese participants, we observed the following themes: did not achieve academic/personal/professional goals ($n = 9$); did badly in an exam or a job ($n = 8$); failed expectations (own: $n = 8$; other's: $n = 5$); acted selfishly/did not help others ($n = 4$); and was not studying well ($n = 2$).

For *can kui (shame 2)—failure to attain a personal ideal* in European Canadian participants, we observed the following themes: did not achieve academic/personal/professional goal ($n = 13$); failed/did badly at an exam or at work ($n = 12$); and failed responsibilities/duties of their social roles ($n = 2$).

For *diu lian (shame 3)—loss of face/reputation* in Chinese participants, we observed the following themes: failed expectations (own: $n = 11$); did badly in an exam or a job ($n = 10$); had a clothing malfunction ($n = 6$); criticized/blamed/mistreated others ($n = 6$); made a mistake ($n = 3$); and stole ($n = 2$).

For *diu lian (shame 3)—loss of face* in European Canadian participants, we observed the following themes: criticized/blamed/mistreated/teased ($n = 12$); did badly in an exam or a job ($n = 7$); made a mistake ($n = 4$); failed expectations (own: $n = 3$; other's: $n = 2$); and had a negative body image ($n = 2$).

For *xiu kui (shame 4)—personal failure and harm to someone else* in Chinese participants, we observed the following themes: intentionally hurt/betrayed someone ($n = 8$); cheated ($n = 4$); denied making mistakes ($n = 4$); failed expectations (own: $n = 4$; other's: $n = 3$); unintentionally hurt someone ($n = 3$); did badly in an exam or a job ($n = 3$); engaged in bad parenting ($n = 2$); and criticized/blamed others ($n = 2$).

For *xiu kui (shame 4)—personal failure and harm to someone else* in European Canadian participants, we observed the following themes: intentionally hurt someone (n = 9); failed expectations (other's: n = 5); unintentionally hurt someone (n = 2); lied (n = 2); and acted selfishly (n = 2).

For *nan wei qing (shame 5)—embarrassment* in Chinese participants, we observed the following themes: made a mistake (n = 8); was caught/exposed making a mistake (n = 6); needed/had insufficient money (n = 5); failed expectations (own: n = 5; other's: n = 2); experienced an uncontrollable physical event (n = 4); was caught wearing inappropriate clothing/had a clothing malfunction (n = 2); and received excessive praise (n = 2).

For *nan wei qing (shame 5)—embarrassment* in European Canadian participants, we observed the following themes: was caught/exposed making a mistake (n = 11); was drunk (n = 4); was blamed/misunderstood (n = 3); was caught being rude (n = 3); had a negative body image (n = 2); felt inferior to others (n = 2); and observed others' inappropriate actions (n = 2).

Higher Order Categories from Guilt and Shame Scenarios in Chinese Participants and European Canadian Participants

The lower level themes of guilt and shame from the two cultures could be classified into eight higher order categories. These were as follows: (1) *Others' inappropriate actions*: shame and guilt feelings were caused by other people's improper behavior. This higher order category included the following lower level themes: received excessive praise; others' inappropriate actions; and was criticized, blamed, rejected, mistreated, teased, or misunderstood by others. (2) *Displayed/had a flawed character/self*: this had many varieties of lower level themes including negative body image; made a mistake; denied making a mistake; was drunk/an alcoholic; felt inferior to somebody; acted selfishly/did not help others; exhibited laziness; was rude; needed/had insufficient money; experienced an uncontrollable physical event; engaged in bad parenting; not faithful in religion; persevered in an argument when they knew they were wrong; felt no shame in breaking the law/rules; and had a clothing malfunction. (3) *Breaking own expectations:* this included failed own expectations; did badly in an exam or a job; did not engage in studies; could not achieve academic/personal/professional goals; showed something private in public without expectation; and failed a test/competition/performance. (4) *Breaking others' expectations:* this included failed others' expectations; neglected family; broke a promise; broke a confidence; and failed to execute duties of a social role. (5) *Unintentionally harming others*: this included played a prank with negative consequences for others, and unintentionally/accidentally/thoughtlessly hurt someone. (6) *Intentionally harming others*: this included had aggressive behavior/thoughts; said/did something mean (interpersonal); and intentionally said/did something that hurt someone. (7) *Intentionally breaking social norms/rules*: this included stole; disobeyed traffic law; cheated; lied; engaged in infidelity; was caught/exposed making a mistake; and was caught spitting. (8) *Unintentionally breaking social norms/*

Table 14.2 Frequencies of higher order categories of shame and guilt in two cultures

	CS (N = 192)	CG (N = 151)	ES (N = 157)	EG (N = 132)
1. By other's impropriate action	18 (9%)	0 (0%)	22 (14%)	30 (20%)
2. Displaying flawed character/self	33 (21%)	2 (2%)	27 (18%)	11 (9%)
3. Breaking own expectations	68 (35%)	13 (9%)	47 (30%)	7 (5%)
4. Breaking other's expectations	12 (6%)	34 (23%)	11 (7%)	33 (25%)
5. Unintentionally harming others	4 (2%)	14 (9%)	2 (1%)	7 (5%)
6. Intentionally harming others	10 (5%)	41 (28%)	18 (12%)	28 (22%)
7. Intentionally breaking social norms/rules	23 (12%)	35 (24%)	20 (14%)	39 (30%)
8. Unintentionally breaking social norms/rules	12 (6%)	1 (1%)	4 (3%)	0 (0%)

CS Chinese shame, *CG* Chinese guilt, *ES* European Canadian shame, *EG* European Canadian guilt, *N* number of scenarios which reflect that theme

rules: this had only one lower level theme, which was accidently/thoughtlessly making mistakes that break rules. The frequencies and proportions of the higher order categories are shown in Table 14.2.

Higher Order Category Comparisons for Guilt and Shame Within Cultures

Chi-square analyses were used to analyze the proportion of each of the eight higher order categories by culture (European Canadians versus Chinese) and type of emotions (guilt versus shame).

There were significant interactions in "other's inappropriate actions," $X^2(1, N = 73) = 9.90$, $p < 0.05$, in "displaying/had flawed self," $X^2(1, N = 73) = 4.37$, $p < 0.05$, and in "intentionally harm others," $X^2(1, N = 73) = 4.19$, $p < 0.05$. These were explored further by using chi-square analysis to analyze the proportion of the higher order categories by emotion within each culture.

There was a significantly greater proportion of "other's inappropriate actions" reported in shame concepts (9%) than in guilt concepts (0%) for Chinese participants, $X^2(1, N = 39) = 9.00$, $p < 0.05$, but there was no significant difference in reporting "other's inappropriate actions" between shame (14%) and guilt scenarios (20%) for Euro-Canadian participants, $X^2(1, N = 34) = 1.06$, *ns*. Thus the "other's inappropriate action" was more strongly associated with shame situations than guilt situations in China only.

In Chinese participants, there was a significantly greater proportion of "displayed flawed self/character" in shame situations (21%) than guilt situations (2%), $X^2(1, N = 39) = 15.68$, $p < 0.05$. Thus, the "displayed flawed self/character" was more strongly associated with shame situations than guilt situations in China. For European Canadian participants, the proportion of scenarios describing a flawed self did not differ between guilt (9%) and shame (18%), although the difference fell in the same direction, $X^2(1, N = 34) = 3.00$, *ns*.

In Chinese participants, there was a significantly greater proportion of "breaking own expectations" in shame concepts (35%) than in guilt concepts (9%), $X^2(1, N = 39) = 15.36$, $p < 0.05$, and there was also a significant difference for Euro-Canadians (shame: 30%; guilt: 5%), $X^2(1, N = 34) = 17.86$, $p < 0.05$. Thus, "breaking own expectations" was more strongly associated with shame situations than guilt situations in both countries, as reflected by the lack of interaction in between culture and gender obtained in the earlier analysis.

For proportions of "breaking others' expectations" in Chinese participants, there were significantly fewer mentions in shame scenarios (6%) than in guilt scenarios (23%), $X^2(1, N = 39) = 9.97$, $p < 0.05$. Similarly, there was also a significant difference in "breaking other's expectations" between Euro-Canadian shame scenarios (7%) and guilt scenarios (23%), $X^2(1, N = 34) = 10.12$, $p < 0.05$. Thus, "breaking other's expectations" was more strongly associated with guilt situations than shame situations in both countries, once again reflecting the earlier lack of interaction.

For proportions of the higher order category of "unintentional harm to others," 9% of guilt concepts and 2% shame concepts included this theme for Chinese participants. These proportions were significantly different, $X^2(1, N = 39) = 4.46$, $p < 0.05$. In the Euro-Canadian data, 5% of the guilt scenarios and 1% of the shame scenarios included this category; these proportions did not differ, $X^2(1, N = 34) = 2.66$, *ns*.

In Chinese participants, there was a significantly lower proportion of "intentional harm to others" in shame scenarios (5%) than in guilt scenarios (28%), $X^2(1, N = 39) = 16.04$, $p < 0.05$. In the Euro-Canadian data, 22% of guilt scenarios were associated with harm to others, compared to only 12% of shame concepts, but this difference did not reach significance, $X^2(1, N = 34) = 2.94$, *ns*.

For the proportions of the higher order category of "intentionally breaking of social norms/rules" in the Chinese data, 24% of guilt concepts were associated with the theme, compared to only 12% of shame concepts, $X^2(1, N = 39) = 4.00, p < 0.05$. In Euro-Canadian data, 30% of guilt concepts were associated with "intentionally breaking social norms/rules," compared to only 14% of shame feelings, $X^2(1, N = 34) = 5.80$, $p < 0.05$. Thus, "intentionally breaking social norms/rules" appears more within guilt scenarios than shame scenarios in both cultures.

For proportions of the higher order category of "unintentionally breaking social norms/rules" in the Chinese data, 1% of guilt scenarios and 6% of shame scenarios included this theme, $X^2(1, N = 34) = 3.58$, *ns*. In Euro-Canadian data, no guilt concepts were associated with this theme, compared to only 3% of shame concepts, $X^2(1, N = 34) = 3.00$, *ns*. Thus, there was no significant difference in the frequency for the "unintentionally breaking social norms/rules" between shame and guilt concepts in either culture.

Higher Order Category Comparisons for Guilt and Shame Between Cultures

Chi-square analyses were also used to analyze the proportion of each of the eight higher order categories between the two cultures. We found that there was only a significant difference in the proportion of “other’s inappropriate action” between Chinese guilt scenarios (0%) and European Canadian guilt scenarios (20%), $X^2(1, N = 73) = 5.40, p < 0.05$. Therefore, Euro-Canadian participants were more likely to associate guilt feelings with other people’s actions than were Chinese participants.

In sum, Euro-Canadian participants associated “other’s inappropriate actions” with guilt concepts to a greater extent than mainland Chinese participants. However, within cultures, mainland Chinese participants reported more “other’s inappropriate actions,” “displaying flawed self/character,” and “breaking own expectations,” and fewer “breaking other’s expectations,” “unintentional harm to others,” and “intentional harm to others” in shame scenarios than guilt scenarios. European Canadians reported more “breaking own expectations,” and fewer “breaking other’s expectations” and “intentional breaking social norms/rules” in shame scenarios than guilt scenarios. Given that more differences were found between the shame and guilt scenarios in the Chinese sample than the Euro-Canadian sample, the results suggest that shame and guilt may be more differentiated for mainland Chinese than European Canadians.

Discussion

Main Themes of Guilt and Shame Between Two Cultures

Main Themes of Guilt Between Two Cultures

In this study we found similarities as well as differences in reports of shame and guilt between Chinese culture and European Canadian culture. With respect to the guilt category *nei jiu-1 (guilt 1)—shang hai ta ren (harm to another person)*, they shared common themes such as intentionally saying something that hurt someone, accidentally/thoughtlessly saying something that hurt someone, lying/cheating, failing one’s expectations, and failing the responsibilities/duties of their social role. But the difference between the two cultures was that Chinese participants had a theme of aggressive behaviors (e.g., I had a fight with my classmate and injured his head; When I was young, I fought with my best friend.).

For *nei jiu-2 (guilt 2)—wei bei xin ren (trust violation)*, the common themes between the two cultures were broke a promise, broke a confidence, failed one’s expectations, said/did something mean, lied/cheated/engaged in infidelity, and failed responsibilities/duties of their social roles. European Canadian participants, however, also had a theme of intentionally hurting someone, which they had included in descriptions *nei-jiu-2* (guilt 2), suggesting that perhaps there is less of a distinction between the two types of guilt among European Canadians.

For *zui e gan (moral transgression)*, there was a lot of variability in the themes generated by participants in these two cultures, although there were some common themes as well. Common themes were not doing studies, failing one's expectations, lying/cheating, and selfishness. However, European Canadian participants provided many different scenarios that also reflected violating morals, such as saying/doing something mean, disobeying a traffic law, being rude, and not being faithful in religion. These results showed that a broader range of occurrences were identified as violating morals for European Canadians.

For *fan zui gan (law/rules transgression)*, the common themes between the two cultures included theft and lying/cheating. Interestingly, European Canadians gave ten examples of the same scenario, which involved violating traffic laws/rules—perhaps because driving cars is a very common activity for Western people. In contrast, most Chinese adults in mainland China do not have their own cars, and thus driving behavior/events seldom happen to them. Also, European Canadians gave examples of feeling no shame in breaking the law/rules, and saying/doing something mean, but mainland Chinese focused on playing a prank with negative consequences for others, and failing expectations. This suggests a different understanding of this category between the two cultural groups.

Main Themes of Shame Between Two Cultures

For *xiu chi (deep shame)*, there were some common themes between these two cultures, namely saying/doing something mean, doing badly on exams/at jobs, criticizing/mistreating, and being rejected by others. European Canadians also included some other unique themes: showing something private in public unexpectedly, bad parenting, and cheating/lying. Unique Chinese themes included being caught spitting in public, theft, persevering in an argument when they knew they were wrong, and being caught making a mistake. Public spitting is actually quite a common behavior in China but is currently discouraged. If somebody is caught spitting in a public place, not only will they lose their face and be criticized, but they would also be fined right away.

For *can kui (failure to attain a personal ideal)*, there were some common themes between these two cultures, namely not achieving academic/personal/professional goals and failing/doing badly on exams/at jobs. European Canadians also included the unique theme of failing responsibilities/duties of social roles. A unique Chinese theme was not doing well at one's studies.

For *diu lian (loss of face)*, there were some common themes between these two cultures, such as failing one's expectations, doing badly in exams/at jobs, making a mistake, and criticizing/blaming/mistreating/teasing others. European Canadians included one unique theme, negative body image. Unique Chinese themes were clothing malfunctions, such as having an article of clothing break or wearing it inside out, and theft.

For *xiu kui (personal failure and harm to someone else)*, common themes between these two cultures were intentionally hurting someone, unintentionally hurting someone, failing expectations, and cheating/lying. However, European Canadians also included selfishness. Chinese participants also provided some unique themes: criticizing/blaming others and denying making mistakes.

For *nan wei qing (embarrassment)*, common themes between these two cultures were being caught/exposed making a mistake, criticizing/teasing/rejecting/misunderstanding and failing to meet expectations. European Canadians had several unique themes: negative body image, other's inappropriate actions, caught being rude, drunkenness, and feeling inferior to others. Chinese unique themes were clothing malfunctions, receiving excessive praise, being uncomfortable with sex related things, and having insufficient money.

Themes that appeared only in European scenarios were "disobeyed the traffic law," "was not faithful in religion," "was caught being rude," "was drunk/alcoholic," "felt no shame after breaking the law/rules," "having a private thing shown in public unexpectedly," "other's inappropriate actions," and "negative body image." These unique themes from European Canadians suggest that in modern Western societies, people tend to focus on positive self-image, healthy lifestyles, belief in religion, protecting one's own private rights, and maintaining good manners. Themes that appeared only in Chinese scenarios were "played a prank with negative consequences for others" (from guilt scenarios), "persevered in an argument when they knew they were wrong" (from guilt and shame scenarios), "was caught spitting," "was uncomfortable with sex related things," "received excessive praise," "needed/had insufficient money," "denied making a mistake," and "had a clothing malfunction." These themes were from both guilt and shame scenarios. This pattern suggests that mainland Chinese participants still advocate traditional Confucian values such as having a humble and modest attitude, being polite to others, and engaging in more self-blame than criticizing others; even not talking about sex related things in public is a norm that has existed for many years in mainland China.

However, some themes appeared more in types of guilt or shame for Chinese scenarios than European scenarios. For example, "made a mistake" appeared in all Chinese shame themes, but only in European *diu lian*, and *nan wei qing* categories; "aggressive behavior" appeared in Chinese *nei jiu-1, zui e gan*, and *fan zui gan* but appeared only in European *zui e gan.* Some themes appeared in both shame and guilt for Europeans but appeared in only guilt for Chinese. For example, "*failed responsibility/duties of the social roles*" only appeared in Chinese *nei jiu-1 (shang hai ta ren)* and *nei jiu-2 (wei bei xin ren)* but appeared in European *nei jiu-1* and *nei jiu-2, zui e gan*, and *can kui.*

As noted above, some themes appeared in both guilt and shame concepts for Europeans, such as "failed one's expectation" (own or other's), "lied," "cheated," "stole," "intentionally hurt someone," "unintentionally hurt someone," "did badly in an exam/at a job," "said/did something mean," "acted selfishly," and "failed responsibility/duties of the social roles." Similarly, some themes also appeared in both guilt and shame concepts for Chinese participants, such as “failed expectations,” “lied,” “cheated,” “stole,” “intentionally hurt someone,” “unintentionally hurt someone,” “did badly in an exam/at a job,” “said/did something mean,” and “acted selfishly.”

Thus, similar scenarios could be described in either shame concepts or guilt concepts. This is consistent with previous studies, in which researchers found that shame and guilt are often experienced simultaneously (Hynie & MacDonald, 2001; Sabini & Silver, 1997). However, the distinctions between shame and guilt experiences seemed to differ between cultures, such that some situations were much more clearly associated with only one of the emotions in only one of the cultures. Moreover, some events were associated with shame or guilt in only one culture and were not mentioned in any of the scenarios in the other culture.

In a similar study, Henkin (2004) asked 146 mainland Chinese college students and 72 European American college students to recall situations that caused them to experience either shame or guilt. In her study, the experiences of shame and guilt were coded by themes and categories, and she explored the similarities and differences between Chinese and American cultures. Her findings suggest that shame is more closely related to Chinese culture, and guilt is more closely related to American culture. In contrast from Henkin’s study, the current study was based on five types of shame and four types of guilt. Nonetheless, we found themes that were similar to those found in Henkin’s study. These include cheating, infidelity, deceit, being exposed making a mistake, intentionally saying something that hurt someone, saying/doing something mean (knowingly doing something wrong in Henkin’s study), failing the responsibility/duties of the role (did not do something they should have in Henkin’s study), experiencing an uncontrollable event, as well as drunkenness (lost control in Henkin’s study), others’ inappropriate actions (ashamed by others’ perception or embarrassed by others’ actions in Henkin’s study), selfishness, unintentionally hurting others, clothing malfunction, private things showing in public unexpectedly or being criticized/teased (public embarrassment in Henkin’s study), not achieving academic/personal goals, doing badly on exams/at jobs (poor academic performance in Henkin’s study), receiving excessive praise (ashamed by others’ action/perceptions in Henkin’s study), being rude (rude to others), failing responsibilities/duties of the social role (unfulfilled obligations or regret not spending much time with family in Henkin’s study), and breaking a promise (forgetfulness in Henkin’s study).

We also found about 15 themes in this current study that did not appear in Henkin’s study. These themes included aggressive behavior, failing one’s own expectations, theft, disobeying a traffic law, not being faithful in religion, playing a prank with negative consequences for others, persevering in an argument when one knew one was wrong, being caught spitting, making a mistake, engaging in bad parenting, having insufficient money, negative body image, denying making mistakes, being uncomfortable with sex related things, and feeling inferior to others.

The results of this study showed that although participants were from two different cultures and used two different languages to provide examples and describe their shame and guilt feelings, they seemed to experience a range of similar types of shame and guilt experiences. European Canadians, for example, were able to provide examples that had similar characteristics to Chinese examples, even when they did not have concepts and/or words for many categories. These results are consistent with the observation that shame and guilt are universal self-conscious emotions and perhaps quite pervasive and complex in everyday life (Wang, Zhang, Gao, & Qian, 2009). An examination of the differences suggests that many cultural differences had more to do with opportunities for specific behaviors (e.g., driving) or specific cultural norms (e.g., spitting).

Interestingly, as noted above, there were many themes that appeared in descriptions of both shame and guilt situations. Therefore, similar situations may generate either shame or guilt (or both) in both cultures. This suggests that it may be individual differences that determine which of these self-conscious emotions are experienced (cf. Tangney, 1995). Moreover, there were several scenarios where participants reported feeling both shame and guilt simultaneously, suggesting that these two types of emotions can be experienced together, and this appeared to be true for both cultural groups (Hynie & MacDonald, 2001; Tangney, Miller, Flicker, & Barlow, 1996).

Our findings showed that all the scenarios of shame and guilt in this study involved socially painful experiences. They also appeared to involve negative self-labeling, which was consistent with Buss's study (2001). The themes generated showed that the range of experiences was wider than in previous studies, perhaps because we required participants to generate several examples of shame and guilt (one for each sub-type). However, this may better reflect the full range of shame and guilt experiences. In sum, within two different cultural groups and languages, participants could express a range of self-conscious emotions and situations, even when their language lacked a full vocabulary for their expression. This result supports the global consistencies of experiencing shame and guilt (Wang et al., 2009).

Higher Order Categories Comparisons Within and Between Cultures

The results showed that the higher order category "others' inappropriate action" was more strongly associated with shame situations than guilt situations in China. Chinese participants associated more shame than guilt with other people's excessive praise, their inappropriate actions, and their critiques and teasing. This is consistent with Henkin's finding (2004) that the theme "ashamed by other's perceptions" was dominant in shame stories but not in guilt stories of Chinese participants. This might be related to the fact that Chinese participants come from a more collectivist culture, which focuses on relationships with others and trying to be accepted by others. Thus, others' negative evaluations would have a very strong influence on their reports of shame.

This result also supports Hwang's (2001) explanation that Chinese people are concerned with saving face and avoiding loss of face. Huang emphasized that self-identity plays a key role in experiencing shame. This theme was most strongly represented in Chinese shame stories. However, European Canadian participants had more scenarios associating guilt with others' inappropriate action (i.e., the categories of others' inappropriate actions, being blamed/criticized/rejected/mistreated/teased/misunderstood by others) than Chinese participants (i.e., the categories of excessive praise, being blamed/criticized/rejected/mistreated/teased/misunderstood by others). Perhaps European Canadians, who live in an individualistic culture, responded to others' negative evaluations with less severity than mainland Chinese, who live in a more collectivistic culture. Euro-Canadians experienced guilt feelings more easily by others' inappropriate action/perception than did Chinese participants.

For Chinese participants, "displayed/having a flawed self/character" was more strongly associated with shame situations than guilt situations. Chinese participants' description of scenarios that elicited shame included descriptions of shortcomings, such as their selfishness, laziness, negative body image, drunkenness, and inferiority to others. If individuals had exposed mistakes/errors in their roles, their feelings of belonging would be threatened, and they might then feel devalued and feel shame. This result was consistent with what would be expected for participants from collectivist cultures, and with findings from past studies (Harvey, Gore, Frank, & Batres, 1997; Qian, Liu, & Zhu, 2001; Wang et al., 2009). This theme was more strongly represented in Chinese shame stories than European Canadian shame stories.

Both cultural groups reported that "breaking own expectations" was associated with more shame than guilt, whereas "breaking other's expectations" was associated with more guilt than shame. This clearly mirrors past research on shame and guilt, in which shame is more self-focused and guilt is more other-focused. Individuals do not like to violate their own expectations. If they do, they feel disappointed with themselves and evaluate themselves negatively. When they cannot reach their expected goals, they then feel ashamed of themselves. For breaking other's expectations and feelings of guilt, participants reported that when they failed their parent's, spouse's, and good friend's expectations, they felt regret for those people who were concerned about them and put their hopes in them. This theme of "breaking own expectations" was more strongly represented in Chinese shame stories than in European Canadian shame stories. However, the theme of "breaking other's expectations" was more strongly represented in European guilt stories and shame stories than in Chinese guilt and shame stories. Although one might expect a greater emphasis on others' expectations in a collectivist culture, this finding is consistent with the observation that Chinese morality emphasizes positive duties; in other words, living up to one's own positive expectations. A failure to do so would be a moral failing, and should therefore elicit negative self-conscious emotions.

The results also showed that "unintentional harm to others" elicited more guilt feelings than shame for Chinese participants. This theme was more strongly represented in guilt stories than in shame stories in both cultures, but was more strongly represented in Chinese guilt stories than European guilt stories. The results also showed that "intentional harm to others" elicited more guilt feelings than shame for

Chinese participants. This theme was more strongly represented in guilt stories than in shame stories in both cultures, but was more strongly represented in Chinese guilt stories than European guilt stories. The greater emphasis on reporting harm to others for Chinese participants perhaps reflects a cultural norm for thinking about the consequences of one's actions for others. The results also showed that "intentional breaking social norms/rules" elicited more guilt feelings than shame for both Chinese and European Canadian participants. This theme was more strongly represented in guilt stories than in shame stories in both cultures, but was more strongly represented in European guilt stories than Chinese guilt stories.

Limitations and Future Directions

Although we obtained 343 Chinese scenarios and 289 European Canadian scenarios from the participants, the sample size in this study was not very large. Moreover, the samples were not randomly selected. Future studies should recruit more participants in both cultures and randomly select them. In this way, we can get more representative scenarios describing experiences and expressions in shame and guilt events.

The questions we asked in this study were quite general and therefore answers were not as detailed as they might have been if we had led participants through a series of more detailed questions. Participants were only asked to describe a situation where they experienced a particular emotion in as much detail as possible. A more detailed set of questions such as specifically asking "What happened?", "Who was present?", "What were you thinking when it happened?", or "What did you do afterwards?" might have elicited more relevant information. However, we also obtained the scenarios as participants thought of them, and therefore obtained the most salient aspects that came to participants' minds.

Finally, we did not measure any possible mediating cultural variables like interdependence and independence. We can therefore only infer which variables might explain the cultural differences we observed, and they may indeed be due to other cultural differences that we have not thought of. It remains to be seen whether differences observed in how participants described their experiences might be affected by psychological variables that are thought to differ between cultures, or whether they are due more to social/cultural norms about self-regulation and emotion expression.

Appendix: Survey

The following questions ask you to recall a personal and potential distressing event. Please answer them as honestly as possible. Note that your answers will be completely anonymous, and you are free to not answer any question, or to discontinue participation at any time. Please answer the following questions in Mandarin.

1. Imagine a time when you experienced the following emotion: *guilt about harming another person*. In the space below, please describe the situation in as much detail as possible.
2. Imagine a time when you experienced the following emotion: *guilt about trust violation*. In the space below, please describe the situation in as much detail as possible.
3. Imagine a time when you experienced the following emotion: *guilt (zui e gan) about breaking moral*. In the space below, please describe the situation in as much detail as possible.
4. Imagine a time when you experienced the following emotion: *guilt (fan zui gan) about breaking the law or rules*. In the space below, please describe the situation in as much detail as possible.
5. Imagine a time when you experienced the following emotion: *shame (xiu chi) about very deep shame* (Feeling of shame that occurs with perceived social failure; A stain on the face). In the space below, please describe the situation in as much detail as possible.
6. Imagine a time when you experienced the following emotion: *shame (can kui) about feeling of shame that occurs with failure to attain a personal ideal*. In the space below, please describe the situation in as much detail as possible.
7. Imagine a time when you experienced the following emotion: *shame (diu lian) about loss of face* (Feeling of shame that occurs with loss of reputation or standing in the eyes of others). In the space below, please describe the situation in as much detail as possible.
8. Imagine a time when you experienced the following emotion: *shame (xiu kui) about feeling of shame occasioned by perceived personal failure resulting in harm to someone else*. In the space below, please describe the situation in as much detail as possible.
9. Imagine a time when you experienced the following emotion: *shame (nan wei qing) about embarrassment due to social impropriety*. In the space below, please describe the situation in as much detail as possible.

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Chapter 15
A Cross-Cultural Study on Dimensions of Experiences of Shame and Guilt Between Mainland Chinese and Euro-Canadians

Chang Su and Michaela Hynie

Introduction

Confucius (551–479 BCE), one of China's best known philosophers said: "A person must restrain his behavior with a sense of shame." Confucius also said, "Knowing shame is akin to courage." As this quote shows, shame is seen as a desirable state in China, and as essential to moral development. However, this perspective on shame is not universally shared.

Shame and guilt are painful, self-conscious emotions following violations of morals or social norms (Fischer & Tangney, 1995; Ho, Fu, & Ng, 2004). The experience of shame and guilt guides individuals toward the internalization of social standards and the regulation of their behavior to be consistent with them (Bedford, 2004). Thus, these negative, self-conscious emotions may repair social relations and increase the likelihood of not being rejected by others (Hynie, MacDonald, & Marques, 2006).

Experiences of shame and guilt are often intertwined (Harper & Hoopes, 1990). The terms "shame" and "guilt" usually have been used interchangeably in North America (Hynie, Lalonde, & Lee, 2006). However, a growing body of research has demonstrated their unique qualities. Shame and guilt are distinct in both their phenomenology and their behavioral consequences (Lutwak, Panish, & Ferrari, 2003; Schmader & Lickel, 2006; Tangney & Dearing, 2002). Shame results in negative evaluations of one's self. Shame focuses on the entire self that would be evaluated

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negatively by others in response to a transgression (Tangney & Dearing, 2002). The person experiencing shame feels exposed, which leads them to desire to escape, to hide or to sink into the floor and disappear (Tangney, 1998). Shame is accompanied by a sense of shrinking or of being small, and a sense of passivity in correcting the perceived mistakes (Tangney & Dearing, 2002).

In contrast, guilt results in negative evaluations of one's behavior (*How could I have done that?*) (Fischer & Tangney, 1995; Tracy & Robins, 2004). Guilt is a negative feeling of responsibility or remorse for having done something (Hoffman, 1998). It has been proposed that guilt is primarily a private experience in which the feelings of guilt do not generally need an audience (Qian & Qi, 2002). Guilt involves self-criticism for a specific action (Lewis, 1971). People in guilt often wish they had behaved differently or could somehow undo the deed (Kubany & Watson, 2003).

Types of Guilt and Shame in China

Although the differences between guilt and shame have been studied for several years now, the literature in Western countries cannot provide a complete picture of guilt and shame in Chinese culture (Bedford, 2004; Bedford & Hwang, 2003). To the extent that language shapes and reflects cognition and social behaviors (Rafferty, 1974), the relative breadth of linguistic terms for shame in Mandarin suggests that shame may be experienced differently from how it is experienced by English speakers. Whereas English speakers typically use only a small number of categories in describing shame (Frank, Harvey, & Verdun, 2000), Chinese culture has a continuum of levels of shame ranging from the equivalent of very mild embarrassment to utter mortification, each with distinct terms associated with them (Wilson, 1973). However, past studies exploring the types of situations that induce the negative feelings of shame and guilt typically used the single simple terms of *xiu chi* (shame) and *nei jiu* (guilt) (Henkin, 2004; Lewis, 1971; Tangney, 1992). As noted earlier though, there are some studies that have described and identified subsets of shame and guilt that occur in Chinese culture (Bedford, 2004; Bedford & Hwang, 2003; Frank et al., 2000).

Bedford's two studies (1994, 2004) identified the Mandarin terms for guilt and shame. Three main types of subjective guilt emerged: *nei jiu* (failed personal responsibility), *zui e gan* (moral transgression), and *fan zui gan* (law/rules transgression); and four main types of subjective shame emerged: *diu lian* (loss of face), *can kui* (failure to obtain ideal), *xiu kui* (personal failure), and *xiu chi* (social failure). Gore and Harvey (1995) had 280 American undergraduate students from the University Colorado rate 30 scenarios in the Dimensions of Conscience questionnaire on a five-point scale of how good or bad a portrayed event was. Five clusters containing all 30 scenarios were obtained. The clusters revealed three guilt clusters including impersonal transgression, harm to another person, and trust violation. The clusters of social impropriety and exposed inadequacy were reflective of shame. Frank et al. (2000) developed a study based on Bedford's characterizations of the five forms of shame and intended to evoke *diu lian, can kui, xiu chi, xiu kui*, and *nan wei qing* shame feelings, and also added scenarios for two guilt factors which include *shang hai ta ren* (*harm to another person*), and *wei bei xin ren (trust violation)* (Gore & Harvey, 1995). Their American participants responded differently to the different types of shame and guilt. According to previous studies with Chinese and American participants, we identified and generalized four categories of guilt and five types of shame. These are described as follows.

Different Types of Guilt

Although three types of guilt were identified by Bedford (2004), one of them was a general term for guilt, which is *nei jiu* in Chinese. We therefore decided not to use this term, since it seemed to be a superordinate guilt category. Frank et al. (2000) had two specific guilt terms which differed from those of Bedford, which were *shang hai ta ren*—harm to others, and *wei bei xin ren*—trust violation. We decided to utilize two terms from Frank et al. and two terms from Bedford to generate four specific guilt concepts, namely *nei jiu-1* (*shang hai ta ren*—harm to others), *nei jiu-2* (*wei bei xin ren*—trust violation), *zui e gan* (moral transgression), and *fan zui gan* (law/rules transgression). These are defined in more detail below.

Interestingly, two of the concepts share the same linguistic term (*nei jiu*), suggesting that the distinction between these different kinds of guilt in Mandarin may not be as clear as the distinction between the other guilt concepts, although each had a different word associated with it suggesting that they are unique and separable concepts in Chinese culture. On the other hand, just as past research suggests that North Americans can distinguish between different types of shame and guilt despite lacking different terms for these concepts, so too Chinese participants may distinguish between these two different types of guilt despite lacking different terms for them.

The following are the definitions of the different concepts of each category of guilt.

Nei jiu-1—harm to another person—shang hai ta ren (Frank et al., 2000) is failure to uphold an obligation or personal responsibility to another; not fulfilling that responsibility and hurting somebody; feeling sorry and the sense of owing others.

Nei jiu-2—trust violation—wei bei xin ren (Frank et al., 2000) is failure to uphold trust from others and awareness of the negative consequences that happen to a person who asked for your help and did not receive it. It is related to internal feelings of obligation.

Zui e gan (Bedford, 1994, 2004) is the feeling of personal moral transgression. It is connected to moral responsibility and obligation to others. It involves the feeling of having done something terribly wrong, although not of being evil or inferior. It arises through violation of negative duties. It can be a much stronger feeling of guilt than the two kinds of *nei jiu*, but it's not like breaking a law. Rather, it is more likely to be associated with harm to others. It is a transgression of one's personal morality.

Fan zui gan (Bedford, 1994, 2004) concerns social responsibility. As a member of society, one should obey the rules established for everyone's benefit. It is the feeling of breaking a law, having committed a crime or broken a rule that all society members must obey. It generally entails violation of negative duties and is a way of processing norm violation into self-punishment. It is experienced more strongly than *zui e gan*, which is a violation of internal standards. In contrast, *fan zui gan* is the transgression of external obligations. Nonetheless, it is an impersonal guilt, not felt toward people, but rather it is the internal recognition of breaking a requirement (Bedford & Hwang, 2003). Moreover, individuals need to only believe that they are breaking a rule or a law, regardless of whether the rule actually exists.

In sum, all four types of guilt (*nei jiu-1, nei jiu-2, zui e gan*, and *fan zui gan*) include a sense of responsibility. The two *nei jiu* terms represent two different types of guilt and imply responsibility to another person. *Zui e gan* is moral responsibility to others more generally. *Fan zui gan* concerns social responsibility in a more abstract sense. The intensity of guilt depends on the degree of the violation. *Fan zui gan* is more severe than *nei jiu-1, nei jiu-2*, and *zui ge gan*. All four types of guilt are aroused as a result of one's own behavior. They are all associated with a sense of indebtedness.

Different Types of Shame

The central issue of the shame emotions is identity. The five types of shame are *xiu chi*, *can kui*, *diu lian*, *xiu kui*, and *nan wei qing* (Bedford, 2004; Frank et al., 2000). The following are the definitions of each category of shame.

Xiu chi (Bedford, 2004; Frank et al., 2000) is the strongest feeling of shame and is perceived as a social failure. It is a very deep shame, associated with the violation of social norms and described as the feeling of having a stain on one's face. It is the result of an act that easily gets universal condemnation when other people find out about it.

Can kui (Bedford, 2004; Frank et al., 2000) is a mild feeling of shame, perhaps even a wistful feeling. It is a combination of shame and regret that one did not do something better. It involves failing to attain a personal ideal or meeting another person's ideal rather than the actual transgression of a standard. It may often be connected to a failure to carry out a positive duty. The essence of the negative affect derives from having let down another person. For instance, this shame might be felt by a student who does not prepare an oral presentation properly, which then goes poorly. This student might feel *can kui* after the presentation as he recalls the event while on his own (without other people around).

Diu lian (Bedford, 2004; Frank et al., 2000) is about a loss of face that indicates loss to a person's dignity or self-respect in front of other people or loss of standing in the eyes of others. It is caused by transgression of public identity. Traditionally, Chinese children are expected to be well behaved, especially in public. A consequence is fear of "losing face" in public (Locke, 1998). Losing face involves public embarrassment and is an extreme feeling of shame. It may be akin to "shame anxiety" (Wurmser, 1981).

Xiu kui (Bedford, 2004; Frank et al., 2000) is when one discovers a negative aspect of oneself or some personal inadequacy or can be the result of a violation of a self-expectation. It is a personal failure resulting in harm to someone else. It is associated with a heavy stain on the heart. People who experienced *xiu kui* feel marked as deficient in their own eyes. This is due to a threat to their private identity.

Nan wei qing (Frank et al., 2000) means embarrassment due to social impropriety. It is mild, situation-specific, and transient. It is also associated with the tendency to wish one could disappear.

In this current study, *nan wei qing* (embarrassment) is included as one of the subcategories of shame because of past research that has categorized it as such. However, past research has also distinguished embarrassment from general guilt and shame. Embarrassment is the least negative and the most fleeting of the three emotions. Ho et al. (2004) stated that shame is commonly accompanied by the fear of being humiliated, ridiculed, or laughed at; guilt is elicited by inner conscience and a feeling of owing somebody and wanting to apologize; embarrassment is more likely than guilt, and even shame, to be accompanied by physiological changes (e.g., blushing and increased heart rate), and is closely related to the personality traits of bashfulness and shyness. According to these authors, unlike shame, embarrassment touches the outer social self but does not penetrate the inner private self. Guilt and shame are therefore more enduring than embarrassment.

In sum, all the shame concepts relate to "face," either in fear of losing face or a moment when face is already lost. The intensity of shame depends on the nature of the violation. Among these five categories of shame, *xiu chi* is a stronger deep shame feeling than *can kui*, *diu lian*, and *nan wei qing*. The five types of shame include common experiences such as exposure, inadequacy, and concern with identity although they differ with respect to transgression issues and function.

Dimensions of Differences of Shame and Guilt

In contrast to the categorical approach to differences between and within shame and guilt, described above, research has also suggested that shame and guilt can be distinguished along three dimensions. The first dimension is a "public" or "private" perspective, namely whether there is an audience present. In theoretical work on shame and guilt, shame was initially viewed as a more "public" emotion than guilt, namely shame was thought to only be experienced when one's transgressions were made public (Benedict, 1946). It was argued that shame arises from public exposure (facing an actual audience) and public disapproval. On the other hand, guilt was believed to be a more "private" experience arising from self-generated conscience

(Benedict, 1946). However, many empirical studies have failed to support this public–private distinction; it appears that shame and guilt can both be experienced in either public or private (Tangney & Dearing, 2002; Tangney, Miller, Flicker, & Barlow, 1996; Tangney et al., 1994), although shamed people may feel more exposed, and shame is more easily experienced than guilt when others are present (Li, Wang, & Fischer, 2004).

Research with Chinese samples has mirrored the findings with Western samples. For example, Xie and Qian (2000) found that Chinese college students could experience shame and guilt in both private and public situations, whereas Qian and Qi (2002) found that participants felt more shame with others but reported feeling guilt with or without others present. Thus, there is some research that suggests that in both China and North America, both shame and guilt can be experienced in either private or public, but shame is more likely to be associated with an audience which is present. However, there is no research that has directly compared Chinese and North American experiences.

Linking this dimension to the Chinese concepts of shame and guilt, *diu lian* and *nan wei qing* are easily generated in public situations where there are audiences present, although they can also be generated in private situations, where there is no audience present. *Can kui, xiu chi*, and *xiu kui* should be generated less often in public than *diu lian* and *nan wei qing*, especially *can kui*, which seems to be a private type of shame. Based on the definitions of the types of guilt, *nei jiu-1—harm to others* is easily generated in public, *nei jiu-2—trust violations, zui e gan—moral transgression*, and *fan zui gan—laws/rules transgression* are easily generated in private situations.

The second dimension is about focusing on the "self" or on one's "behavior." Helen Block Lewis (1971) stated that the difference between shame and guilt is a function of their differences in the role of the self in terms of how one evaluates negative situations that elicit shame and guilt. She wrote the following:

> The experience of shame is directly about the self, which is the focus of evaluation. In guilt, the self is not the central object of negative evaluation, but rather the thing done or undone is the focus. In guilt, the self is negatively evaluated in connection with something but is not itself the focus of the experience. (p. 30).

Generally, shame involves a fairly global negative evaluation of the self (Tangney & Dearing, 2002); it is experienced as a reflection of a bad self. With this painful scrutiny of the self, the individual sees him/herself as a bad person, and experiences a feeling of loathing against the entire self (Lewis, 1971, 1985; Morrison, 1996; Tangney, 1991). As a result, the individual is concerned about his/her own feelings rather than those of the person who has been violated. Individuals experiencing shame are likely to feel disgust and aversion toward themselves and lack the feeling of pride. Thus, shame focuses on negative evaluations of one's self ("*I* did that horrible thing"), and shame is often viewed as more devastating to people's self-concepts and self-esteem than guilt. When people attribute their transgressions to their global and stable self, they experience shame (Tangney, 1991, 1994; Tracy & Robins, 2004).

In contrast, guilt is elicited from self-generated pangs of conscience (Tangney & Dearing, 2002). It is an emotion associated with behavior that violates internal standards ("I *did* that horrible thing") rather than self (Lewis, 1971, 1992). When people attribute their transgressions to transient actions or states, they experience guilt. Guilt doesn't affect one's core identity, the self remains basically intact (Anolli & Pascucci, 2005; Fischer & Tangney, 1995). Although most research suggests that guilt focuses on actions rather than the self (Lewis, 1971), some studies have found there were no significant differences between blaming the action and blaming the self when people experienced shame and guilt (Tangney et al., 1996).

Niedenthal, Tangney, and Gavanski (1994) used a counterfactual thinking approach to study the distinction of self versus behavior focus. They coded participants' counterfactual thinking responses to shame and guilt according to whether aspects of the self, behavior, or situation were "undone" (e.g., "If only …."). They found very strong support for Lewis' (1971) claim that shame and guilt differ in focus on self versus behavior. People tried to "undo" aspects of the self more often when the events were associated with shame experiences, and more often tried to "undo" aspects of their behavior in connection with guilt experiences.

Very interestingly, mainland Chinese scholars Xie and Qian (2000) also used counterfactual thinking to study whether mainland Chinese undergraduate students focused on self factors or behavior factors when they tried to change a shame or guilt event. She found that Chinese participants experiencing shame wanted to change their actions rather than their self, and there was no difference in changing self between the shame and guilt groups. Thus, this difference between shame and guilt, which seems to be quite well established in North American samples, may not be as relevant for Chinese populations.

Linking this second dimension to the Chinese concepts of shame and guilt, it is not easy to identify which types of shame focus on the self or focus on behaviors; it is hard to determine the evaluations of blaming self or one's behaviors from the definitions. However, based on the definitions of the types of guilt, *nei jiu-1— harm to others* is more easily focused on blaming one's actions than *nei jiu-2—trust violations, zui e gan—moral transgression*, and *fan zui gan—laws/rules transgression*.

The last hypothesized difference between shame and guilt is that individuals experiencing shame have the desire to hide and escape, whereas those experiencing guilt have a desire to correct their actions. When experiencing shame, the individual feels inferior and incapable of completing the task at hand, feels exposed, and is concerned about others' appraisals. Experiencing shame leads to avoidance and withdrawal (Tangney & Fischer, 1995); the individual experiencing shame often feels the need to hide, escape, or avoid others, and has the desire to sink into the floor and disappear. With guilt, the individual often wishes to engage in some sort of corrective action, like confessing, atoning or remedying, apologizing, or making-up for the act with compensatory actions, and to repair the damage done. However, the previous findings were obtained with Western samples. As noted earlier, the motives associated with shame may differ in collectivist and individualist cultures and, in particular, may differ between European Canadians and Mainland Chinese. One might imagine that people from a culture that places emphasis on shame to correct behavior (i.e., China) would be less likely to focus on hiding and withdrawal following shame and be more focused on engaging with others than those from other cultures.

Linking this third dimension to the Chinese concepts of shame and guilt, the definitions of *diu lian* and *nan wei qing* suggest that people can easily respond with withdrawal behavior rather than responding with corrective behavior. Based on the definitions of the types of guilt, *nei jiu-1—shang hai ta ren* (*harm to others*) is easily focused on using withdrawal to respond than *nei jiu-2—wei bei xin ren—trust violation, zui e gan—moral transgression*, and *fan zui gan—laws/rules transgression*.

The Purpose of This Study

Although there were quite numerous studies focused on the differences between shame and guilt either in Western countries or in mainland China, cross-cultural comparison studies were scarce (Qian & Qi, 2002; Tangney, 1992; Tangney & Fisher 1995; Xie & Qian, 2000). Moreover, the concepts of shame and guilt in past studies did not provide a full range of shame and guilt concepts to their participants. In addition, past empirical studies on shame and guilt seldom directly analyzed the types of events that elicit shame and guilt. Therefore, a more thorough comparison of shame and guilt between North Americans and Chinese participants needs to be explored regarding the differences across these nine different concepts of shame and guilt. Research has suggested that shame and guilt can be distinguished along three dimensions. However, most research on shame and guilt has been conducted in North America, and there is limited cross-cultural research exploring these differences in different cultural contexts. The main aim of this study was thus to explore three dimensions (private versus public; self versus other; withdrawal versus reparative action) of guilt and shame in Chinese and European participants by using the full range of Chinese shame (five types) and guilt (four types) concepts.

Methods

Participants

The first author recruited 39 native mainland Chinese Mandarin speakers (their age ranges from 20 to 45 years: 18 women, mean age = 26.4; SD = 6.5; 18 men, mean age = 27.8; SD = 8.4; three respondents did not report their gender) via e-mail using snow-ball sampling. The additional participants were recruited through a university teacher living in the North-East of China through her networks. All of the participants grow up in mainland China and living in the North-East of China and had never gone abroad.

The first author also recruited 34 European adults living in Canada (their age ranges from 19 to 44 years: 19 women, mean age = 25.6; SD = 8.7; 15 men, mean age = 31.0; SD = 10.2). Fifteen female and seven male European Canadian participants completed the survey online through the Undergraduate Research Participant Pool (URPP) at York University. Four females and eight males were recruited through random approach in the author's neighborhood in a northern suburb of Toronto.

Materials

Participants completed a brief demographic questionnaire asking about age, gender, and cultural background. Chinese participants were given all the materials in Mandarin, and European Canadians were given the same surveys in English. Participants were given the definition of each type of shame and guilt: five Chinese shame categories (*xiu chi, can kui, diu lian, xiu kui*, and *nan wei qing*) and four Chinese guilt categories (*nei jiu-1 (shang hai ta ren), nei jiu-2 (wei bei xin ren), fan zui gan*, and *zui e gan*) (Bedford, 2004; Bedford & Hwang, 2003; Frank et al., 2000). They were asked to read each concept definition, in turn, and then write out an example of a situation where they had experienced the type of emotion described (see Appendix A).

Procedure

The procedure was approved by the University ethics committee. Participants in mainland China were contacted by e-mail and directed to a website for the study. Participants first agreed the consent form and then answered all the questions; they received a written debriefing by e-mail after returning the package to the researcher by e-mail. Chinese participants completed all materials in Mandarin. The first author translated survey into Mandarin and a second bilingual Mandarin speaker back-translated.

Canadian URPP participants completed the survey online through the similar procedure. They completed all materials in English. The author approached some community adult samples who appeared to be of European origin on the street, briefly explained the survey was about. Five people approached declined to participate but 13 agreed. All participants answered the survey at home and let the first author picked up after they completed the survey or dropped it off at the author's home.

Data Analysis

A total of 343 stories were collected from Chinese participants and 289 stories from European participants. There were a few participants who wrote more than one scenario for one of the concepts (Chinese: $N = 4$; European Canadian: $N = 1$). Therefore, a total of 192 scenarios were reported for the shame scenarios and 151 for the guilt scenarios for the Chinese participants. For the European Canadian participants, a total of 157 scenarios were reported for the shame scenarios and 132 for the guilt scenarios.

Two coders independently sorted the responses into the three dimensions for two cultural groups. The two coders were given the descriptions of the three dimensions before they started coding, then they individually sorted all of the scenarios in each category according to the three dimensions of shame and guilt. After finishing all the sorting, the coders met together to resolve any disagreements.

The inter-rater reliability of the shame concepts for the three dimensions in the Chinese data was 0.89. The inter-rater reliability of the guilt concepts for the three dimensions in the Chinese data was 0.88. In European Canadian data, the inter-rater reliability for the shame categories was 0.92, and for the guilt categories was 0.90. The data were analyzed by using Chi-square statistics to examine differences in the three dimensions between shame and guilt within and between cultures.

Results

Three Dimensions of Guilt and Shame

Dimension 1: Focus on Public Versus Private

Chinese participants were examined first. The first dimension focuses on whether participants described their experiences of shame and guilt as public or private, namely whether there was an audience present when people experienced the emotion. A scenario was coded as "public" if one could infer that an audience was present, and it included people in addition to the victim, for example, "I was not responsible because I did not arrive on time for my sister's wedding. I was late, and that caused the wedding to start late. I felt very guilty for not upholding my obligation to be on time for such an important event." The scenarios were coded separately when transgressors were with victims only, for example, "when I do not help out a family member when they ask for help from me at times." This was coded "public—transgressor was with victim only." However, if the scenario did not show the presence of the victim and/or other people, the scenario was coded as "private." For example, "In an anonymous paper voting for a new leader, I gave very bad evaluation to a candidate leader who actually did not do too badly in his job." If the scenario did not clearly indicate whether an audience was present it was coded as "unknown." An example would be, "One day, I had not finished my work which I should have completed on time."

For the combined guilt scenarios in the Chinese data, 13% had an audience present, and 35% showed only the transgressor and the victim together, for a total of 48% (19 out of 39) in public (with audience or victim present). Another 47% (18 out of 39) described feeling guilt in private (no audience) and 5% (2 out of 39) were unknown. A Chi-square comparing the proportion of guilt scenarios that were coded as private showed that private experiences of guilt were not distributed equally across the four categories. Rather, a minority (18%) of *nei jiu-1* scenarios were associated with no audience, whereas the majority of scenarios of *nei jiu-2* (57%), *zui e gan* (51%), and *fan zui gan* (62%) were associated with private experiences. Chi-square analysis showed that the proportion of private varied significantly across these four categories of guilt, $X^2(3, N = 39) = 25.15$, $p < 0.05$. *Fan zui gan* had higher number of private and significantly differed from *nei jiu-1* (harm to others) and not significantly differed from *nei jiu-2* and *zui e gan*, and *nei jiu-1* (harm to others) was different from the others.

In Chinese participants, for the combined shame scenarios, 58% showed the transgressor was with other people present, and 11% showed the transgressor was alone with the victim for a total of 69% (133/192) in public (with audience and/or victim present), whereas a minority (22%, 43 out of 192 scenarios) felt shame in private. Another 9% were unknown (16 scenarios). The proportion of shame scenarios that were private was compared across the five categories of shame and was not found to be distributed equally. Two categories *diu lian* (8%) and *nan wei qing* (12%) showed lower numbers of private scenarios than the other categories (*can kui*: 50%; *xiu chi:* 23%; and *xiu kui:* 19%), which also showed higher proportions of private scenarios, particularly *can kui,* $X^2(4, N = 39) = 48.64$, $p < 0.05$, which is different from the other categories and had the highest number experienced in private.

Chi-square analyses were used to compare proportions of public and private scenarios by the two types of emotions (overall guilt and overall shame) within Chinese participants. There was a significant interaction between whether an audience was present or not present and whether the emotion being described was shame or guilt within Chinese participants, $X^2(1, N = 39) = 12.75$, $p < 0.05$. In shame situations, public (69%) was higher than private (22%) when experiencing shame, but not in guilt situations (48% guilt and 47% shame). Thus, the presence of an audience was more strongly associated with shame situations, but the presence or absence of an audience did not matter in guilt situations. However, as noted above, there was also variability in the public versus private dimension as a function of the specific types of shame and guilt being described.

European Canadian participants were examined next. For guilt scenarios overall, in terms of the "public" or "private" perspective, 37% showed an audience present, and 21% showed the victim only present. Thus, 58% showed that the transgressor felt guilt in public. There were 27% who reported no audience and 15% were "unknown." These results suggest that the presence of an audience is associated with guilt feelings for European Canadian participants. We compared the proportion in each dimension across the different categories of guilt and showed that the private experiences of guilt were not distributed equally across the four categories, $X^2(3, N = 34) = 14.26, p < 0.05$. Rather, several (38%) of the *fan zui gan* scenarios, which had the highest number, were associated with no audience, whereas fewer scenarios of *nei jiu*-1 (24%), *nei jiu-2* (21%), and *zui e gan* (26%) were described as private. This suggests that the different categories of guilt were associated with different situations for European participants but unlike the Chinese participants, for whom it was *nei jiu-1* that differed from the others, for Euro-Canadian participants it was *fan zui gan* that differed from the others.

For shame scenarios overall, 63% showed that an audience was present, and 14% showed that the victim was present, with 77% overall showing that the transgressor felt shame in public. There were 12% where the transgressor felt shame in private and 11% were unknown. Thus, shame was also experienced primarily in public. The proportion of shame scenarios that were private were not distributed equally across the five types of shame, $X^2(4, N = 34) = 92.60, p < 0.05$, with one category *can kui* (41%) showing a higher number of private scenarios than the other four categories (*xiu chi:* 9%; *diu lian:* 3%; *xiu kui:* 3%; and *nan wei qing:* 3%). This suggests that the different categories of shame varied on this dimension for European Canadian participants and that most categories of shame were not experienced in private.

Chi-square analysis was used to analyze proportion of public and private by the two types of emotions (overall guilt and overall shame) within European participants. There was a significant interaction between whether an audience was present or not present in overall shame versus overall guilt scenarios within European Canadian participants, $X^2(1, N = 34) = 7.52, p < 0.05$. However, for European Canadians, public scenarios were more frequent than private scenarios in both shame and guilt. Further post hoc tests showed that there was a significant difference in whether there was no audience present in overall shame versus overall guilt, $X^2(1, N = 34) = 5.77, p < 0.05$. Thus, European participants reported experiencing more guilt than shame scenarios in private.

Cultural effects of audience's presence on overall shame and guilt were also examined. Chi-square analysis was used to analyze the proportion of scenarios with an audience present for overall shame and overall guilt between the two cultures. There was no significant interaction between whether an audience was present in shame versus guilt scenarios and culture, $X^2(1, N = 73) = 0.10$, *ns*.

Dimension 2: Focus on Self Versus Action

The second dimension refers to whether people focus on the "self" or their "action" when experiencing shame and guilt. In other words, whether people who violate social norms or morals feel themselves to be a bad person or just feel that their behavior was wrong. A scenario was coded as focusing on blaming the self when the transgressor stated that they blamed him/herself, for example, "*I feel very selfish.*" It was coded as focusing on blaming their actions when the transgressors focused on their behaviors, for example, "I was caught for spitting on the bus." If the scenario did not clearly indicate whether the person blamed him/herself or their behaviors, it was coded as “unknown.” An example would be “My lies were exposed.”

For the combined guilt scenarios in Chinese participants, 10% showed people focusing on the self, and 90% showed people focusing on the action. For the breakdown of the patterns by individual guilt concepts, the proportions in this dimension were not found to differ across the four categories of guilt, $X^2(3, N = 39) = 1.44$, *ns*. This suggests that Chinese people in guilt situations focused on blaming their actions across these four different types of situations.

For the combined shame scenarios overall in Chinese participants, 38% (15 out of 39) were focused on the self, and 60% (23 out of 39) were focused on action. There were 2% unknown. For the individual concepts of shame, most categories of shame focused “action” although the categories *can kui* (52%) and *nan wei qing* (49%) were almost equally distributed across focusing on self and behavior. However, chi-square tests showed that there were no significant differences in the proportion of scenarios focused on action across these five categories of shame, $X^2(4, N = 39) = 5.78$, *ns*. This suggested that people in most shame situations still focused on blaming their actions.

Chi-square analysis was used to analyze the proportion of self focus and action participants. There was a significant interaction between type of blame and type of emotion within Chinese participants, $X^2(1, N = 39) = 22.31$, $p < 0.05$. Chi-square was used to explore further, we found that there was significant difference in the proportion of scenarios of blaming self between overall shame scenarios (38%) and overall guilt scenarios (10%), $X^2(1, N = 39) = 16.32$, $p < 0.05$. Chinese people in shame situations appear to have focused on blaming themselves more than in guilt situations. Moreover, there was a significant difference in focusing on blaming their actions between overall shame (60%) versus overall guilt (90%), $X^2(1, N = 39) = 6.00$, $p < 0.05$. Thus, Chinese people in guilt situations focused more on blaming their actions than in shame situations.

We also examined the differences of focusing on blaming “self” versus blaming “action” in each shame and guilt situations for Chinese participants. The results showed that participants focused on blaming their actions rather than self within both shame situations, $X^2(1, N = 39) = 4.94$, $p < 0.05$, and within guilt situations, $X^2(1, N = 39) = 6.40$, $p < 0.05$.

For the combined guilt scenarios overall in the Euro-Canadian participants, 8% showed people focusing on the self, 81% showed people focusing on their actions, and 11% was unknown. The proportions in this dimension were compared across the different categories of guilt and showed that all the categories of guilt focused on “action,” specifically *nei jiu-1* (88%), *nei jiu-2* (73%), *zui e gan* (91%), and *fan zui gan* (70%), $X^2(3, N = 34) = 4.09$, *ns*. This suggests that European Canadians in guilt situations focused on blaming their actions rather than blaming themselves across all four types of guilt concepts. For the combined shame scenarios overall in the European Canadian participants, 15% showed people focusing on the self, 73% showed people focused on actions, and 12% were unknown. The proportions in this dimension were compared across the different categories of shame all of which focused on "action" (*xiu chi:* 85%; *can kui:* 80%; *diu lian:* 76%; *xiu kui:* 52%; and *nan wei qing:* 70%). Chi-square showed that there were no significant differences in the proportion of action focus across these five categories of shame, $X^2(4, N = 34) = 8.97$, *ns*.

Chi-square analysis was used to analyze proportion of self focus and action focus by the two types of emotions (overall guilt and overall shame) within European Canadian participants. There was no significant interaction in whether participants focused on blaming themselves or blaming the actions as a function of the type of emotion within European Canadian participants, $X^2(1, N = 34) = 2.54$, *ns*. In both shame and guilt situations, scenarios focused more on the action rather than the self.

Chi-square analysis was used to analyze proportion of scenarios focusing on blaming self for overall shame and overall guilt between the two cultures. There was no significant interaction between the type of emotion and culture, $X^2(1, N = 73) = 1.60$, *ns*. In sum, for focus on self versus action, mainland Chinese and European Canadians blamed their actions more than they blamed themselves.

Dimension 3: Social Withdrawal Versus Repairing Behaviors

Chinese participants were examined first. The third dimension reflects the extent to which the scenarios focused on social withdrawal behaviors or repairing behaviors after experiencing shame and guilt. A scenario was coded as focusing on social withdrawal when participants wanted to hide or escape from others, for example, "Now I hardly talk to my friend because I feel guilty." A scenario was coded as focusing on reparative behaviors when participants who did something wrong wanted to fix what had happened, for example, "I apologized profusely." A scenario was coded as "unknown," which means the coders could not identify whether it described withdrawal situation or repairing, in many cases because there was simply no information, for example, "I said bad words behind somebody's back, but later he knew what I said."

Few people responded with either withdrawal (0%) or repairing (17%) in either culture because we did not specifically ask about how people responded, so few gave that information. However, the results we were able to code showed the following patterns.

For the combined guilt scenarios in the Chinese participants, 17% showed people focused on repairing behaviors, and 83% were unknown (uncoded behaviors). For patterns within the separate guilt concepts, the proportions of "repairing behaviors" across the different categories of guilt varied as a function of the type of category of guilt, $X^2(3, N = 39) = 9.92, p < 0.05$. This suggests that the repairing behaviors were not distributed equally across the four guilt concepts, with *zui e gan* showing the lowest frequency. However, all people who reported actions in guilt situations responded with repairing behaviors.

For the combined shame scenarios overall in Chinese participants, 1% participants showed a focus on social withdrawal behaviors, 7% showed a focus on repairing behavior, and 92% were unknown, which means participants did not give further explanation about how they reacted to their situations or dealt with them. For an analysis of this dimension by individual shame concepts, the proportion of repairing behaviors in this dimension did not differ across the different categories of shame, $X^2(4, N = 39) = 6.12$, *ns*. However, we noted that most people in shame situations who described their actions following the event reported mostly repairing behaviors.

Chi-square analysis was used to analyze proportion of withdrawal behaviors and repairing behaviors by two types of emotions (overall guilt and overall shame) within Chinese participants. There was no significant interaction between whether participants focused on withdrawal or repairing behaviors and type of emotion within Chinese participants, $X^2(1, N = 39) = 2.21$, *ns*.

European Canadian participants were looked at next. For the combined guilt scenarios overall in the Euro-Canadian participants, 7% showed people focusing on withdrawal, 45% showed people focusing on repairing behaviors, and 48% were unknown. For the proportions in the individual concepts of guilt, the proportions in this dimension were compared across the different categories of guilt. All the categories of guilt focused more on "repairing actions," but there was a significant difference in the proportion of repairing actions across the four categories of guilt, $X^2(3, N = 34) = 11.80$, $p < 0.05$. This suggests that in the European Canadian sample people in guilt situations focused on repairing to a different extent depending on the type of guilt. Specifically, they focused on repairing behaviors more in *nei jiu-1* than in the other types of guilt.

For the combined shame scenarios overall in the Euro-Canadian participants, 36% showed people focusing on social withdrawal behaviors, 11% showed people focusing on repairing behavior, and 55% were unknown. There was a significant difference in the proportion of repairing actions focus varied on these five categories of shame, $X^2(1, N = 34) = 30.30$, $p < 0.05$. The proportion of "repairing behaviors" in this dimension across the different categories of shame showed most categories of shame had only a small proportion focused on "repairing behavior," except *can kui*. *Can kui* in Euro-Canadians had an equal proportion of repairing and withdrawal responses, whereas the other categories had more withdrawal than repairing.

Chi-square analysis was used to analyze the proportion of withdrawal actions and repairing actions by the two types of emotions (overall guilt and overall shame) within European Canadian participants. There was a significant interaction between participants' focus on social withdrawal or repairing their actions and type of emotion, $X^2(1, N = 34) = 40.07$, $p < 0.05$. Further post hoc tests showed that, in shame situations, European Canadians focused on social withdrawal (36%) rather than focusing on repairing behaviors (11%), $X^2(1, N = 34) = 13.30$, $p < 0.05$, while in guilt situations, they focused on repairing behaviors (45%) rather than social withdrawal (7%), $X^2(1, N = 34) = 27.76$, $p < 0.05$.

Regarding cultural effects on withdrawal focus in overall shame and guilt, Chi-square analysis was used to analyze the proportion of scenarios focusing on withdrawal for overall shame and overall guilt between the two cultures. There was no significant interaction between type of emotion and culture, $X^2(1, N = 73) = 0.87$, *ns*.

In sum, both European Canadians and mainland Chinese participants focused more on repairing actions in guilt than shame scenarios.

Interestingly, in guilt *nei jiiu-1*, there were five cases with both shame and guilt feelings; in guilt *nei jiu-* 2, there were two cases with both, and in *fan zui gan*, there was one case with both. For example, one scenario from the concept of *nei jiu-1*, which was guilt about harming another person, is described as follows.

> A close friend had divulged some personal information to me. When I was with another group of friends (we shared the same circle of friends), I told everyone what my friend had told me earlier. I immediately knew that I broke my friends trust and hoped that she would not come to know. The feeling of guilt and having disappointed my friend was very overwhelming. I knew that I spoke out in haste trying to prove that we were the closest amongst all our friends. I was afraid that this would ruin our friendship. My friend did find out that I had told everyone her confidential information and she confronted me. I was very ashamed and I felt a lot of guilt for having broken my friends trust. When I saw my friend after the incident, I apologized profusely. She did accept my apology, but there was tension for some time. The feeling of guilt was more long term and it slowly faded once I saw our relationship return. Today our relationship is as strong as ever.

Discussion

Three Dimensions of Guilt and Shame Comparisons

As noticed above, although the English language lacks equivalent terms for all the categories, European Canadians also distinguished between the different types of shame and guilt. This suggests that European Canadians have a much richer representation of shame and guilt than their limited linguistic terms might suggest. However, the concepts are not identical; the patterns based on the three dimensions were not the same even though based on the definitions of five types of shame and four types of guilt rather than actual terms.

Public Versus Private

This study showed that Chinese participants reported shame and guilt scenarios in both “public” and “private” situations, which is consistent with some Chinese scholars’ findings (Xie & Qian, 2000). In contrast, though Qian and Qi (2002) found that Chinese participants felt more shame with others but reported feeling guilt with or without others present.

With respect to the differences in the “public” versus “private” dimension in the European Canadian participants of the current study, they also reported shame and guilt scenarios in both “public” and “private” situations. This is consistent with past studies in Western countries (Tangney, 1995; Tangney & Dearing, 2002; Tangney et al., 1994, 1996). European Canadian participants reported more private guilt than private shame scenarios. However, we found that for both samples, the absence of an audience was more strongly associated with guilt situations than shame situations, and the presence of an audience was more strongly associated with shame situations than guilt situations. This is consistent with Chinese scholars' studies (Li et al., 2004) with Chinese participants and also consistent with Western scholars' work with Western data (Tangney, 1995). However, although there was a significant difference between "audience present" and "not present" in both shame and guilt situations, we still found that several participants reported "private shame" and "public guilt" in both cultures, which is also consistent with some past studies (Hong & Chiu, 1992; Tangney et al., 1996; Xie & Qian, 2000).

With respect to the differences between Chinese and European Canadian participants, Chinese participants reported significantly more "private" guilt than European Canadian participants. Maybe this was the influence of cultural background. Chinese transgressors, who are from a more collectivist country, may be more concerned about their relationship with others and want to save face when they do something wrong. This means that they could feel guilty even if no one knows their wrongdoings, because they may focus automatically on others' concerns and opinions more, or they may worry more about the strength of their relationships than do European Canadians.

Self Versus Action

Previous research describes that an individual who feels shame feels as if the self as a whole person is at fault for committing the action that resulted in shame (Lewis, 1971), and feels the entire self is bad or wrong. In contrast, an individual who feels guilt feels as if part of the self did wrong action, and thus guilt results from the self's actions (Lewis, 1971). Although most research suggests that guilt focuses on actions rather than self (Lewis, 1971; Niedenthal et al., 1994), there have been some arguments about whether people blame the self or blame others when they experience guilt and shame (Tangney et al., 1996). However, Chinese scholars Xie and Qian (2000) found that people experiencing shame wanted to change their actions rather than their self, and there was no difference in changing self between the shame and guilt groups, suggesting that this distinction may not exist in Chinese samples.

In this study, Chinese participants and European Canadian participants both reported blaming their actions more than themselves overall in both shame and guilt situations. This is consistent with previous findings with Western samples and may be because action blaming causes less tension and is less painful than self blaming. However, Chinese participants blamed themselves more than European Canadian participants did in shame situations, and Chinese participants in shame situations focused on both self and actions when experiencing shame, whereas Euro-Canadians focused more on actions in both shame and guilt scenarios.

This greater emphasis on self-blame among Chinese participants might be caused by Confucian moral standards that made Chinese participants feel very bad about themselves and blame themselves harshly after wrongdoings compared to European Canadians. However, it may also be the result of norms regarding responses to wrongdoing. The social norm in Chinese society expects more self-blame when one speaks of transgressing, and thus the differences in self-blame may reflect cultural norms for discussing transgressions, rather than actual differences in self-blame. Chinese traditions in which Confucius emphasized the sense of shame have retained their influence, even to the present day in mainland China. Since the People's Republic of China was established in 1949, Chairman Mao advocated criticism and self-criticism for the entire society (Ou, 2002), which means that when a person does wrong things, everybody should point it out and criticize his/her mistakes, and that he/she should also criticize himself/herself in order to serve the well-being of the society. Most Chinese people become accustomed to criticizing themselves in order to improve themselves, and this may be the cause of the differences in self-blame between the two cultures.

Social Withdrawal Versus Repairing Behavior

Past research explains that an individual experiencing shame may wish to hide or try to escape the situation (Buss, 2001; Lewis, 1992; Tangney, 1991; Tangney & Fischer, 1995). In contrast, an individual who feels guilt often has the desire to correct their actions (Buss, 2001; Tangney, 1991). In this study, participants in both cultures focused more on repairing behaviors in guilt than shame scenarios. They all wanted to apologize to the victims and wanted to repair their wrongdoings in guilt situations. However, European Canadian participants focused more on withdrawal in shame than guilt situations. In contrast, no Chinese participants raised the possibility of withdrawal in guilt situations and only 1% raised it as a possibility in shame situations. This may be because shame is thought to be a very negative emotion in Western countries, but shame has a positive meaning in China. Western people might therefore prefer denying and suppressing this feeling and withdrawal in these situations, relative to Chinese participants (Wang, Zhang, Gao, & Qian, 2009).

Very interestingly, in both shame and guilt situations, Chinese participants focused on repairing behaviors more than social withdrawal. Because the maintenance of harmony is of central importance in Chinese culture, which advocates that citizens have a sense of shame, Chinese participants should know their wrongdoings and self-criticize and correct their actions (Ou, 2002). Shame therefore can and should be publicly discussed. On the other hand, European Canadian participants in shame situations focused on social withdrawal more than on repairing behaviors, but in guilt situations, they focused on repairing behaviors rather than social withdrawal. This is consistent with other studies conducted with Western samples. For example, a study of American undergraduates found that guilt improved relationship outcomes while shame harmed them (Leith & Baumeister, 1998). Differences between interdependent and independent self-construal might explain these findings. Shame primarily serves as a threat to the uniqueness and self-worth of European Canadians who live in an individualist culture. Moreover, Americans experience guilt as a moral transgression. Shame is felt when identity is called into question and has no necessary connection with responsibility (Lindsay-Hartz, 1984).

Thus, social withdrawal was not a response to shame or guilt situations for Chinese participants, whereas European Canadian participants' shame and guilt scenarios focused on more withdrawal than Mainland Chinese scenarios did. However, the majority of the responses to shame and guilt could not be coded in terms of withdrawal or repairing actions; most scenarios were coded "unknown." This is no doubt because we did not specifically ask questions regarding the actions taken following the event. If we added more detail to the questions we asked about how people would respond to shame and guilt situations, we would have had more information from a greater proportion of the participants. In light of how few respondents provided information about how they responded to these shame and guilt eliciting situations, caution must be taken in interpreting the findings. Additionally, there were some cells with low frequencies in the Chi-square analyses that examined actions taken, including some frequencies equal to zero. Because Chi-square analyses conducted with low and null frequencies are unstable, caution must be taken in any interpretations of this dimension.

Limitations and Future Directions

This study has several limitations that should be considered in future research. First, for mainland Chinese participants, we only collected data from mainland China, but we did not collect data from Hong Kong and Taiwan. In a future study, I would like to collect data in multiple locations and see whether there are differences due to origin. Second, considering the sample size was not very large, although we recruited over 30 samples from each culture and totally obtained 343 Chinese scenarios and 289 European Canadian scenarios from each cultural group. Third, the samples we recruited were not selected randomly. Our future direction for the studies needs to recruit more participants from both cultures and randomly select them in order to obtain more representative scenarios describing experiences and expressions in shame and guilt events. The questions we asked in this study had only general questions, in our future study, we would ask participants questions with more details. In this way, participants will provide more wide expressions and feelings about writing the scenarios. Moreover, the cultural variables such as self-construal (interdependence and independence) also should be considered as well. Furthermore, there might be other psychological factors that affect experience of shame and guilt, such as cultural beliefs, cultural norms about self-regulation, and responses to these self-conscious emotional expressions.

Despite these limitations, the findings obtained in this study were similar to previous studies (Tangney, 1991), and support the theoretical and phenomenological literature (Lutwak et al., 2003) but deepen our understanding of how universal emotions like shame and guilt can be shaped by one's cultural environment.

Appendix A: Survey

The following questions ask you to recall a personal and potential distressing event. Please answer them as honestly as possible. Note that your answers will be completely anonymous, and you are free to not answer any question, or to discontinue participation at any time. Please answer the following questions in Mandarin.

1. Imagine a time when you experienced the following emotion: *guilt about harming another person*. In the space below, please describe the situation in as much detail as possible.
2. Imagine a time when you experienced the following emotion: *guilt about trust violation*. In the space below, please describe the situation in as much detail as possible.
3. Imagine a time when you experienced the following emotion: *guilt (zui e gan) about breaking moral*. In the space below, please describe the situation in as much detail as possible.
4. Imagine a time when you experienced the following emotion: *guilt (fan zui gan) about breaking the law or rules*. In the space below, please describe the situation in as much detail as possible.
5. Imagine a time when you experienced the following emotion: *shame (xiu chi) about very deep shame* (Feeling of shame that occurs with perceived social failure; A stain on the face). In the space below, please describe the situation in as much detail as possible.
6. Imagine a time when you experienced the following emotion: *shame (can kui) about feeling of shame that occurs with failure to attain a personal ideal*. In the space below, please describe the situation in as much detail as possible.
7. Imagine a time when you experienced the following emotion: *shame (diu lian) about loss of face* (Feeling of shame that occurs with loss of reputation or standing in the eyes of others). In the space below, please describe the situation in as much detail as possible.
8. Imagine a time when you experienced the following emotion: *shame (xiu kui) about feeling of shame occasioned by perceived personal failure resulting in harm to someone else*. In the space below, please describe the situation in as much detail as possible.
9. Imagine a time when you experienced the following emotion: *shame (nan wei qing) about embarrassment due to social impropriety*. In the space below, please describe the situation in as much detail as possible.

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Chapter 16

Social Capital and the Quality of Life of Parents of Children with Autism Spectrum Disorders: A Comparison Between Bedouin Fathers and Mothers

Iris Manor-Binyamini and Fares Ka'Abeya

The Bedouin Community in the Negev

The Bedouin Arabs belong to a stream within Islam, but differ from other Arabs because of their family structure and unique culture as well as their settlement in the desert. Bedouin Arabs can be found in the nomadic tribes of the Middle East and North Africa, in countries such as Egypt, Jordan, Saudi Arabia, and Lebanon (Peters, 2009). The Bedouin society in the Negev is similar in some of its socio-demographic and cultural characteristics to other Arab Bedouin societies in the Middle East, including marriage among relatives, polygamy, living within the extended family, and traditional and patriarchal society. In addition, it has its own unique characteristics. The Bedouin population in the Negev numbers close to 220,000 people (The Knesset Research and Information Center, 2015).

The Bedouin community belongs to a society that is characterized as a non-Western, Traditional, collective society. On the one hand, an individual's needs, interests, style of thinking, attitudes, beliefs, and values are compatible with those of the family or the tribe. On the other hand, the individual's behavior is shaped according to social norms (Dwairy, 2002). According to Dwairy, approximately 80% of the global population still lives within traditional-collective societies.

Approximately half of the Bedouin population in the Negev lives in towns, and the other half lives in unrecognized settlements. People living in the unrecognized settlements live in tents without access to basic services such as electricity, paved roads, transportation, education, and health services. The Bedouin population in the Negev is characterized by difficult socio-economic conditions; 60% of Bedouin children in the Negev live below the poverty line. Within Bedouin society, there is a clear division of roles between men and women. This gender division begins during

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childhood and is expressed at every level of the organization of the Bedouin family. Historically, Bedouin society is a patriarchal, collectivist society in which the status of men is higher than that of women (Dwairy, 2002). Based on these values, women in Bedouin society have no role in the public sphere. Their responsibilities are confined to the area surrounding the home or to the family's tent, and they are responsible for all of the housework and raising the children. The fathers are responsible for the representation of the family within the public sphere; as such, they are the mediators in the relationship between the family and the medical establishment.

> As one of the interviewees stated: "in my family, my decision making is strong to the point that I have the option of containment and permission to speak on behalf of my family (my spouse, children, parents and siblings and sometimes, when it considerably concerns the broader family I can make an authoritative decision)."

Fear of the stigma regarding femininity and motherhood of a child with autism, as well as the threat of their husband divorcing them and marrying another woman, add difficulties to these mothers' lives.

> In addition to what was said, when we asked the interviewees what they most appreciated in the Bedouin community, one of them answered: "I highly appreciate the generosity of our community, which is part of the tradition we inherited from our ancestors, and by which we honor the serve others with what we have. According to this, if have guest(s) we must serve them what we drink and eat and not suffice with one attempt if the guest said "no, thanks", we should try again and again. Also, I highly appreciate in our community the unity among all Bedouins under the common denominator that we all belong to one another in terms of culture, values and morals, and in some cases even in terms of blood relations or consanguineous marriage within the Bedouin community. I also like and highly appreciate our spoken language, which also unifies us under a single language all Bedouins understand."
>
> Another interviewee added: "in my community I highly appreciate the over concern on the part of community members (relatives and neighbors) that often plays a role of assistance, care, proper relations, protection and safekeeping against dangers. Another thing I like in my community is the confidentiality and loyalty within the community to a certain extent. I also appreciate the patience and tolerance in my community which, despite the difficulties and barriers, Bedouins are required to fulfill their mission when faced by difficulties and barriers."

Parenting Children with Autism Spectrum Disorder (ASD): Quality of Life

In the arena of paternal research, it is generally agreed that Quality of Life is a key indicator for the psychological health of parents raising children with a disability. Therefore, studying the Quality of Life of those parents is fundamental to supporting their psychological adjustment (Yamada et al., 2012). Quality of Life is determined according to the individuals' perception of their position in life, in relation to their sociocultural context, goals, expectations, standards, and concerns (World Health Organization, 1996). Moreover, Quality of Life affects and is affected by multiple factors and variables related to individuals' physical health, psychological state, social relationships, and relationships with salient features of the environment (World Health Organization, 1996).

A recent systematic review found that the Quality of Life of parents of children with ASD is lower than that of parents of typically developing children or the general population (Vasilopoulou & Nisbet, 2016). Various factors are associated with parents of children with ASD reporting lower Quality of Life. These factors include increased challenging behaviors of the child with ASD (McStay, Trembath, & Dissanayake, 2014), severity of ASD (Pozo, Sarria, & Brioso, 2014), lower household income (Dardas & Ahmad, 2014), decreased levels of social support (Pozo et al., 2014), parental distress (Dardas & Ahmad, 2014), and parental coping style (Dardas & Ahmad, 2014; Pozo et al., 2014).

Some studies have compared the experiences between mothers and fathers of children with ASD. For example, there is emerging evidence to suggest that mothers of children with ASD experience lower levels of Quality of Life than fathers (McStay et al., 2014).

In comparison, fathers who are less stressed are more likely to have a better Quality of Life, and can better enhance their children's Quality of Life. One main demographic factor was found to influence fathers' Quality of Life: family income. Fathers with a higher family income tend to report lower levels of stress and better Quality of Life. Higher income can help fathers feel less restricted in their parental roles, more satisfied with their spouses, and better able to provide help and support for their families (Dardas & Ahmad, 2014).

> One of the interviewed fathers mentioned that for him, Quality of Life is: "first and foremost, to be a healthy person with responsive conscience. Don't hurt or harm others. Also, subsistence and stable financial condition are also important parts that my quality of life would be compromised in their absence. Also, to see my children happy and have their needs attended to is where I feel I have a good quality of life. Finally, I think that to enjoy a good quality of life it is to keep my parents satisfied (my father and mother – and have their valued blessing). In fact, my parents are dear to me more than anything else, even more than my wife, so when they are satisfied with me I am very glad and feel that everything else is could be obtained."
>
> One of the mothers stated that for her, quality of life is:
>
> "Quality of life is to live with dignity and peacefully, without any interference or harassment to me or my neighbors, because the pain of my neighbor is mine as well, and if they are in pain today then tomorrow it could reach me, and thus it is important that we help one another as much as possible and the quality of life would increase. Moreover, for me quality of life is to observe the ethical codes of the community and abide by the norms to prevent anomalies from rearing their heads and harm the position of the community."

Parenting Children with ASD: Social Capital

Social Capital may be an important resource in improving the Quality of Life of parents. Social Capital is a resource that enables the individual to cope effectively with various crises that occur throughout their life, and strengthens the person's ability to cope and improve their personal well-being and Quality of Life (Wouter, 2012).

Social Capital has various definitions that differ in their focus but are all based on one common denominator: they all emphasize the importance of social networks, trust, commitment, and the norms of reciprocity among members of social groups. The literature discusses three types of Social Capital. Bonding Social Capital is common in close-knit social networks that are characterized by the homogeneity of the members of the network and may ensure intense social support during times of stress, crisis, or illness. Bonding Social Capital is based on mutual trust and cooperation among the members of the network, and is reinforced by the common history of the members and their behavior over time (Putnam, 2000; Warren, Thompson, & Saegert, 2001).

Bridging Social Capital can be found in dispersed networks that are characterized by the heterogeneity of the members of the network and by relatively weak social relationships. Because of the diversity of the group's members, the resources available to them are more varied than those associated with Bonding Social Capital (Brisson & Usher, 2005).

Linking Social Capital refers to the mutual relationships and trust that exist outside of any local social networks, especially between different groups that have no natural connection, and it is based on a shared experience of coping with challenges (Warren et al., 2001).

The present study focused on the various aspects of Social Capital, with Bonding Social Capital representing a close relationship within a homogeneous community of people, Bridging Social Capital representing close relationships within a heterogeneous population with an attempt to connect groups of people, and Linking Social Capital representing relationships that link different communities on the levels of resources and authorities, and in particular, their accessibility in terms of shaping public policy and their ability to influence it (De Silva, McKenzie, Harpham, & Huttly, 2005).

Social Capital includes the norms, understandings, rules, expectations, and the knowledge shared by the members of the community regarding the interaction patterns that individuals and the group bring into action (Fwin & Lev Ari, 2003). Studies on Social Capital differ in their focus on the micro level (the individual) or on the macro level (the community/society). At the micro level, Social Capital is defined as a resource or a set of resources available.

> When asked for the meaning of social capital, one of the fathers interviewed stated: "to be surrounded by many people with whom I have mutual relations, people who care about the community's, not just their, well being. For me, social capital is the nature of relations among community or family members, which are being expressed by expanding the relations and maintaining their quality. I mean that people within the community should work together to promote mutual goals based on shared values and trust among community members, and also between them and the government authorities."
>
> One of the mothers commented that for her, quality of life is:
>
> "In my opinion, this means strong association under an ultimate goal that benefits one and all. I believe that association equals power, and in fact power that causes one to feel

> supported and backed up has a positive impact on maintaining the core values of Man: morality, dignity and reciprocity within the Bedouin community."

Little research has been conducted regarding the specific characteristics of Social Capital and the Quality of Life of parents of children with ASD in general, with even less conducted regarding parents in the Middle East, and less than that regarding fathers.

The present research intends to address this gap in the literature for the first time. Specifically, the objectives of the study were to examine the following questions:

1. Are there any differences between the Social Capital of Bedouin fathers and mothers of children with ASD?
2. Are there any connections between the components of Social Capital and those of Quality of Life, and are there any differences in such connections between the two groups (fathers and mothers)?

Methods

Participants and Procedures

A total of 200 Bedouin parents of children with ASD participated in the study: 100 fathers and 100 mothers from the Negev (see Table 16.1). For this study, the respondents had to meet the following inclusion criteria: a Permanent Resident of Israel aged 25 years, a member of the Bedouin communities, capable of providing consent, literate in Arabic, and have a child who was enrolled in an ASD-oriented school within the Bedouin community. Children in Israel are referred to special education schools after completing tests and receiving a diagnosis of ASD. The criteria were established by the Diagnostic and Statistical Manual of Mental Disorders, fourth Edition (American Psychiatric Association, 2013). The parents

Table 16.1 Socio-demographic and clinical characteristics—a comparison between Bedouin fathers and mothers of children with ASD

Characteristics	Values	Fathers $N = 100$ (%)	Mothers $N = 100$ (%)	χ^2
Age	25–35	54.8	46.6	9.03*
	36–46	45.2	34.5	
	47+	1	19	
Education	Secondary	16.7	51.7	12.93*
	Tertiary	19	31	
	Academic	64.3	17.2	
Source of income	Not working	31	51.7	2.68
	Working part-time	26.2	31	
	Working full-time	42.9	17.1	

$*p < 0.05$

were contacted through the students' homeroom teachers. Interested parents were invited to participate in the research.

Ethical approval was obtained from the Review Board of the University of Haifa, Israel, prior to the start of the study, and written informed consent was obtained from all respondents. Table 16.1 presents the socio-demographic background of the parents who participated in the study.

Table 16.1 shows similarities between the two groups, with most participants in both groups ranging in age from 25 to 45 years old. Significant differences were found in education, with over half of the fathers (64%) having an academic education compared to 17% of the mothers. For the participants' sources of income, a difference was found among the participants. With regard to the fathers, 69% of them were working part- or full-time, compared to 49% of the Bedouin participants.

Study Instruments

Demographic Background Questionnaire The following data was examined: the parent's age, education, and source of income.

Social Capital Questionnaire The questionnaire was developed by Bullen and Onyx (2000), and found to have a reliability of $\alpha = 0.89$. Six items were omitted from the questionnaire due to cultural incompatibility (e.g., items that examine Social Capital related to employment, since some of the fathers were not employed). The reliability of the questionnaire in this study is Bonding Social Capital $\alpha = 0.88$, Bridging Social Capital $\alpha = 0.94$, and Linking Social Capital $\alpha = 0.92$. The questionnaire was translated separately into Hebrew and Arabic and examined through a re-translation. The items in the questionnaire were scored on a scale of 1–5, and the total score was obtained by calculating the average score of all the items.

Quality of Life Questionnaire A Shortened World Health Organization Quality of Life questionnaire was used (WHOQOL-100) (World Health Organization, 1996). The questionnaire was translated separately into Hebrew and Arabic, and examined through a re-translation. The reliability of the questionnaire in this study is Physical Quality of Life $\alpha = 0.91$, Mental Quality of Life $\alpha = 0.88$, and Environmental Quality of Life $\alpha = 0.89$. The items in the questionnaire were scored on a scale of 1–5.

Data Analysis

All the questionnaires were analyzed with the SPSS program. The frequencies, means, and standard deviations for both populations were calculated. In addition, a MANCOVA analysis was performed to examine the differences between the two research populations. The Pearson test was also used to calculate the correlations between Social Capital and Quality of Life for both groups.

Results

A MANCOVA analysis was conducted to determine whether there were any differences in the components of Social Capital (Bonding, Bridging, and Linking) between Bedouin fathers and mothers of children with ASD. Table 16.2 presents the comparisons between the two groups.

Table 16.2 shows that fathers of children with ASD have more Bridging Social Capital and Linking Social Capital than do Bedouin mothers of children with ASD; however, these differences were not statistically significant. Additionally, no differences were found between the two groups for Bonding Social Capital.

A MANOVA analysis was conducted to examine whether any differences existed for the Quality of Life components (physical, mental, and environmental) between Bedouin mothers and fathers of children with ASD. Table 16.3 presents the comparisons between the two groups.

Table 16.3 shows that fathers of children with ASD have a higher Physical Quality of Life, Mental Quality of Life, and Environmental Quality of Life than do Bedouin mothers of children with ASD; however, these differences were not statistically significant.

Pearson correlations were calculated to examine the relationships between Social Capital and Quality of Life. A comparison was made between Bedouin fathers and

Table 16.2 Means and standard deviations of the components of Social Capital—a comparison of Bedouin Fathers and Mothers of children with ASD

	Mothers (N = 100)		Fathers (N = 100)			
	M	SD	*M*	SD	*F* (1.197)	μ^2
Bonding Social Capital	3.358	0.824	3.205	0.824	1.410	0.006
Bridging Social Capital	3.011	0.771	4.327	1.010	1.80	0.247
Linking Social Capital	1.802	0.846	3.082	1.021	4.13	0.135

Table 16.3 Means and standard deviations of the components of Quality of Life—a comparison of Bedouin mothers and fathers of children with ASD

	Fathers (N = 100)		Mothers (N = 100)			
	M	SD	*M*	SD	*F* (1.198)	μ^2
Physical Quality of Life	3.220	0.534	3.300	0.325	4.13	0.107
Mental Quality of Life	3.078	0.505	3.441	0.401	2.35	0.083
Environmental Quality of Life	2.755	0.537	3.112	0.556	4.66	0.058

Table 16.4 Correlations between Social Capital and Quality of Life—a comparison of Bedouin fathers and mothers of children with ASD

	Bonding Social Capital	Bridging Social Capital	Linking Social Capital	Physical QoL	Mental QoL	Overall Sense of Coherence	Hope
Fathers						−0.382***	−0.272**
Mothers							
Fathers	0.142*					−0.547***	−0.402***
Mothers	0.012						
Fathers	0.154	0.242**				−0.515***	−0.287**
Mothers	−0.012**	0.515**					
Fathers	0.332**	0.355**	0.257**			−0.571***	−0.370***
Mothers	0.141*	0.110*	0.104				
Fathers	0.376**	0.241**	0.174**	0.623**		0.908***	0.551***
Mothers	0.135*	0.020	−0.077	0.381**			
Fathers	0.718**	0.301**	0.347**	0.501**	0.433**	0.928***	0.491***
Mothers	0.758**	0.134	0.133	0.275**	0.206**		

$*p < 0.05$, $**p < 0.01$, $***p < 0.001$
QoL Quality of Life

mothers of children with ASD. Table 16.4 presents the correlations that were found between the two groups.

Table 16.4 shows that in general, there are stronger connections between the Social Capital components and the Quality of Life components among the Bedouin fathers compared to the mothers of children with ASD. Regarding Bonding Social Capital, it was found that among the fathers of children with ASD, there are stronger connections between Bonding Social Capital and Physical Quality of Life and Mental Quality of Life compared to the mothers. However, it was found that the relationship between Bonding Social Capital and Environmental Quality of Life is higher among fathers of children with ASD.

Regarding Bridging Social Capital, it was found that among the fathers of children with ASD, there are stronger connections between Bridging Social Capital and Physical Quality of Life, Mental Quality of Life, and Environmental Quality of Life compared to mothers.

Discussion

The present study examined the factors affecting the Quality of Life of Bedouin parents of children with ASD. It was designed to examine the relationships among Bonding, Bridging, and Linking Social Capital and the Quality of Life of parents of children with ASD, while comparing fathers with mothers. This relationship has not yet been studied in Bedouin parents of children with ASD. In addition, the differences between the two groups have never been investigated.

Differences in Bridging and Linking Social Capital Between Bedouin Fathers and Mothers of Children with ASD

The findings of the study showed that fathers of children with ASD reported higher levels of Bridging and Linking Social Capital; however, these differences were not statistically significant. No differences between the two research groups for Bonding Social Capital were detected. These findings reveal that fathers are more connected by heterogeneous social networks, meaning that they benefit from more varied resources of greater availability, mainly because of the great diversity that exists among members of their social network (Putnam, 2000).

Therefore, they can make better use of the social resources available from each of these factors. Fathers also have higher levels of Linking Social Capital; that is, they have more relationships with people and groups in positions of power, especially those who have control over resources for economic and social development (Healy & Hampshire, 2002).

> In relation to this finding, the following statements of one of the interviewed fathers could be presented, who said: "my relations with some officials in the area and region are very strong, for example, my relations with the head of the council, department heads within the council, school principals, etc. Using my relation we hold discussions, meetings and personal conversations and make decisions. I do all this for me and my family due to the gender-related sensitivity in our culture."

Fathers also benefit from connections outside their own local social network, specifically with groups that have no natural connection with their group, based on shared challenges (Warren, Thompson, & Saegert, 2001).

> In relation to this finding, the following statements of one of the interviewed fathers could be presented, who said: "without any doubt, my relations with various types of people reach outside the realm of my immediate environment. Thus, for example, in the framework of my work and studies I meet various friends and establish relations in various aspects, such as friendships, business, recreational activities, etc. Also, these relations teach me a lot about myself and the other person."

Therefore, it appears that fathers of children with ASD are characterized by having a more extensive social network that extends beyond the narrow local social network. These findings may be explained by the clear division of roles between men and women in the Bedouin community. Bedouin society is a patriarchal, collectivist society, in which the status of men is higher than that of women (Dwairy, 2004). Based on these values, women in the Bedouin society have no role in the public sphere and don't have connections outside their own local social network. These findings may also be explained by the higher level of education in the fathers' group. Education appears to allow fathers more significant human capital as a basis for social support from more distant social circles that are not necessarily physically accessible or available.

> In relation to this finding, the following statements of one of the interviewees could be presented, who said: "having a master's degree allows me to serve in various wonderful social, educational and organizational positions that contribute a lot to me and my family.

> In fact, such positions spread new horizons before me without religious or geographical dependence due to the fact I am a male, which allows me this freedom of choice."

Regarding Bonding Social Capital, the similarity between the fathers and the mothers stems from the notion that Bonding Social Capital reflects the nature of a basic relationship that provides social support to the parent in his/her immediate environment, and therefore others appear to develop social, cultural, and economic mechanisms designed to preserve their Bonding Social Capital. Within the framework of the Bonding Social Capital, the father is assured of intensive support in situations of distress, where there is mutual trust and cooperation between the members of the network.

> In relation to this finding, the following statements of one of the interviewed fathers could be presented: "my regular relations, such as general arrangements, house design, spending time with the family, celebrations, household, etc., within the family and the immediate surroundings allow freedom of expression as nearly equal as in internal matters, such as between men and women, but in external matters the situation is different and more complex in terms of gender and culture."

The Bedouin society is characterized by collective characteristics; that is, it perceives social commitment and social cohesion to be of higher value than individualism and self-realization (Al-Haj, 1987). As part of this harmony with the social environment, there is also a preference for the preservation of family ties and collectivist behavior over individualistic orientations and behavior (Hag-Yaha, 1994). It appears that within the Bedouin society, there are collectivist cultural mechanisms that preserve the fathers' Bonding Social Capital.

This explanation is supported by previous research, which found that fathers of children with ASD who belong to the Bedouin community are accompanied by comprehensive and active support networks (Manor-Binyamini, 2019). It may be possible that the fathers also have Bonding Social Capital, similar to the Bedouin mothers, in that they form their own systems of Bonding capital. Fathers also have mechanisms by which they preserve the social cohesion of the groups that they are members of, but with the fathers, the emphasis is on extra-familial group structures, such as social activities and other types of social frameworks. It appears that despite the different means by which Bonding Social Capital is maintained in both groups, their levels of Bonding Social Capital are similar. The findings of the study show that the fathers of children with ASD benefit from more types of Social Capital than do the Bedouin mothers.

Differences in Quality of Life Between Bedouin Fathers and Mothers of Children with ASD

The findings of the study show that fathers of children with ASD reported a higher Quality of Life than mothers of children with ASD across all Quality of Life components: physical, mental, and environmental. However, these differences were not statistically significant. This finding can be explained by the fact that fathers in the Bedouin community have more access to support services, which contribute to a higher Quality of Life. All of these factors increase their sense of autonomy and control, and therefore they feel that their daily functioning is better in terms of physical, mental, and environmental aspects. Bedouin mothers, on the other hand, have relatively lower human capital (in terms of education or economic abilities) and therefore they have fewer opportunities to develop a better Quality of Life.

> In relation to this finding, the following statements of one of the interviewed fathers could be presented, who said: "if I was given the opportunity to study and work I would have achieved much more than I do today. But unfortunately, my parent decided for me that I would terminate studies in fifth grade to help my mother in house chores and attend the great needs of my siblings. In my dreams I planned a totally different lifestyle… I have already accepted the current situation because I passed the point where I should have made a significant change long ago."

In addition, it is possible that this finding can be explained from a different point of view; for example, the explicit link that *Bedouin* mothers of children with autism make between structural exclusion and the exclusion that comes with being the mother of a child suffering from an illness, which carries with it a significant stigma. Motherhood for a child with autism in the Bedouin community has been described as increasing the mothers' experience of exclusion, and further intensifying the tyranny of the existing structure, as well as the mothers' agentic ability to resist it (Manor-Binyamini & Shoshana, 2018).

Relationships Between Social Capital and Quality of Life Across the Entire Sample

The findings of the study show that in general, there are stronger ties between Social Capital components and Quality of Life components among Bedouin fathers compared with mothers of children with ASD. With regard to Bonding Social Capital, it was found that among Bedouin fathers of children with ASD, there are stronger relationships between Bonding Social Capital and Physical Quality of Life and Mental Quality of Life compared to mothers. This finding may be explained by the fact that Bonding Social Capital provides the basis upon which people living in poor communities can develop their capacities to cope with the problems associated with living in poverty, rebuild their communities, and gain greater control over their lives (Putnam, 2000; Warren et al., 2001). At the same time, the relationship between Bonding Social Capital and Environmental Quality of Life was found to be higher for fathers of children with ASD.

With regard to Bridging Social Capital, the findings of the study show that among fathers of children with ASD, there are stronger relationships between Bridging Social Capital and Physical Quality of Life, Mental Quality of Life, and Environmental Quality of Life compared to mothers of children with ASD.

In the present study, positive relationships were found between Social Capital components and Quality of Life components. These findings reinforce previous research findings that show that social relationships can reduce the impact of these life events during the normal course of a person's life, and thereby maximize his or her Quality of Life (McMichael & Manderson, 2004). For example, Taylor, Chatters, Hardison, and Riley (2001) examined the relationship between informal support networks and Quality of Life. These researchers found that the strongest relationships exist between family relationships and levels of happiness, as well as levels of life satisfaction. The study also found that the more friends people reported having, with whom they could share their problems, the higher their level of life satisfaction. These findings have also been replicated in other studies, such as the study by Requena (2003). These types of findings, as well as the findings of the present study, indicate the great importance of Social Capital in the maintenance of happiness, satisfaction, and a higher level of physical, mental, and environmental Quality of Life.

Differences Between Social Capital and Quality of Life: A Comparison Between Bedouin Fathers and Mothers of Children with ASD

The findings of the study show that in general, there are stronger ties between Social Capital components and Quality of Life components among Bedouin fathers compared with mothers of children with ASD. With regard to Bonding Social Capital, it was found that among Bedouin fathers of children with ASD, there are stronger relationships between Bonding Social Capital and Physical Quality of Life as well as Mental Quality of Life compared to mothers. However, it was found that the relationship between Bonding Social Capital and Environmental Quality of Life is higher among fathers of children with ASD. With regard to Bridging Social Capital, the findings of the study show that among Bedouin fathers of children with ASD, there are stronger relationships among Bridging Social Capital, Physical Quality of Life, Mental Quality of Life, and Environmental Quality of Life compared to mothers of children with ASD.

These differences may be explained by the fact that the Bedouin mothers have historically grown up under conditions of distress relative to the fathers; the economic and social resources of the Bedouin population are lower (Manor-Binyamini, 2019). In the absence of other resources, the Quality of Life of this population relies mainly on the social relationships that exist within the community. This explanation is consistent with the findings of other studies that showed that strong relationships between Social Capital and Quality of Life were found among populations living in conditions of crisis and distress (McMichael & Manderson, 2004; Mehmet & Mehmet, 2005). These findings were also replicated among populations of women who grew up in refugee camps (Boateng, 2010).

Therefore, it appears that among fathers of children with ASD, when the level of internal social cohesion (Bonding Social Capital) and the level of external social support (Bridging Social Capital) are higher, Quality of Life increases because these fathers rely heavily on social support as a resource for coping with their child with ASD. This finding reinforces the findings of a previous study that indicated the importance of social support within the Bedouin community (Manor-Binyamini, 2019). This type of support may be particularly important, given the lack of material resources in Bedouin society.

In contrast, among mothers of children with ASD, even though significant relationships were found between Social Capital and Quality of Life, these relationships are weaker, indicating that mothers of children with ASD rely less on social support in order to improve or enhance their Quality of Life. On the other hand, it is possible that fathers have other resources that are not based on social relationships but are based on more objective means, including economic support and human capital (such as education).

It is important to emphasize that the relationship between Bonding Social Capital and Environmental Quality of Life was found to be higher among fathers. This finding may be explained by the fact that among Bedouin fathers of children with ASD, when internal social relationships are closer, they may feel that they have more control over their immediate environment, and therefore their Quality of Life may be higher in this context.

Recommendations

All the results so far have indicated the importance of culturally sensitive support services (Strier, 2009), and a number of significant recommendations arise which could be practically applicable. First, it is necessary to invest resources in increasing the Social Capital and Quality of Life of fathers and mothers of children with ASD living in the Bedouin community. It is important that support services are consulted in planning intervention and empowerment programs for these parents. In any intervention program, it is recommended to invest mainly in increasing the parents' Bridging and Linking types of Social Capital because these components were identified as showing the greatest gap between the two groups of parents of children with ASD. It appears that investment in these components may lead to an increase in the Physical Quality of Life, Mental Quality of Life, and Environmental Quality of Life of Bedouin parents of children with ASD, and any such program should also include adaptation to the social environment in which the parents live.

Conclusion

This is a rare study on the Quality of Life and Social Capital of parents in Bedouin society, which is a non-Western community that reflects a traditional lifestyle in transition. Our results suggest the need to invest resources in increasing Social

Capital, as it is a contributing factor for the improvement of Quality of Life, especially among mothers of children with ASD. This population is at risk of harm with regard to the different components of Social Capital, especially Bridging and Linking Social Capital, compared to fathers of children with ASD.

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Chapter 17
Culture and Psychopathology: Contributions of the Philosophical and Clinic Phenomenologies

Virginia Moreira, Lucas Bloc, and Thabata Castelo Branco Telles

Concern about culture, within the psychopathology field, is not a new task in contemporary research (Kirmayer, 2006a, 2006b; López & Guarnaccia, 2000). Historically, research in this area became necessary, to the extent that globalization processes began to intensify. The motivations that supported these investigations seemed to revolve around the following question: how do we understand the disease process (or better yet: how to identify if this process is occurring) in others, with life experiences so different from ours, contemplating a different cultural context? This question has been studied in different ways, pointing to several paths of understanding.

One of the problematic routes of this issue focuses on the field of phenomenology. Phenomenology is understood herein as the development of a component that is based on the philosophical perspective created by Husserl, and continued by authors such as Merleau-Ponty, Heidegger, and Sartre, among others. Within the clinic, psychiatrists such as Binswanger, Minkowski, and Tatossian, to name a few,

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have appropriated philosophical phenomenology as a means of inspiration to build a clinical perspective and a proposal for psychopathology (Moreira, 2009; Tatossian, Moreira, Chamond, & Collectif, 2016). Thus, the ballast of phenomenology extends and enables discussions, not only in the field of philosophy, but also in terms of the clinic and psychopathology, which are the focus of this chapter.

Increasingly, researchers (Csordas, 1990, 1993, 2008; Felder & Robbins, 2011; Sam & Moreira, 2012; Telles & Moreira, 2014) have proposed to discuss the issue of cultural psychopathology from this perspective. Among the many phenomenologists that could be remembered in this endeavor, we cite herein the phenomenology of Maurice Merleau-Ponty, French philosopher, who developed his works through constant reflections on the relationship between man and the world, inevitably passing through the issue of culture.

Still with regard to the discussions influenced by phenomenology, now in the clinical context, we emphasize the movement of phenomenological psychopathology that, from 1920, undertakes a look at psychopathology which focuses on lived experience and its meanings. Representative of contemporary phenomenological psychopathology, Arthur Tatossian, a French psychiatrist of Armenian origin, contributed significantly to discussions involving culture and psychopathology from a phenomenological perspective. He recognizes the important role of culture in disease processes and the fecundity of a phenomenological look of culture in psychopathology—the axis of this chapter.

This paper aims to discuss the relationship between psychopathology and culture through the lenses of philosophical phenomenology, by Maurice Merleau-Ponty, and clinical phenomenology, by Arthur Tatossian. Therefore, it is divided into three parts, as follows: (1) a brief presentation of the phenomenology of Merleau-Ponty, focusing on his discussions of man, the world, and culture; (2) an introduction to the phenomenological psychopathology of Tatossian, especially regarding his developments dedicated to the relationship between culture and illness; (3) a brief discussion of case studies in cultural psychopathology, along with a critical reflection on how to think about the contribution of these two phenomenologists to current research in the area.

The Philosophical Phenomenology of Merleau-Ponty and the Ambiguity of the Relationship Between Nature and Culture

The phenomenology of Merleau-Ponty is marked by an ambiguous perspective, proposing a radical overcoming of dualities such as indoor–outdoor, subjectivism–objectivism, and natural–cultural (Matthews, 2010). This question is important for us to understand the concept of man in Merleau-Ponty, as well as the conceptions of psychopathology and culture. Now, if it were not possible to understand what is exclusively natural or cultural, we begin from the idea that thinking man, and his disease processes, necessarily imply that we contemplate cultural issues.

In this sense, to investigate and intervene in the field of psychopathology, under a phenomenological bias, requires the understanding that biological and cultural issues are intertwined with each other. This discussion is not new in the field of cultural psychopathology,[1] but it is here that it becomes necessary to define what is the specific design of phenomenology—philosophical and clinical—in this harvest.

Regarding the specificity of the Merleau-Ponty discussions, the philosopher, in *The Phenomenology of Perception* (1945/2000), presents the notion of man as a situation constructed mutually with a cultural world. Thus, the importance of understanding man beyond a physical and natural order is highlighted. In *The primacy of perception and its philosophical consequences*, Merleau-Ponty (1947/2007) writes that "but in reality the ideas which we give our assent are valuable only for a period of our lives or for a period in the history of culture" (p. 89). This quote points to the understanding that man in his relationship with culture implies in assuming that this is a dynamic operation. In the field of psychopathology, what is considered a disease today may be a part of a common organization mode tomorrow, and vice versa. In other words, in addition to understanding man from his physical character nuances, both natural and cultural, it is necessary to understand that the way these nuances interact are not given statically, but in mutual relationship with political, historical, social, and ideological issues, among others (Moreira & Sloan, 2002), which puts us in a constant state of questioning, with respect to the features previously attributed to illness modes, without considering this dynamism.

This perspective is in line with recent discussions about how culture is contemplated in diagnostic manuals, which mostly comprise psychopathology as a result of a number of factors that would not be within what is considered normal. However, these normal parameters are graded in a Western culture, among other aspects that could come to mind. In other words, that is, one is considered ill that is not within the parameters of normality of a given society, and not from the lived experience of the patient. It is in this sense that the Tatossian discussions contribute a great deal, as we shall see in the following pages.

Merleau-Ponty (1969/2010) discusses the impossibility of understanding culture without considering history, speech, and gestures. One might think that there might be two equal gestures, for example, by ignoring the condition in which they occur, since history, culture, and language are interconnected. In an ambiguous perspective, the expression is never purely the same, but not purely different because

> With regard to this particular gesture that is the word, the solution consists in recognizing that in the dialogue experience, the word of the others touches our meanings, and our word, as attesting the answers, touches their meanings, invades each other, since we belong to the same cultural world and the same language, and my acts of expression and those of the other emerge from the same institution. (Merleau-Ponty, 1969/2010, p. 1533)

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[1] Refer to Kleinman (1988a, 1988b, 1997) and Morris (1998).

It is in this intersubjective aspect that, despite the differences between our experience and that of the others—mostly on a cultural level—a common understanding is possible. In other words, language is closely related to culture, which allows for different understandings of human expression, but also the existence of an institution, as a common background, that enables the structural understanding of a certain experience, which is described. The Merleau-Ponty notion of institution does not reflect a static character but is characterized as a movement, action, capacity for the new (Chauí, n.d.). It is in this context that it is appropriate to think of expression and culture, in the phenomenology of Merleau-Ponty, as belonging to the same soil, but that is dynamic, always in motion. Each person may have different nuances, even with respect to the same common base.

In this context, the description of symptoms or experiences reported by the patient will be related to their lived experience and, therefore, words and gestures that are able for him/her to use at that time will be in fact used. However, since there is an intersubjective relationship, it is possible for the caregiver (whether a doctor, psychologist, etc.) to have an understanding of what is being said, because there is a common background that allows for this dialogue to happen. This is observable, working in several different inter-human relations.

In the words of Merleau-Ponty (2001/2006), "culture can be defined as the set of attitudes tacitly recommended by society or by different groups in which we live, attitudes that are inscribed in the material order of our civilization" (Merleau-Ponty, 2001/2006, p. 377). This quote is a rare moment in which Merleau-Ponty, throughout his works, directly defines the concept of culture. Although we realize the conceptual definition, we can also read the need to understand it in motion, linked to *multiple contours* (Moreira, 2009), such as social and personal factors, among others. In addition, in the same work, Merleau-Ponty says that "between the psychic life and the collective or social life there is a mediation, a means: it is culture" (Merleau-Ponty, 2001/2006, p. 378). We can understand the notion of culture while allowing for the ambiguous relationship between man and world, psychic and social life, inside and outside.

Merleau-Ponty (1956/2000) considers geographical, social, political, and economic conditions in relation to culture. He questions the possibility of considering autonomy, for example. The phenomenologist regains his sense of engagement and considers that we have a certain autonomy, since we conduct ourselves ambiguously in the making of the world and, therefore, with regard to the other and to culture. This engagement perspective differs from the notion of man as totally autonomous, which would conduct his/her decisions based only on him/herself, without considering the weight of culture and the other in his/her choices.

These discussions do not stop us from thinking about the promotion of autonomy; when we refer to mental health, however, a critical eye is needed, through the concept of engagement. Merleau-Ponty treats the way we situate ourselves in the world and problematizes that we are nothing but 'can-bes', conceptualizing the notion of engagement: "A sane conception of engagement seems to be one in which autonomy is not separate from relationships with others" (Merleau-Ponty, 1956/2000, p. 189).

In this perspective, we can realize the lack of pure autonomy or freedom, since choices are always tied to culture and to others with whom we live (Moreira & Telles, 2016). It is in this sense that we can think with a more critical look at cultural psychopathology.

We remember that Merleau-Ponty emphasizes the importance of understanding man in the intertwining of culture—nature, stating that:

> The distinction of the two plans (natural and cultural) is, in fact abstract: everything is cultural in us (our Lebenswelt is 'subjective') (our perception is cultural-historical) and everything is natural in us (even the cultural rests on the polymorphism of the wild Being) (Merleau-Ponty, 1964/2007, p. 229).

Here, Merleau-Ponty (1964/2007) explains that only ambiguously can we understand the relationship between man and culture, where both are mutually constituted. Thinking the natural is to think of what is culturally constituted and vice versa, and only then can we understand the notion of culture in Merleau-Ponty (Weiss, 2008). The Merleau-Ponty phenomenology allows us to contemplate, beyond the ambiguous interweaving of nature and culture, the constitution of man and the contingencies that surround him, since he is always in a conditioned freedom incarnate in situation. The subject exists only in his/her mutual constitution with each other and with the world, structured in language, on a culturally inherited basis. Nature and culture, man and the world, are ambiguous relationships, situated bodily, continuously expressed in an always conditioned and engaged freedom.

But after all, what does it mean when we refer to the field of cultural psychopathology? In short, these discussions seem to point to the understanding that not only continuing the development of research that emphasizes the links between culture and nature in the field of psychopathology that phenomenology rescues the understanding that this relationship is constitutive of man and is also understood ambiguously, making it impossible to think of nature and culture separately, since it also requires a committed way of thinking about the issue of autonomy.

Phenomenological Psychopathology and Culture: The Contribution of the Clinical Phenomenology of Tatossian

The theme of culture, in its relationship to psychopathology, can be considered a central theme in the clinical phenomenology of Arthur Tatossian. With four specific texts on the subject and a constant reference to the culture theme in other texts on phenomenological psychopathology, Tatossian undertakes a critical perspective that finds in phenomenology a fruitful source, able to avoid the constant determinisms, dichotomies, and excessive oversimplification that the discussion about culture in psychopathology assumes constantly. Culture cannot be limited to one way of relativizing the notions of normal and pathological and justifying the development of psychiatry for each culture, because it is, in itself, able to provide clues for the understanding of the different ways of illness, necessarily beholding the world in which it is inserted. So, considering culture does not mean either the rejection of the consideration of subjectivity or its restriction, but does imply in thinking of it in its interweaving with the culture in which we operate.

Tatossian (2001a, 2001b) considers that, since the eighteenth century, the relationship between psychiatry and culture is confrontational and of opposition, defending the approach to this issue in its practical and theoretical character. In practice, it is urgent that the patient's understanding imply a "cultural neutrality," taking culture as part of his/her experience, and also that he/she consider the subcultures within the same culture, an idea supported by other contemporary authors (Kirmayer, Rousseau, Jarvis, & Guzder, 2008). In theory, he differentiates classical transcultural psychiatry, where there is the prevailing idea that psychiatric nosologies are universal and culture would be an external modifier from recent transcultural psychiatry, which would threaten the validity of research conducted with a more classical approach. Tatossian alerts us to the risk of cultural relativism in psychiatry, in general, and recognizes the need to seek the authentic psychopathological experience that reaches both the singular and the universal, by recognizing the mutual constitution between man and the world (Bloc & Moreira, 2016).

Therefore, it is necessary to go beyond the symptom, aiming at the phenomenon as a global way of being of the subject that necessarily includes the meanings of behaviors and lived experience (Tatossian, 1986). Thus, the direction of the symptom from the phenomenon is searched for, in that the symptom of what is the index of that which is not shown, that is hidden—the phenomenon. Thus, phenomenology aims precisely to reveal this phenomenon, which is also cultural. To think based only on symptoms would consider only what is observable, reducing the psychiatric clinic to facts. However, to consider the lived experience and the understanding of psychopathology, as a phenomenon, implies contemplating the cultural horizon, which is a constituent of the meaning of lived experience (Tatossian, 1981, 2001a, 2001b).

When positioning culture as constitutive of the subject, Tatossian recognizes the importance of defining what would be normal or pathological. This is about going beyond the deviation concept, since a "behavior is not pathological by its low frequency or social maladjustment, but its significance and, more precisely, its individual significance, in other words, more by living experience than structure" (Tatossian, 1981, p. 341). Thus, he claims "the only acceptable pathological definition is undoubtedly that of Blankenburg, who argues that a behavior or experience are pathological when the-subject-cannot-present this behavior, or cannot-submit-to-this-experience" (Tatossian, 2001b, p. 144). That is, it is about understanding a psychopathological process when there is a stiffening in the relationship between man and the world, where there is only one way of being in the world. This definition includes cultural aspects, because it is not a moral or normalizing concept, in that psychopathology would be seen as something out of the rule, disregarding cultural issues in this pattern, and has great emphasis on lived experience as a possibility and movement that, in this case, would be stagnant and restricted (Bloc & Moreira, 2016). This bias has as axis in the issue of freedom to consider the disease as the inability to make choices or even the consideration that such experience is the only possibility of the subject, characterizing, thus, a lived experience as psychopathological.

The distancing of the symptom as a priority and superficial parameter, far from what is considered more important, the phenomenon, is seen by Tatossian as an initial step toward what he calls a psychiatry and psychopathology metaculture. This is a hermeneutic movement that may have as basis, among other possibilities, phenomenology. With an eminently phenomenological orientation, Tatossian (1994) recognizes and even emphasizes the potential of phenomenology to the understanding of culture, conceiving of it as a method that, as such, "forbids the separation of the subject and the object, the individual and the world, and, more specifically, the human world. The phenomenological lived experience inseparably connects external behavior and meaning" (Tatossian, 1981, p. 342). In addition, he further states that the "analyses of the lived time and space, corporeality and the world, in the phenomenological sense, are always implicitly cultural analyses, because culture is, *a priori*, present and because subjectivity is always intersubjectivity and historicity, or, in other words, culturality" (p. 342).

Tatossian (1981, 1994) uses the term culturality to emphasize this rooting and traversal of man, by culture, in its historical immersion. This is a culturality that constitutes us and at the same time we also contribute to its institution. Furthermore, we understand that this term seeks to establish a movement in the understanding of culture that should not be seen as static, but as part of human existence and, as such, is always in (re)construction.

It can be said that to phenomenologically understand culture means, for Tatossian, to incorporate the description and analysis of the *Lebenswelt* (world lived or the world of life) in its everyday dimension, as lived culture (Bloc & Moreira, 2016). In other words, to seek "to understand the human being in its original sociality and its mandatory culturality" (Tatossian, 1981, p. 343), which would be the condition for a metacultural psychiatry. It is common to find, in his writings, the emphasis on the need for constant contact with the subject and his psychopathology, stepping into his lived world and seeking to approach their experience as much as possible; unthinkable immersion without the consideration of culture as constitutive, of both the clinical itself and the patient, who lives the sickening in such a manner.

With an ambiguous cultural lens in psychopathology (Bloc & Moreira, 2016), Tatossian denotes the interlacing, in the same phenomenon, of biological and cultural aspects. He recognizes the existence of a similar experience, even if patients are part of different cultures. It is a common experience, which is essential, for example, in the categorization of certain psychopathology frames. However, he also identifies that, with cultural variations, forms of expression and their meanings are potentially variable according to culture, and this aspect is also of fundamental importance. So, one can observe an ambiguous understanding toward both conceiving an intersubjective dimension traversed by a lived culturality and in developing a psychopathology model able to "escape" the cultural influence, presenting in its common dimension as a phenomenon present in different cultures, which could also be seen above, in the philosophical phenomenology of Merleau-Ponty.

By proposing, under a phenomenological bias, the understanding of many psychopathological conditions such as, for example, schizophrenia and depression, Tatossian seeks to return to experience, focusing on the possibility of these experiences. A discussion about the time lived in depression, for example, seeks to understand how the changes of the lived time can create conditions for a stagnant time experience. This lens seeks to go beyond the cultural dimension, considering that there is a way of being depressed, which is common to patients who live this experience. However, culture will always be taken into account, inasmuch as the insertion of the subject in the world also passes through the constitution ways and, above all, the meaning of the experiences.

This understanding makes us emphasize the importance of cross-cultural studies. On the one hand, an experience of illness, as in the cited case of depression, has common points that allow us to name it as such. But, on the other, recognition of the different meanings produced is essential, according to the culture where it is inserted, in addition to the possible impact of culture itself in the production of suffering and its consequent illness. It is important to also note that contemporary tools, such as the internet, have profoundly changed the contact modes and access to different aspects that were unique, and even characteristic, of certain cultures.

Ambiguity, a common dimension of the phenomenology of Merleau-Ponty and of the phenomenological psychopathology of Tatossian, is an indispensable mechanism to break the usual dichotomies when we enter the field of psychopathology. Individual and society, nature and culture, cannot be classified as opposite poles. It is about conceiving of our rootedness in the world and the illness modes of a subject, with its particular aspects, but which are marked by their worldliness, by their culturality, as Tatossian entails.

Current and Future Prospects of Cultural Psychopathology from the Phenomenology of Merleau-Ponty and Tatossian

As examples of cross-cultural research in Brazil, we highlight two investigations: the first attempted to explore the theme of schizophrenia in Brazil and Chile (Moreira & Boris, 2006), while the second was held to study the depression phenomenon in Brazil, Chile, and the USA (Moreira, 2007). They both used the phenomenological perspective, inspired by the philosophy of Merleau-Ponty, as a methodological tool.

With regard to the research on schizophrenia, 50 patients were interviewed in São Paulo and Santiago. The results found that in both countries "1. The schizophrenic experience is lived as an experience of oppression and lack of power; 2. The description of the experience made patient refers largely to the fact that they feel trapped in psychiatric hospitals; 3. Their description constantly refers to the fact that they are taking strong drugs; 4. Patients feel lonely and suffer because of the stigma of mental illness" (Moreira & Boris, 2006, p. 10). However, with specific regard to

Brazil, we see the strength of the religious issue, so there is mutual relationship between the spiritual and psychopathological components in the expression of the schizophrenia experience. With regard to Chile, there was a close collaboration with historical and political issues, some showing the relationship of this disease process with other issues—such as religion, in the case of Brazil.

As another example of a cross-cultural study, we present a survey conducted by Moreira (2007), about the meaning of the lived experience of depression in Brazil, Chile, and the USA. The authors interviewed 72 patients in Fortaleza, Santiago, and Boston. In this research, it is possible to observe that the forms of expression and their meanings can vary according to the cultural environment in which they manifest. However, with respect to the presented symptomatology aspects, no significant variation was observed.

Issues such as family, work, unemployment, loneliness, and stigma appear strongly in the respondent answers, although each of these topics are presented in line with the cultural processes of each country, which led to further studies (Moreira & Callou, 2006; Moreira & Telles, 2009). Specifically, it is emphasized that, in Brazil, urban violence and religiosity were prominent points. In the USA, racism and the need to be productive and in the labor market has emerged as a source of suffering, linked to lived depression and, in Chile, elements of the dictatorship the country lived in previous decades can be found. Thus, we conclude that, even if the symptoms are similarly present in different cultures, it is essential to consider the culture as constitutive pathway of the lived experience. It is about designing the subject's condition in the world, inserted in their culture as constitutive of the meanings of their experience.

After exposing these studies as an illustrative means of a phenomenological lens of culture in psychopathology, we consider that the significant contributions of Merleau-Ponty and Tatossian open perspectives for the development of this bias. Although there are peculiarities in their considerations, given that the former is in the field of philosophy, and the second, in the clinical field, we could observe convergences throughout this chapter that assert the constitutive nature of culture and its implication in the illness modes. Culture marks the subject's state of being in the world and, in a phenomenological perspective, allows us to envision the current and future discussions of cultural psychopathology.

Among the current perspectives, Moreira (2002), by understanding the lived experience in disease processes, recovers studies in cultural psychopathology and proposes a critical psychopathology. With the Merleau-Ponty lens, critical psychopathology suggests that man must be seen in a worldly way, seeking to overcome man-world, indoor–outdoor dichotomies.

This proposal includes a non-individualized notion of psychopathology, considering cultural, historical, social, ideological, biological, and political issues, among others, as constituents of psychopathology. This is not to relativize the notion of man, but to contemplate him in his different dimensions, necessarily, as present and intertwined. This attitude also collaborates for the refusal of a look overly focused, for example, on the biological or, on the other hand, purely relativistic.

Another major discussion held in the proposal by Moreira (2002) is a de-ideologizing understanding of psychopathological processes, understanding the ideology as a way to exert power over others. Tatossian emphasizes the importance of daily life, the constant contact with the patient and the recognition of their movement. It is necessary to recognize the interests involving these relationships and that the developed modes of care are also traversed by culture and power. If we currently live governed by a logic dedicated to the biological, for the use sometimes excessive of drugs, this bias follows interests that need to be recognized and deconstructed. However, it is important not to fall into too relativistic an understanding, so that there may be a specific attention for each illness mode.

To think critically of culture and psychopathology, an inherent dimension of a phenomenological method, is without doubt a fruitful way of deconstructing these political wards governed by our economic dynamics and the illusion of a quick cure, which should turn only to the subject who gets sick when, in fact, we may be living in a sick society. On the other hand, this process of construction cannot occur fully, because we believe that there is the possibility of a common background shared between illness experiences, which aids in the understanding and proper care of specific psychopathologies.

Further corroborating the understanding of the psychopathology of Tatossian (1981, 2001a, 2001b), Moreira (2009) considers that psychopathology can be identified when a stagnant existence is present, without the construction movement of this existence. Both in psychosis and neurosis, in an analogy with Cezanne's paintings,[2] the lived experience of psychopathology is the absence of color. This is a sharp reduction of the possibilities of the subject in the world, a limit that does not allow him/her to live, using the expression of Tatossian (1993/2014) as subjectivity or possibility of subjectivity. A distinct understanding of a purely nosological understanding—common in psychiatric manuals—is thus observed in the identification and attention of disease processes. From a phenomenological perspective, this recognition is given from the lived experience of the patient.

Sam and Moreira (2012) conducted a discussion on cultural psychopathology, comparing the lived experience of illness in culturally different situations. Researchers resume studies on cultural psychopathology and claim that cross-cultural studies show noted critical potential, that is often lost by a movement of 'psychologizing' culture, by psychologists who give priority to research that is restricted to measuring symptoms, merely to compare them between cultures. Culture is not only something that influences mental illness, but is an essential part of psychopathology: "to understand mental illness is to understand culture and understanding culture makes mental illness comprehensible" (p. 6). As a mental health constituent (and of sickening modes), culture must be addressed in a dimension covering its political, historical, social, anthropological, and ideological aspects, avoiding a naive look at the cultural phenomenon (Sam & Moreira, 2012). Psychopathology should be understood through a mental disease experience that will always be reciprocally incorporated with culture.

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[2] For a better understanding of the works of this painter, refer to Becks-Malorny (2007).

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