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Hollow from the Inside: Experiences of Racialized Immigrant Fathers When Their Child Dies

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Hollow from the Inside: Experiences of Racialized Immigrant Fathers When Their Child Dies

by

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A THESIS

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Abstract

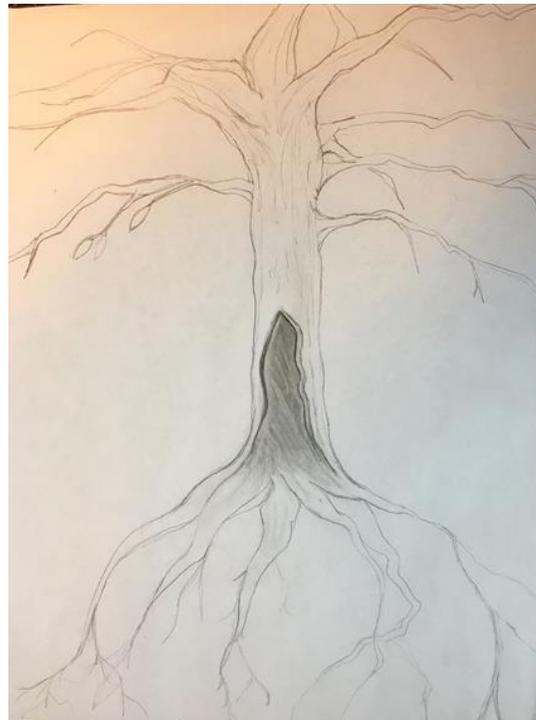
Understanding the meaning of loss for racialized immigrant fathers and addressing their experiences in a culturally competent manner is important in an increasingly ethnoculturally diverse country like Canada. Culture, customs and rituals influence fathers' grief and culture impacts how individuals discuss death and dying as well as how they perceive the death of a child. This qualitative research examines the experiences of racialized immigrant fathers who experienced the death of a child. Charmaz's (2010, 2014) constructivist grounded theory was the methodological approach in this research and was applied to develop the theoretical framework grounded in this research: Hollow from the inside - the death of a child served as a reinforcing process for ongoing loss linked to racialized immigrant fathers' experience of immigration. Findings suggest that for racialized immigrant fathers their migration experience compounds their losses in unexpected ways when their child has died.

Epigraph

Children are not supposed to die... Parents expect to see their children grow and mature. Ultimately, parents expect to die and leave their children behind... This is the natural course of life events, the life cycle continuing as it should. The loss of a child is the loss of innocence, the death of the most vulnerable and dependent. The death of a child signifies the loss of the future, of hopes and dreams, of new strength, and of perfection.

(Arnold & Gemma, 1994)

Figure 1: Fathers' Metaphor - Hollow from the Inside



Artist Credit: Michaela Lynn, 2017

Caption

This figure has three renderings in this dissertation. A key metaphor emerged from the interviews with one father identified feeling that the experience of the death of his child left him feeling like a tree that was “hollow from the inside”. As I interviewed all the fathers, similar experiences of emptiness emerged. As I thought of a way to visualize this metaphor and the impact the hollowness and emptiness had on the fathers. I asked an artist to draw a tree that reflected this metaphor. The words “hollow from the inside” were crucial to constructing grounded theory that was deeply rooted in the experience of fathers. The tree is an appropriate

metaphor and is included as Figures 1a, 1b and 1c in the dissertation to reflect the codes and categories that informed the construction of grounded theory. The tree was located at the beginning of this thesis and it shows a very strong looking tree with roots, trunk, and stems but not a lot of leaves.

Preface

Losing a child can be devastating for anyone. However, losing a child in a new host country where one might be facing a diversity of challenges may compound the experiences of loss and the grief journey. The findings of this research revealed one major link between the experiences of all the fathers. All the fathers felt in one way or the other “*hollow from the inside*”. Hollow from the inside was mentioned by one of the fathers as a metaphor to describe how he perceived the impact of losing his child. This father compared what he has been feeling after his son died to a tree that was completely hollow from the inside. This was then echoed in different ways by the rest of the research participants as they described the impact of losing their child. The father who used this metaphor perceived himself as a tree, presumably deeply rooted in the ground and standing tall. The irony about this comparison according to this father is that this tree, however, was completely hollow and empty from the inside. This emptiness was difficult to communicate, share and express with other individuals and men often fear being misunderstood and perceived as weak and unable to cope in the face of adversity. It was a void, a particular feeling of nothingness, hollowness that was difficult to describe. Feeling hollow from the inside was expressed by the fathers in this study in a variety of ways in relation to the strains and difficulties in employment/underemployment, marriage, religion, spirituality, health and taking care of surviving children. This metaphor is connected to the major categories: objectification of fathers in the health care system, of managing feelings; bicultural grieving in two cultures; making meaning of the death of their child; multiplicity of roles as a father; and managing their own health status in light of the death of their child. Feeling empty and not being able to address this experience can have disastrous physical and emotional health outcomes for these fathers.

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CHAPTER I: BACKGROUND

A wife who loses a husband is called a widow. A husband who loses a wife is called a widower. A child who loses his parents is called an orphan. But . . . there is no word for a parent who loses a child—that's how awful the loss is! (Neugeboren, 1976, p. 154)

The death of an individual affects the entire family and the stress that family members experience at the time of such a loss is devastating (Howarth, 2011). The death of a child, however, adds another layer to the experience of loss. Death of a child is considered the most traumatic type of death because it is perceived as both unfair and untimely (Cook & Oltjenbruns, 1998). This study examines the experience of racialized immigrant fathers who have suffered the death of a child and the effect this has on the father's health.

Grief support services have largely been developed from the perspectives of research completed with bereaved mothers (Cook, 1988; Davies et al., 2004). As a result, health care providers might find it difficult to provide grief support to men when they have suffered the loss of a child due to the lack of a clear evidence-based direction for service delivery. Fathers tend to be less active than mothers in seeking grief supports, services and resources (Doka & Martin, 2010; Martin & Doka, 2000). This situation is heightened in the case of racialized immigrant men who may benefit from incorporating their cultural beliefs in bereavement services when a child has died (Kagawa-Singer & Blackhall, 2001). Racialized is a term recognizing the dynamic and complex processes in which dominant groups form racial categories in ways that entrench social inequalities and marginalization (Ontario Human Rights Commission [OHRC], 2009). The term racialization refers to the experiences of individuals or groups who are not from the dominant racial group in society (Banton, 2005). Racialization means the imposition of labels and stereotypes based on skin colour, accent, speech, mannerisms, beliefs, attire, practices,

and habits (University of Guelph, 2015). The findings of this study provide a foundation for educating healthcare providers about some of the barriers experienced by racialized immigrant fathers when their child dies. The results draw attention to the need for culturally competent bereavement care and enhanced access to appropriate healthcare services for racialized immigrant fathers.

Overview of the Dissertation

This chapter provides an overview of the organization of the dissertation document and describes the background and context that form the framework for the study. The chapter concludes with a discussion of the rationale for, and the multifaceted implications, of the study. This dissertation follows a standardized format. In total, the dissertation is comprised of six chapters. An introduction to relevant social work theories is included in chapter two. This chapter discusses the concepts and theories that underpin this study including critical race theory, anti-oppressive theory, intersectionality, and racialization. In particular, the concept of racialization is explored in detail in order to provide the reader with an understanding of what it means to be racialized. Chapter three includes an extensive literature review on the effects of child death and the associated loss and grief on parents, the influences of culture in death and dying, and other related topics such as the effect of immigration on men and fathers. In order to build understanding of the experiences of immigrant fathers in accessing healthcare services in Canada trends in immigration, the healthy immigrant effect, health equity, and social work in healthcare are discussed in the literature review. Since this study is about the health and well-being of bereaved immigrant fathers, the literature review also presents a discussion of the historical development of the Canadian healthcare system. Chapter four describes the research methodology, including the design, procedures, and implementation of the study. This chapter

provides details regarding the application of constructivist grounded theory methods within the study, including the data collection and data analysis procedures. A discussion of ethical considerations, scientific rigour, limitations, and my positionality as the researcher is also provided. The findings, including description of the categories and codes, are presented in chapter five. Finally, chapter six presents a discussion of the findings, as well as a discussion of the practice, research, and knowledge translation implications of the study.

Ethnic, Racial and Cultural Diversity as the Context for the Study

Prior to 1986, Canadian immigration policy favoured newcomers from Western Europe, resulting in the majority of immigrants arriving in Canada at that time having European cultural and ethnic backgrounds (Boyko, 1998). Over time, policy has evolved and since 1995, the profile of immigration to Canada has changed radically, with the largest groups of newcomers arriving from Asia—mainly China, India, Philippines, Pakistan, and Iran (Statistics Canada, 2011b). Canada has encountered increasing diversification in regard to immigrants' countries of origin, cultural backgrounds, lifestyles, and socio-economic statuses. In 2013, approximately 61.8% of immigrants in Alberta, the province which is the focus of my study, were from Asia and the Pacific, with newcomers from Africa and the Middle East (18.1%) being the next most numerous group, followed by those from Europe and the United Kingdom (9.5%) (Statistics Canada, 2011a).

Immigrants bring an abundance of skills, education and other resources to Canada, a prime example being their contribution to the Canadian labour force (Yssaad, 2012). In my experience as an immigrant and in knowing other immigrants, many come to Canada for a better life for their children and families. Push and pull factors or forces are situations that make people move from their country of origin. These factors could be related to socio-economic, poverty,

religious freedom, education and lifestyle changes (Schoorl, Heering, Esveldt, Groenewold, & Van der Erf, 2000). The push factor refers to forces that push people away from where they live and the pull factors relate to situations that are attractive in the country that individuals would like to move to (Schoorl et al., 2000).

In order to more fully appreciate the contributions of immigrants to the Canadian economy an example from a large urban centre in Alberta illustrates this point. The labour force participation rate (which measures the total labour force relative to the size of the working-age population) among males in the Calgary Census Metropolitan Area was estimated at 79.9%, compared to 68.8% among females in the 2011 Census (Statistics Canada, 2011a.). This means that more males than females in Calgary participated in the labour market. Calgary's unemployment rate among males and females was 5.7% and 6.1% respectively at the time. A key labour market indicator illustrating the health of the labour force is the labour force replacement ratio (which measures the ratio of the population that is 15 to 24 relative to the population that is over 45 years of age). This ratio was estimated at 2.4 and 2.3 respectively for male and female immigrants in the Calgary Central Metropolitan Area (Statistics Canada, 2011b). The ratios for total males and females in the Calgary Central Metropolitan Area was projected at 0.4 and 0.3 in 2011 (Statistics Canada, 2011a). As such, it can be inferred that many racialized immigrant fathers, when healthy and able to work, contribute to the Canadian labour force. The contributions of racialized immigrant fathers help the Canadian economy to flourish.

In order to understand the experiences of immigrant fathers when their children die, it is important to gain an awareness of the roles of immigrant men and fathers in Canadian society. This study took place in the province of Alberta. In many cultures, there is an expectation that the father or father figure, protects the family from harm and assumes the role of the main

financial provider (Debs-Ivall, 2002; Srivastava, 2007). Fathers are often expected to provide for the needs of their children and spouse (Srivastava, 2007), which may be a challenge when they experience the loss of a child. Currently, grief and loss programs exist for families; however, these programs are often inaccessible to racialized immigrant fathers specifically, for a variety of reasons. This fact is often combined with societal pressures to complete the grief process as soon as possible, or even not to mourn in their preferred manner (O'Leary & Thorwick, 2006). Such pressures may result in the racialized migrant fathers' inability to attend to their own physical and emotional needs and those of their family members during bereavement following the death of a child.

Rationale

The aim of this research was to develop an understanding of the experiences of racialized immigrant fathers when their child died and the impact this has on their health status. A secondary interest was to develop an understanding of how healthcare systems provide quality bereavement support to these fathers. It is known that the experience of immigrants including diversity in language, culture, religious beliefs, and values, results in challenges and pressures being placed upon health and human services organizations, including healthcare providers in Canada (Al-Krenawi & Graham, 2003; Kongnetiman, Lai, & Berg, 2008). Healthcare providers are often expected to understand the experiences of immigrants in accessing healthcare, including the role of culture, immigration, health disparities, illness, beliefs, paths of healing, and end-of-life issues that fall within that experience (Srivastava, 2007). On the other hand, researchers have identified that many new immigrants to Canada experience barriers in accessing and retaining healthcare services (Reitmanova & Gustafson, 2007; Srivastava, 2007; Young, Spitzer, & Pang, 1999). McGibbon and Etowa (2009) indicate that access to health care is a

major challenge for racialized populations. Further, McGibbon et al. (2005) identify specific barriers such as experiences of being racially profiled, insensitivity to the needs of different cultures by healthcare providers, lack of culturally competent services including language and communication barriers and a lack of translated health information. Race, ethnicity and socio-economic background may affect the ways in which individuals perceive the type of service and accessibility of available healthcare services (Doyle, Joe, & Caldwell, 2012). For instance, race and ethnicity have been identified as contributing to problems in accessing preventative healthcare services in some groups such as African Americans, foreign-born Black fathers in the United States, and Muslim women in Canada (Doyle, Joe, & Caldwell, 2012; Sharif, Dar, & Amaratunga, 2000).

Barriers in accessing healthcare services related to race, ethnicity and culture arise from differing worldviews on health and illness and lack of understanding of the cultural content and context of available resources (Sharif et al., 2000). Racialized individuals experience racism and racial discrimination in the healthcare system (James et al., 2010; McGibbon & Etowa, 2009). Barriers to accessing healthcare services exist as racialized immigrant families don't always know about the types of healthcare services that are available, including grief and bereavement care programs. Challenges exist in racialized immigrant families in accessing culturally diverse bereavement programs.

Bereavement in an Ethnically, Racially and Culturally Diverse Context

Meeting the healthcare needs of racialized populations has become an increasing concern for healthcare professionals (Srivastava, 2007). This is especially important when caring for families who have a child with a disability, with a serious illness, or when a child has died (Kongnetiman et al., 2008). Healthcare professionals should, therefore, take into consideration

the cultural context, beliefs, customs, values, and the worldviews held by racialized immigrant families regarding health, illness and healthcare (Clements et al., 2003; Kongnetiman et al., 2008).

Consideration of gender, specifically, gender-based differences in grief responses and processes are also important. Neglecting masculine grief continues to marginalize racialized immigrant men in expressing their grief following the death of a child (Zinner, 2000). Having better understanding of the lived experiences and health statuses of racialized immigrant fathers when their child dies will provide healthcare providers with information on how to meet the needs of the fathers and ensure their health and ongoing involvement in society and the labour market.

Some of the grief and bereavement studies conducted in Canada and the United States have concentrated on studying variations in grief and bereavement processes and outcomes in relation to factors such as gender, age, and cultural norms (Cook & Oltjenbruns, 1998). However, most of the research specifically related to parental grief and bereavement following the death of a child has dealt with the experiences of bereaved mothers (Badenhorst, Riches, Turton, & Hughes, 2006; Cacciatore, 2010; Davies et al., 2004; O'Leary & Thorwick, 2006; Rice, 2000). In many cases these studies examined either the differences between mothers' and fathers' grief; or the experiences of mothers losing a child in a particular culture or due to a particular illness (Badenhorst et al., 2006). A limited amount of recent research has focused on family-centred care services provided to bereaved fathers within paediatric settings in the United States (Davies, Baird, & Gudmundsdottir, 2013). On the other hand, numerous studies dating back several decades have investigated cultural norms and patterns of grieving more broadly (Barley, 1997; Davies et al., 2013; Rice, 2000; Rosenblatt, 1993; Rosenblatt, Walsh, & Jackson,

1976). In regard to specific grief, loss and mourning rituals, studies completed in various locations throughout North America have examined funeral rites and roles of the deceased after death (Clements et al., 2003; Gijana, Louw, & Manganyi, 1989); as well as the importance of receiving social support during bereavement (Raphael & Nunn, 1988; Zinner, 2000). While most of this research does not evaluate the experiences of fathers specifically, one study, an evaluation of an intervention program for bereaved fathers, was recently completed in Finland (Aho, Tarkka, Astedt-Kurki, Sorvari, & Kaunonen, 2011).

The majority of studies regarding death and bereavement are conducted from a Western perspective and, as such, reflect a Western ethnocentric perspective of loss and grief. This is problematic because completing death and bereavement research from a purely Western perspective fails to address other unique and diverse perspectives. Western-centrism is a significant limitation in the existing death and bereavement literature because the voices and perspectives of the individuals that arguably need the bereavement programs the most – culturally, ethnically and racially diverse families are not included in the research as participants or researchers, and therefore, these populations are not benefitting from the development and implementation of bereavement support programs tailored to their unique needs, preferences and lived experiences (Rosenblatt, 2001; Stroebe & Schut, 1998).

Although many studies have been conducted on cross-cultural bereavement (Clements et al., 2003; Gupta, 2011; Rosenblatt, 2001), there is an identifiable gap in research studies on the bereavement experiences and support needs of specific ethnic groups. In particular, it is necessary to conduct research to build understanding of specific ethnic groups' experiences of bereavement (Hayslip & Han, 2009).

Gender is an important area that warrants further investigation in bereavement research. One might draw the conclusion that women need more formalized bereavement support than men because past studies (Li, Precht, Mortensen & Olsen, 2003; Staudacher, 1991) have found that men and women grieve differently from one another and that women are more expressive in their grief compared with men. However, this understanding may disadvantage fathers in regard to receiving grief support when their child dies. As discussed above, healthcare providers may not recognize male ways of grieving during their assessment of bereaved racialized immigrant fathers. In some cases, due to lack of knowledge, service providers may assume that the mother needs grief support and in turn, make arrangements for the mother to access grief and bereavement services, while failing to consider the father's grief support needs.

As discussed above, men's grief has not been as well researched as women's and therefore men may be more prone to experiencing disenfranchised grief (Zinner, 2000). Doka, (2016) identifies disenfranchised grief as losses that are "unrecognized and unsupported by other members of society" (p.7). Further, Doka identifies the issue of grief in relation to cultural expectations around mourning including the concern that, "When you violate...cultural or generational norms, you find your support is limited-your grief disenfranchised" (p. 222). This disenfranchisement is linked to misunderstanding of the fathers' non-expressive ways of grieving when their child has died (Cholette, 2012). Disenfranchisement of bereaved fathers' grief may lead to a lack of appropriate grief supports and emotional vulnerability. As a result, some fathers might be at increased risk of experiencing physical and emotional health issues, including suicide (Li, Precht, Mortensen, & Olsen, 2003). These risks are discussed further in Chapter three.

Problem Statement

The death of a child is a major life event and it is perceived as being more stressful for a parent than any other type of death (Chambers & Chan, 2000). The experience of losing a child can cause grief responses including stress, anger, resentment, and physical and emotional distress (Li et al., 2003). Chan et al. (2005) noted, with anguish, that in some cases “the white-headed witnesses the death of the black-headed” (p. 934), meaning that parents should not bury their children (Irish, Lundquist, & Nelsen, 1993). However, our understandings of parental bereavement remain limited. In particular, the voices of racialized immigrant fathers who have lost a child have been largely excluded from the parental bereavement research completed to date. To my knowledge, little research has been conducted from the unique perspectives of racialized immigrant fathers who have experienced the loss of their child. Without research evidence, it is challenging for healthcare providers to recognize, understand and address the grief support needs of these fathers. The perspectives of all who grieve should be included in research and the development of grief support services.

Fathers’ Lived Experiences of Grief and Loss Following the Death of a Child

Staudacher (1991) identified that reflecting on the manner in which the child died and the strong emotions that accompany the loss are crucial for the health of bereaved fathers. Many fathers experience stress related to balancing the task of making decisions for the deceased child’s burial and remaining “strong” for other family members (Staudacher, 1991; Zinner, 2000). Many bereaved fathers try not to openly express their grief due to the role they have as a family provider and caretaker. As a result, their expressions of grief may take on multiple indirect forms (Badenhorst et al., 2006; Staudacher, 1991), including illness, depression, and even death. For example, one study found that symptoms of depression, anxiety, and post-traumatic

stress were evident in fathers who suffered the loss of a child through stillbirth (Badenhorst et al., 2006). Another study noted that within the first 36 months following a child's death, fathers have an increased rate of mortality from natural causes (Li et al., 2003). The trauma of losing a child can often trigger behavioural changes. For example, some parents start smoking, drinking excessively, changing their eating habits, and they may lose the desire to exercise (Li et al., 2003). The stress of losing a child through death is often compounded for racialized immigrant families due to language barriers, cultural differences, and challenges related to immigration processes, as well as social isolation (Kongnetiman et al., 2008).

The death of a child represents a permanent loss and no parent can overcome such a loss easily (Rosenblatt, 2000). However, this is not always well understood socially. After the death of a child, many people may try to be helpful to the bereaved parents. In doing so, they may suggest that the bereaved parents “get over” the loss of their child. Although they are usually well-meaning, these people may not recognize that bereavement is not something that people can “get over”. In many instances bereaved individuals learn to adjust to the reality of their situation over extended periods of time (Hooyman & Kramer, 2010). Parents may learn to live with the loss or adapt to a “new normal” that involves living without their deceased child. However, “getting over” the loss is typically not a realistic bereavement outcome.

Losing a child through death often puts major stress on a couple's marital relationship (Rosenblatt, 2000). Following the death of a child, the couple is changed forever, which sometimes results in dissolution of the marriage and divorce (Rosenblatt, 2000). When there is a death of a child within the context of a marriage, the process of grieving becomes a mutual journey; however, each partner also has their own unique grief and bereavement experiences.

Racialization itself is known to adversely affect health, healthcare, and access to health services for immigrants (Galabuzi, 2005; Hyman, 2009). Furthermore, immigrant families may experience barriers in adapting to the host country's healthcare system and lifestyle (Gardenswartz & Rowe, 1998; Lynch & Hanson, 2002; Pe-Pua, Gendera, Katz, & O'Connor, 2010; Tripodi-Potocky, 2002). The death of a child may compound the sense of loss and hopelessness associated with concurrent barriers and losses such as the ones identified above. In regard to seeking grief support and bereavement services following the death of a child, immigrant families may wish to uphold particular cultural traditions but often they are unable to do so because of a lack of cultural understanding or inability to adapt the services to meet the patient's needs on the part of healthcare providers (Kongnetiman et al., 2008).

As identified above, little research has been undertaken in the context of understanding the effect of child death upon racialized immigrant families and particularly on racialized immigrant fathers. Due to the scarcity of literature on this specific topic, I have explored related topics within the domain of grief and loss, specific to the experiences of racialized immigrants. For example, Sue and Sue (2008) conducted research on the experiences of widows who were immigrants. It would appear that some gender bias exists in bereavement studies as the research overwhelmingly focuses on women and their experiences rather than on men (Bartlett, 2004; Davies et al., 2004).

Some previous research findings have described the effect of child death upon the health of fathers in general but not on racialized immigrant fathers specifically (Li et al., 2003). Due to the scarcity of literature on the topic of the effect of child death upon racialized immigrant families and particularly on racialized immigrant fathers, the need exists for further research on the following topics: (a) the role of culture in the experience of racialized immigrant fathers'

bereavement; (b) the manner in which the “news” of the death is shared with racialized immigrant fathers; (c) racialized immigrant fathers’ experiences in the healthcare system from a male perspective; (d) racialized immigrant fathers’ roles in their communities; and (e) racialized immigrant fathers’ health status pre- and post-bereavement.

Regardless of culture, race, or ethnicity, the type of death that the child suffered, or the age of the child at the time of death, each father’s bereavement experience is unique. This research contributes to enhancing understandings of the lived experiences and health status of racialized immigrant fathers in order to fill some of the research gaps on this topic (Davies et al., 2004). Obtaining information regarding the lived experiences and subsequent health status of racialized immigrant fathers when their child has died has important implications for social work practice and healthcare policy. Understanding the lived experiences and needs of these fathers will contribute to program development in the areas of grief support and bereavement care, which could lead to improved services for racialized men and their families. The results would provide valuable knowledge for social work practice and education, as well as encourage further research. In addition, it would contribute to the health and well-being of bereaved racialized immigrant fathers by providing them with culturally appropriate bereavement supports that could facilitate the development of their capacity to participate fully within their work and family activities in the face of tragic loss. An important objective of this study is to create greater awareness and understanding of the issues affecting racialized fathers when accessing grief support and bereavement services. This has been reported as an ongoing challenge for grief and bereavement counsellors in the child health area of Alberta Health Services (Kongnetiman et al., 2008). In summary, although many racialized immigrant fathers are involved in providing financially for their families and caring for their children on a daily basis (Macfadyen, Swallow,

Santacroce, & Lambert, 2011), their voices have largely been excluded from research on parental bereavement. This study emphasizes and addresses the fact that fathers' grief experiences and ways of coping with child loss have generally been under-researched in comparison to mothers.

The purpose of this study was to explore the lived experiences of racialized immigrant fathers in the healthcare system in Calgary, Alberta, Canada following the death of their child. This research project also explored the effect of the loss on the health status of racialized immigrant fathers.

Research Question

The general question for this research study was: What are the lived experiences of racialized immigrant fathers when their child dies? Two sub-questions were posed as follows: (a) what are the lived experiences of racialized immigrant fathers in their interactions with the healthcare system when their child dies? and (b) how do racialized immigrant fathers understand the effect of the death of their child and their experiences in the healthcare system on their health?

Research Approach

The study adopted Charmaz's constructivist grounded theory (Charmaz, 2009; 2010; 2011) methodology to inquire about the experiences of racialized immigrant fathers who had lost a child through death. Constructivist grounded theory is a qualitative methodology which is part of the grounded theory "family" (Charmaz, 1995; 2000; 2005; 2006; Mills et al., 2006). Qualitative research is a critical tool in the exploration of subjective experiences and situational needs and is well suited to the focus of this research (Shirayev & Levy, 2017). Qualitative research is particularly suited to investigations of phenomena that have not been well-studied. As discussed above, due to limited existing research, the topic of the present study, namely the

experiences of racialized immigrant fathers whose child has died, qualifies as being an understudied topic that merits further investigation.

Constructivist grounded theory methodology results in the co-construction, as opposed to the discovery, of theory based on an “interpretive portrayal of the studied world, not an exact picture of it” (Charmaz, 2006, p. 10). Constructivist grounded theory calls for the participants and the researcher to construct meaning together about the specific experience under study (Charmaz, 1995; 2000; 2010). It is an appropriate approach to assessing and developing theory (Charmaz, 2010; Corbin & Strauss, 2008).

The research questions identified above, focus on lived experiences, interpreted meanings, sense making, and action. Constructivist grounded theory is an appropriate methodology for seeking answers to these research questions because as the researcher, I am concerned with understanding how the fathers make sense of what happened and their responses when their child died.

Constructivist grounded theory supports exploration of social justice issues (Charmaz, 2005). Social justice is centred on fairness, and equal value and treatment for all individuals and groups (Messias, McDowell, & Estrada, 2009). Heinonen and Spearman (2001) define social justice as “an abstract and strongly held social work ideal that all people should have equal rights to the resources of a society and should expect and receive fair and equal treatment” (p. 352). When put into practice, one perspective on social justice emphasizes advocating for the distribution of resources and services in a fair and equitable manner. As a social worker who has worked in the healthcare system this topic holds personal and professional significance to me and the issues of bereaved racialized immigrant fathers is an issue of social justice. As identified above, there is a dearth of research on this topic and it is my own belief in social justice that has

contributed to my undertaking this research, in the belief that the lives and sorrows of the fathers who participated in this research are worth sharing. The construct of social justice is foundational to this research and will be addressed further in this dissertation.

Research Participants

The participants involved in this study included fathers who had a minor child (under 18 years old) that passed away no less than 12 months and no more than five years before the time of the study. The scope of this research is limited to immigrant fathers. Refugee fathers were not included for various reasons. Compared to immigrant fathers, refugee fathers have different pre-migration, migration, and post-migration experiences. In many instances, refugee fathers have additional trauma-related lived experiences connected to their migration separate from the death of their child. Appropriately addressing needs related to these experiences would have required additional resources and attention during and after each interview and it was not possible to include the provision of these resources within the research plan for the present study. While some immigrant fathers might also have experienced trauma related to their migration, it is generally recognized that their immigration journey is considerably different from that of refugees. For example, one distinction is that refugees usually leave their country of origin out of fear of harm and persecution, while immigrants in many instances are newcomers for economic or family reasons (Spitzer, 2011). The above-mentioned reasons for exclusion of refugee fathers in this research were also informed by my experience completing other doctoral research through funding by the Health Quality Council of Alberta in 2012. The focus of the research was to explore the impact of culture on the grief experiences of immigrant and refugee fathers after the loss of a child. The refugee fathers expressed traumatic experiences resulting from their refugee status that I could not attend to within the context of that study. Future

research is needed to examine the experiences of refugee fathers when their child has died, with special attention being paid to their experience of traumatic loss.

The study was conducted through individual face-to-face interviews of eight bereaved fathers with an immigrant background residing in Calgary, Alberta. Participants were recruited through the Children's Hospice and Palliative Care Services at the Alberta Children's Hospital in Calgary. The recruitment procedures and inclusion criteria are discussed in detail in Chapter four. This data analysis generated a detailed, contextual description of the participants' experiences of their children's deaths and the subsequent effects on the health status of participants, which is presented in Chapter five and discussed in Chapter six. The implications of the findings are also discussed in Chapter six.

Summary

An increasing number of immigrants from diverse cultural backgrounds are settling in Alberta. For immigrants, adjusting to life in their new country can be challenging. As a result of existing challenges and stresses associated with migration and adaptation, parental bereavement can be particularly stressful for both immigrant fathers and mothers who lose a child through death. Research in the area of cross-cultural bereavement care has made progress toward advancing understandings of parental bereavement in general however the area of immigrant father's lived experience of bereavement and associated health effects when their child dies is a neglected area of inquiry.

The subject of this study is: (a) comprehending the experiences of racialized immigrant fathers when their child has died, and (b) the effect of bereavement on their health.

Understanding the experiences of these fathers has the potential to provide valuable evidence to inform policy makers, service providers, frontline workers, and others in healthcare to create

and/or optimize services for racialized immigrant fathers. Studies of the experiences of the death of a child exist but since relatively little research has been carried out in Canada specific to the lived experiences of fathers to date, this research is both timely and necessary. The findings support advancing culturally competent services in palliative and family-centred care in order to contribute to the well-being of immigrant fathers and their families.

CHAPTER II: CONCEPTUAL AND THEORETICAL FRAMEWORK

For the purpose of this research four conceptual and theoretical frameworks will be discussed: (a) anti-oppressive practice (Dalrymple & Burke, 1998; Payne 1997); (b) critical race theory (Ford & Airhihenbuwa, 2010; Razack & Jeffery, 2002); (c) intersectionality (Hankivsky, 2011); and (d) racialization (Fassin, 2011; OHRC, 2009). These theories will be explored further within this chapter and in the final discussion.

Theory is the foundation of social work practice (Payne, 1997). By infusing theory into practice and linking theory with research, social workers are able to enhance their clinical skills in a variety of ways (Smith, 1999). Social workers who use a particular theoretical framework to guide their practice and understand the concepts underlying the theory are able to assess and explain their practice (specifically, to justify why they make particular decisions) while being transparent, reliable, and current. Theory “contains within it a method or methods for selecting and arranging, for prioritizing and legitimating what we see and do” (Smith, 1999, p. 38). By applying theory to practice, social workers are better equipped to understand what is happening in their work environment and better able to recognize social power imbalances (Dalrymple & Burke, 1998), which can adversely affect the health of patients. Theory helps to explain what is happening in society and provides practical guides for social workers and policy makers to intervene in issues that individuals, families and groups are experiencing (Hankivsky & Cormier, 2009).

When conducting research, theory aids the researcher in organizing his/her conceptualizations and identifying actions (Smith, 1999). A theory that supports the articulation and analysis of the ideologies and experiences of research participants can be used to clarify the participants’ perspectives and enhance understanding their realities. For example, in order to

achieve social justice in healthcare, social work researchers should conduct their work within a theoretical framework that both explores health inequalities and provides a response that informs social workers and other healthcare providers how to address those inequalities in practice. In short, social workers in healthcare make use of theories that provide suitable underlying philosophies and an ethical stance that corresponds with the perspective that health inequalities are inhumane and unjust (Solas, 2008). As a profession, social work is a regulated health profession and guided by a code of ethics that is critical to applying a social justice framework in practice (Canadian Association of Social Workers, 2005). As a Registered Social Worker for over 25 years my values and ethics in relation to the topic of research have been influential in the theoretical frameworks selected to inform this research.

A plethora of social work theories influence social work practice but the question remains as to which theory is best suited to achieve social justice in the healthcare arena. Applying any social work theory to practice is a personal matter based on preference, social work education, training, and the social worker's ontology and epistemology. Experiences, historical context, country of origin, family background, educational training and work experiences influence each social worker's selection of theoretical framework. Social work theories may influence the way an individual social worker understands, communicates about, and approaches the world. Social workers are thus encouraged to engage in critical self-reflection and articulate the theoretical perspectives that fit within the framework of social justice within their organizational contexts and specific areas of practice.

Some current theories that are used to address health disparities in Canada and elsewhere do not aid in developing understanding of the issues experienced by service users that are entrenched in systemic intersectionalities of oppression, including racism (Dhamoon &

Hankivsky, 2011; Pon, Gosine, & Phillips, 2011). As identified above, four conceptual and theoretical frameworks will be discussed in this chapter: anti-oppressive practice, critical race theory, intersectionality, and racialization. The choice of these four perspectives is based on my personal experience of applying theory to practice while working as a social worker in the healthcare arena over the past 14 years. My theoretical choices are also supported by earlier research that I have carried out on issues of cultural competency in healthcare and on my professional experiences working on various quality improvement projects on issues of diversity in healthcare. Based on these prior experiences I believe that the lived experiences of racialized immigrant fathers could be explained through the selected concepts and theories due to their connection to social justice and issues of marginalization. The pursuit of social justice involves advocating for equity in the distribution of resources and equitable individual rights, as well as actively attending to issues and experiences of marginalized populations (Constantine et al., 2007). Each of the conceptual and theoretical frameworks employed in the present study supports the pursuit of social justice. In tandem with a discussion on cultural diversity and racism, understanding the lived experiences of racialized immigrant fathers through a social justice and social work theory lens supports transparent and honest conversations about the needs of immigrant fathers when a child has died. In this chapter, the conceptual and theoretical framework underlying the study will be presented as the basis for understanding the experiences of the fathers that participated in the study. A discussion of Canada's immigration history will provide additional context for the study.

Rationale for the Selection of the Conceptual and Theoretical Framework

I based the choice of the four social work concepts and theories identified above on how I perceive my practice and how I understand social injustice. Over the past several years I have

applied the principles of these four social work theoretical frameworks in my social work practice. This approach has supported me to ensure that I include the voices of oppressed people into service provision. I am aware that historically, most social work theories were developed from a Western perspective (Payne, 1997) and therefore there is a corresponding need to “decolonize” social work knowledge and practice in order to engage with culturally diverse racialized populations in a useful, ethical and appropriate manner (Smith, 1999). In that regard, I ensure that in my practice my worldviews do not dominate the worldviews of the patients that I work with. I also ensure that when power imbalances exist in service provision they are addressed. The awareness of these theoretical frameworks assists me in recognizing my own issues with “isms” and finding meaningful ways to employ anti-oppressive practice elements in addressing racism, discrimination, sexism, stereotypes and biases. This knowledge has also supported me in this research study as the research methods that I used supported my understandings of the perspectives of the fathers during data collection and data analysis. As such, I was able to better understand the research participants when they shared their experiences with the healthcare system. If healthcare providers could view the experiences of these racialized immigrant fathers through the lens of these four theoretical frameworks it might give them some insight into the social justice and health equity that is needed in order for them to access healthcare services related to grief and bereavement.

Canada’s Immigration History

Exploration of the historical context of immigration policy in Canada reveals entrenched institutional racism that effects service provision for immigrants by various governmental departments and service organizations (Jakubowski, 1997). In part, this research raises issues of inequities in healthcare service provision through the discourse of racialized immigrant fathers

who have lost a child. Institutionalized racism and oppression are embedded in the Canadian healthcare system and the services that it provides (McGibbon & Etowa, 2009).

Racism and discrimination are entrenched as part of Canada's immigration policies and it is important to understand the impact of racialization on the healthcare experiences of patients and their families. However, Canada's immigration history cannot be separated from colonialism and its devastating effects, specifically the colonization of Indigenous peoples (Reading, 2013; Tuhiwai Smith, 1999). Stemming from the history of colonization, today, both non-White immigrants and Indigenous peoples in Canada are racialized groups that experience barriers related to their health and access to healthcare services.

The case of Chinese immigrants to Canada in the late nineteenth and early twentieth centuries provides a further example of the history of racism in Canadian immigration policy (Boyko, 1998; Jakubowski, 1997). During this timeframe, the arrival of Chinese immigrants led to the development of anti-Chinese propaganda in the province of British Columbia. There was a corresponding lack of formal policies or laws to protect the Chinese immigrant community (Boyko, 1998). Chinese immigrants were also excluded politically. For example, the *Vancouver Franchise Act* of 1859 stated that people of Chinese origin or heritage could not vote in elections (Boyko, 1998). The issue of Chinese migration to Canada was discussed in Canadian Parliament as recently as 1947. Then Prime Minister, McKenzie King stated that immigration from China to Canada was to be avoided (Abu-Laban & Gabriel, 2002). To discourage Chinese migration and settlement in Canada, the Canadian government placed taxes on the Chinese community. Around the same time period however, approximately \$10 million was spent promoting migration to Canada from European countries. Between 1910 and 1957 a large influx of

immigrants from European countries, other than England and France, arrived in Canada. This influx marked the beginning of Canada receiving linguistically diverse immigrants.

One example of a discriminatory immigration policy that was introduced in Canada was the points system that chose immigrants based on their ability to contribute to the economic growth of the country (Hiebert, 2006). The points system focused on bringing in new immigrants who were highly skilled and educated, a reflecting a huge shift in immigrants' countries of origin (Hiebert, 2006). This trend has continued over time and immigration to Canada continues at high volumes (Statistics Canada, 2010a, 2011a). Population growth in Canada has been primarily attributed to immigration. Immigrants approximately accounting for 20% of the Canadian population (Chui, Tran, & Maheux, 2007).

Canada is dependent on immigrants to help populate the country and immigration accounts for all net labour force growth in Canada (Statistics Canada, 2010a). However, because of the country's discriminatory immigration history some existing social policies and practices continue to marginalize racialized individuals and groups (Jakubowski, 1997; Pon et al., 2011; Razack, Smith, & Thobani, 2010).

The next section on critical race theory, examines issues for racialized individuals through a social justice lens. Greater understanding of social work theory and social justice in general, and within healthcare in particular, will clarify the health disparities that racialized immigrants face within the historical context of discriminatory immigration policies and practices. The history of critical race theory further explains the barriers that many immigrants experience in accessing healthcare services on a systemic level.

Critical Race Theory

Critical race theory positions race at the centre of laws and policies and advocates for the elimination of racism (Delgado & Stefancic, 2017). The goal of critical race theory is to investigate and change the ways in which race, racism, and power are interrelated. Critical race theorists argue that racism affects individuals on a daily basis. They posit that as a whole, society does not want to eliminate racism due to the benefits that racism affords to White people due to White privilege (Ford & Airhihenbuwa, 2010; Razack & Jeffery, 2002). Labelling individuals according to social constructions of race means that race-based categorizations can be manipulated when necessary in order to maintain systems of privilege and inequality. Critical race theory asserts that people are racialized and perceived differently based on the colour of their skin, their language, and other traits (Delgado & Stefancic, 2001; Pon et al., 2011; Razack et al., 2010).

Critical race theory includes three perspectives: (a) the idealist, (b) the realist, and (c) the materialist (Delgado & Stefancic, 2001). *The idealist perspective* says that assumptions can be unlearned if individuals restructure their mind. *The realist perspective* is that racism is a mechanism to assign privilege and status. Accordingly, people in the realist society have already decided who will be advancing in life, which will be the frontrunners, and who will succeed based on access to better education, good employment opportunities and engaging with the “right kind” of people. *The materialist perspective* leads to abuse of countries and societies through colonization and occupation without investing in any development in these societies. The countries are exploited, plundered, and left to crumble. It is difficult for colonized societies to recover from the type of exploitation resulting from a materialistic perspective (Delgado & Stefancic, 2001).

Critical race theory recognizes the intersectionality of oppressions given that individuals may identify with many layers of oppression in addition to racial discrimination. These layers may include religion, gender, ethnicity, social class, sexual orientation, marital status, where they live, country of origin, language, and numerous other aspects of identity that may affect access to opportunities and resources (James et al., 2010; Razack & Jeffery, 2002). Critical race theory proposes that all groups who are being marginalized based on racism can work cooperatively to challenge their oppression with a unified voice (Delgado & Stefancic, 2001; Razack et al., 2010).

Critical race theory uses narrative analysis and storytelling to gain greater awareness of the ways that individuals perceive race and racism (Delgado & Stefanik, 2017). Through storytelling, awareness regarding the experiences of individuals from racialized backgrounds and the challenges that they experience within society is heightened. When the stories of individuals who have experienced racism are told, a meaningful conduit is established to the often-hidden world and lived experiences of racialized individuals. The stories of lived experiences of racial discrimination influence society by contradicting the image that the media at large has created about racialized peoples. For example, this “counter storytelling” contests the belief that racialized individuals who have committed a crime are worse people or more deviant than Whites who have committed the same crime (Delgado & Stefancic, 2001).

Since race is socially constructed, racism can be deconstructed through open dialogue. Based on open and honest discussion individuals can critically self-reflect and identify their biases, thus leading to real change (Pon et al., 2011). Open discussion is a powerful method to combat and challenge racism, particularly when social workers or healthcare providers use their knowledge of how racialized groups are being treated to ensure services are created to support these individuals (Pon et al., 2011).

Although critical race theory was founded on critical legal studies and radical feminism, it has been utilized in many academic disciplines. Currently, several forms of critical race theory exist such as Asian American critical race theory, Latino critical and queer- critical race theory, and Indigenous critical race theory (Pon et al., 2011; Razack et al., 2010). Critical race theory is thriving, advancing, and becoming more widely used in educational institutions. At the same time, critical race theory continues to be used in legal contexts to protect clients from a legal system that favours White people over racialized individuals (Delgado & Stefancic, 2001; Pon et al., 2011; Razack & Jeffery, 2002; Razack et al., 2010).

Razack and Jeffery (2002) noted that critical race theory and social work practice have much in common. Both social work and critical race theory advocate eliminating social disparities in general and eradicating racial inequality in particular. The critical race theory perspective states that a country's social structure and legal system is affected by race, which in turn means that race affects everyday life (Delgado & Stefancic, 2001; Pon et al., 2011; Razack et al., 2010). Critical race theory encourages individuals to ask critical questions and take action in order to create social change. Along similar lines, social work concerns itself with supporting and improving the health of all individuals including vulnerable and marginalized populations. Critical race theory and social work practice are both action-focused. Acting to solve health inequity for racialized patients is a form of social justice work. This form of action aims to mitigate racism within the healthcare system by making individuals more aware of issues of privilege and power (Abrams & Moio, 2009). This form of raising awareness is an example of translating social work theory into practice for the benefit of a vulnerable and marginalized group. In regard to the present study, the action taken to mitigate racism within the healthcare system would help racialized immigrant fathers who have suffered the loss of a child. However,

raising awareness alone is not sufficient action to create social change. Solving the problem of racism more broadly is important.

Critical race theory provides social workers with an innovative model to apply to investigation of the core problem of health disparity. It is unique because it takes the experience of individuals into account and considers ways to empower patients within the healthcare system (Pon et al., 2011; Razack & Jeffery, 2002). Critical race theory is related to social and race justice ideologies focused on resolution of issues such as barriers to accessing housing, employment, and healthcare (Ford & Airhihenbuwa, 2010). There are clear linkages between critical race theory and social work's social justice mission. However, a barrier to incorporating critical race theory in social work practice is the time commitment required by healthcare providers to identify and eliminate systemic problems affecting patients and families.

Racialization

In Canada, the correct term to apply to those individuals and groups who experience racism is "racialized" (OHRC, 2015). The Commission on Systemic Racism in the Ontario Criminal Justice System (1995) defined racialization as:

The process by which societies construct races as really different and unequal in ways that matter to economic, political, and social life and includes selecting some human characteristics as meaningful signs of racial differences; sorting people into races on the basis of variation in these characteristics; attributing personality traits, behaviours, and social characteristics to people classified as members of particular races; and acting as if race indicated socially significant differences among people. (p. 40)

In addition to being a process, racialization also refers to the experiences of individuals who are not from the dominant racial group within a given society and experience the imposition

of labels and stereotypes associated with skin colour, accent, speech, mannerisms, beliefs, attire, practices, and habits (University of Guelph, 2015). Recognizing that race is a social construct, the Ontario Human Rights Commission (2015) describes an individual as a racialized person and a larger collective as a racialized group instead of the more out-dated and inaccurate terms racial minority, visible minority, person of colour, and non-White. Racialization makes evident the social construction of racism and the corresponding race-based disadvantages embedded in daily interactions, values, policy, and social relations. The term “racialized” is used to recognize the dynamic and complex processes in which dominant groups produce racial categories that entrench social inequality and marginalization (OHRC, 2009).

One example of racialization in Canada has been the attribution of certain conditions or illnesses perceived as harmful to the Canadian public to specific individuals and groups due to their racial identities (Bowser, 2001; Krieger, 2000; Williams & Collins, 1995). As a case in point, when the global Severe Acute Respiratory Syndrome (SARS) epidemic broke out in 2003, one particular racialized group, the Chinese community, was targeted by the media as the group causing the spread and wide-scale prevalence of the disease both in Canada and around the world (Chan, 2003). Racialization is also used as a way to label and identify the unique experiences of people from different racial groups and to explain a variety of other matters related to racial background (Barot & Bird, 2001). The term, however, presents challenges due to sensitivities about its usage, the complex nature of understanding and discussing race and racism, and interchangeable use with other similar and dissimilar terms (Galabuzi, 2005; Hyman, 2009). Racialization is a word that is difficult to understand and when it is used, people may understand it in a variety of ways. Many individuals are unsure when and how to use the term appropriately.

As a result, usage of the term can create silences in conversation and make some individuals uncomfortable.

Individuals become racialized because of how they are perceived and labeled by others; this is part of the process of social construction (Fassin, 2011). According to Fassin (2011), the process of racialization is three-dimensional: someone assigns the racialized classification to an individual, the individual is racialized and realizes what is happening, and bystanders witness the exchange. Through this process individuals are categorized and differentiated on the basis of race, in other words, an external interpretation of racial identity is essentially forced upon them. Racialization frequently has an undertone of judgment, especially when individuals are perceived primarily by the colour of their skin. Sometimes racialization and the associated process of racial assignment is done very subtly within conversations. For example, if a social worker stated the following: “Linda, my professional practice leader, is Black but she is very eloquent in her speech”, this statement would racialize Linda. Through racialization Linda has already been described to a third party as being “different” due to her race before her skills or other attributes are taken into consideration. According to Penner and Saperstein (2008), racialization or being racialized is always related to either individual bodily features, namely one’s skin colour, or to societal categorizations of one’s social group, or to both.

Racialization adversely affects health, healthcare, and access to health services for immigrants (Galabuzi, 2005; Hyman, 2009). Based on my professional experiences engaging in conversations with immigrant patients and my knowledge of their experiences with unequal treatment within the healthcare system, in my opinion there is no single term that adequately captures the experiences of non-White individuals in the healthcare system. Therefore, I have opted to use two terms, racialized and racialization, in this thesis.

According to Miles (1982), terms such as race and race relations do not have any scientific basis. Due to this lack of scientific basis, Miles used the term racialization in place of racial categorization and likewise did not agree with the use of the terms race and race relations (Murji & Solomos, 2005). He stated that in cases where individuals are being treated differently, racism is the culprit. Racialization reveals the workings of the social practice whereby individuals express and replicate a belief in and about races and racism, leading to racial discrimination. This process often happens in situations that were not created by individuals who are being racialized (Miles, 1982). According to Miles, racialization discusses ideological processes that provide race-based meanings for cultural or political practices or conditions where race is employed as a description or manner of understanding.

While some theorists posit that racialization of people began with the forced occupation of countries by European powers – colonization, others perceived it to be based solely on biological traits (Murji & Solomos, 2005). Over time a variety of explanations for and conceptualizations of racialization have emerged, particularly in the field of sociology (Antias & Yuval-Davis, 1993; Banton, 2005; Miles, 1982). One controversy within conceptualizations of racialization has been whether or not the term was inclusive of immigrants and refugees. Miles (1982) excluded immigrants and refugees in his definition of racialization. In contrast, Antias and Yuval-Davis (1993) advocated for the inclusion of the experiences of immigrants and refugees as racialization experiences.

Reeves (1983) conceptualized both racialization and the counter concept of deracialization. According to Reeves, racialization was a process that occurred when race and race-based issues were raised in areas where race had previously not been addressed, such as in politics. Small (1994) is another theorist who advanced the concept of racialization. He

supported Miles' definition of racialization in the context of race and race relations. However, Small was unique in positing that racialization resulted in the development of different racialized obstacles, limitations, and identities. Other theorists, including Smith (1989), Winant (1994), and Malik (1996) added class relations and poverty to the emerging conceptual framework of racialization.

According to my review of the literature, the usage of the term racialization within research started out as a means of discussing issues of race and race relations. However, now the usage has evolved to encompass discussions of lived experiences of racism. Despite the sensitive and complex nature of racialization, it is important that social scientists and health researchers address it, and work is progressing in this regard.

As discussed above, racialization is variously defined and understood according to the following factors; (a) contexts, (b) the complex and often contradictory processes through which people are racialized, and (c) the reasons for engaging in the racialization process (Banton, 2005). The central difficulty with the terms racialized and racialization is that there is a lack of consensus on their definition (Barot & Bird, 2001). Using the alternative expression "members of a racialized group" is also challenging both because it flows awkwardly and because it incorrectly implies that individuals who are racialized have chosen to be racialized. Rather than being racialized by others, individuals and communities should be able to self-identify (Patychuk, 2011). Self-identification is important for individuals because it allows them to identify in their preferred way, based on who they are and how they perceive of themselves. The gap that currently exists between racialization and self-identification presents a challenge for researchers in regard to knowing what terms are appropriate to apply to various individuals and communities within specific contexts.

In an effort to understand how racialization affects individuals, it is important to consider that each human being has many identifying qualities and characteristics. I believe that people need to be perceived based on their entirety, not only according to single identity markers, such as race.

The term racialized emphasizes the social construction of racism (Frankenberg, 1999) and the disadvantage embedded in daily interactions, values, policy, and social relations due to racial discrimination. Inequities in access to healthcare are also a product of racialization and this is unjust. These inequities are reflective of institutional racism. It can be difficult for those who are impacted by inequities to seek change by themselves (Nestel, 2012). Therefore, research on racialization and racialized groups needs to include a focus on creating tangible change as a research outcome (James et al., 2010). For example, the present study seeks to influence healthcare practices, the elimination of systemic racism with healthcare, and the removal of barriers to accessing health services through advocating for the provision of culturally appropriate grief support and bereavement care for racialized immigrant fathers after their child has died.

Intersectional Approach

Intersectionality refers to the process of investigating how sexual orientation, class, national origin, identity, structural oppression, and sex influence one another in different areas of life ranging from employment to social and family structure (Hankivsky, 2011). Crenshaw (1997) brought this theoretical perspective to the forefront in the 1980s although the intersectionality approach had been used earlier (Dhamoon & Hankivsky, 2011). Intersectionality explains complex issues of social inequity (James et al., 2010) grounded in lived experiences of multiple forms of oppression that intersect in various ways (Rossiter & Morrow,

2011). Intersectionality is useful for the present study because it shows the different “ways in which those interacting social constructions of race, ethnicity, class, gender, and sexuality shape both individual and group experience and identity, and together produce something unique and distinct from any one form standing alone” (James et al., 2010, p. 25).

Intersectionality is closely linked to social justice. It can be perceived as being an important lens through which to view power relations in society and develop understandings of how power and oppression affect people’s experiences based on their social location.

It is not an easy task to include intersectionality in health practices due to the problem of institutional racism in the Canadian healthcare system. The system was initially created to service the dominant White population and therefore the inclusion of the cultural needs of racialized individuals was not systemically planned for. I have witnessed the impact of institutional racism firsthand over the past number of years working in the healthcare system, however I have also witnessed the many efforts being made to rectify this situation. Some leaders within the healthcare system are taking action to create programs and services that are inclusive of racialized families’ needs and preferences. Through advocacy for culturally competent services, change is taking place. The fundamental problem however is that these efforts are usually based on specific funding opportunities or individual interest rather than being attributable to political will and action to improve healthcare from a social justice perspective.

Few studies explore intersectionality, yet it has value as a means to theorize and understand the experiences of individuals accessing healthcare services and how their experiences effect their health outcomes (Hankivsky, 2011). Intersectionality is not perceived as being a driving force for political action (Hancock, 2007). In this research, intersectionality is used as a way to discuss the various complex identities of racialized immigrant fathers. By

exploring the intersections of their identities and experiences it is possible to identify the ways in which the participants were both marginalized and privileged (Pon et al., 2011).

Understanding the multiple ways in which race, class, gender, ethnicity, age, sexuality, and country intersect and affect the experience of immigrant fathers who have lost a child through death clarifies each of the father's social locations (Berger & Guidroz, 2009). The fathers' class, race, gender, ethnicity, and age play an important role in their lived experiences of losing a child, of accessing healthcare and of living in Canada. An intersectional approach also provides insights into how equitable bereavement services could be developed to meet the needs and preferences of racialized immigrant fathers (Browne, Varcoe, & Fridkin, 2011). For example, using intersectionality in this study provides clarification on how the death of a child impacts racialized immigrant fathers' perspectives and approaches to seeking grief support services from the healthcare system.

Anti-Oppressive Practice

The word "oppress" is derived from the Latin word "oppimere", meaning to press against or to press on (Dalrymple & Burke, 1998). Oppression may be based on gender, class, race, and a variety of related factors. Oppression is complicated and may be experienced on both structural and personal levels. Oppression is dehumanizing. Oppression often becomes evident when a dominant group misuses its power in order to treat other groups in a degrading, unjust manner (Dalrymple & Burke, 1998; Sakamoto & Pitner, 2005).

Power is a social concept that describes the connections among people and may be viewed from multiple perspectives (McGibbon & Etowa, 2009). For example, power can be used to include and exclude individuals from racialized backgrounds in all aspects of healthcare, from access to healthcare services to participation in research on healthcare practices. Within

health research power is sometimes used to include racialized families in a research project after a study is completed as a form of tokenism (Tuhiwai Smith, 2008).

According to Payne (1997), anti-oppressive practice is influenced by numerous societal, political, and financial elements. Anti-oppressive practice recognizes power differentials among individuals and groups based on social location and seeks to create a more equitable balance of power distribution in society. The notions of power and powerlessness are frequently at the forefront of social workers' minds because these concepts facilitate the identification of oppression and the subsequent implementation of anti-oppressive interventions and practices. Anti-oppressive practice works to ameliorate the power imbalance experienced by marginalized groups and puts race at the centre of action in order to eliminate oppression (Yee, 2005). The role of healthcare providers who practice from this theoretical perspective is to identify the needs of patients and take action against the systemic barriers preventing access to appropriate healthcare services (Sakamoto & Pitner, 2005). Anti-oppressive practice involves developing goals with clearly defined objectives and timelines, evaluating the intervention process, and networking with key stakeholders or community allies. While this theoretical perspective has an overarching value critical in social work, it has been criticized for its inability to achieve equality on the individual and micro level (Sakamoto & Pitner, 2005).

Social workers should be aware of their lack of power in relation to their position within the organizations they are employed in, as well as their power in relation to the marginalized individuals who access social work services (Dalrymple & Burke, 1998; Mattsson, 2014; Sakamoto & Pitner, 2005). Practicing in an anti-oppressive manner helps social workers to allow the voices of oppressed individuals to be heard. Critical self-reflection and self-assessment is a key component of social workers' ability to practice in an anti-oppressive manner (Mattsson,

2014; Sakamoto & Pitner, 2005). Anti-oppressive practice involves critical self-assessment and self-reflection. In attempting to implement anti-oppressive practice, social workers may be limited by a lack of commitment from upper management, inadequate financial resources, and competing priorities. This study establishes that racialized immigrant fathers who have lost a child would benefit from bereavement services that include an anti-oppressive practice approach where clear actions are taken to advance the care provided to these fathers. Anti-oppressive practice is crucial in developing social justice and equitable bereavement services for racialized immigrant fathers.

Summary

This chapter has delineated three crucial components. First, theory is a foundation of social work practice. Four social work conceptual and theoretical frameworks were highlighted: anti-oppressive practice, critical race theory, intersectionality, and racialization. These theories support the promotion of social justice and provide diverse perspectives that have informed the understanding of the experience of racialization adopted within the present study. Second, it is important for healthcare providers to understand how Canada's discriminatory immigration history is linked to racialization, discrimination and oppression within the healthcare system. Employing immigration policies that excluded individuals based on race and country of origin contributed to the spread of systemic racism on many levels and across institutions, including health and human service organizations. As a result, many racialized individuals are unable to access the healthcare services they need to maintain optimal health status. Third, none of the four social work concepts or theories highlighted above, can be perceived in isolation because they are inter-related and serve to inform reducing racism, oppression, and inequality. Understanding the diversity of social work theories supports taking action to address the

systemic institutionalized racism that exists within the Canadian healthcare system. When institutional racism is embedded within the healthcare system, achieving optimal health affects everyone (Ford & Airhihenbuwa, 2010).

The focus of this study is to explore the lived experiences of racialized immigrant fathers when their child has died. Reviewing four conceptual and theoretical social work frameworks was appropriate because I am a social worker. Incorporating these concepts and theories into my research helps to ensure that I focus on the voices and experiences of the racialized immigrant fathers. The next chapter, Chapter three, examines specific research literature that further supports the rationale underlying the study. Chapter three includes a review of studies conducted on parental bereavement, the influences of culture in death and dying, and other related topics such as the effect of immigration on men and fathers. Trends in immigration, the healthy immigrant effect, health equity, and social work in healthcare are also discussed.

CHAPTER III: REVIEW OF THE LITERATURE

In this chapter, the literature is reviewed in order to provide an overview of what is known about the experiences of immigrant fathers who have lost a child through death. This review includes information regarding death in different cultural contexts. As mentioned in Chapters one and two, there is a considerable body of literature exploring the experiences of mothers whose child has died, but there are fewer resources on fathers' experiences of bereavement. Existing studies have generally focused on White fathers living in the United States or other countries but not on racialized immigrant fathers in Canada. The recommendations of many of the existing studies indicate that more in-depth studies are needed in order to better understand fathers' bereavement needs and lived experiences. In qualitative research, "lived experience" means human experiences that researchers probe in order to understand what that experience means to research participants (Charmaz, 2006).

In this chapter, the effect of losing a child on parents and particularly racialized immigrant fathers is first explored in order to illustrate the significance of the loss for bereaved parents. Factors such as the influence of culture on death and dying in adults and children, the experiences of immigrant fathers in regard to receiving healthcare services, and barriers to accessing healthcare services are included to provide a context for understanding the experience of the fathers who participated in the study. The importance of cultural competency within healthcare is discussed. Gaps in the current knowledge base are identified, with particular attention to the need for more qualitative research on grief experiences and health statuses of immigrant fathers.

When a Child Dies: The Impact on Parents

Following the loss of a child through death, the period of mourning and bereavement may be longer than the time the child had lived (Miller & Ober, 1999). Grief is a complicated and personal process. Experiencing the loss of a child is often conceived as being the most traumatic event anyone can endure in their lifetime (Hensley, 2006; Li et al., 2003; Woodgate, 2006). This knowledge underscores the importance of developing grief programs that are targeted specifically to the needs of bereaved parents (Aho et al., 2011). Bereaved parents generally experience a multiplicity of feelings including, but not limited to, “despair, panic, blame, anger, detachment, disorganization, personal growth, shock, disbelief,” resulting in “strong emotional reactions, somatic symptoms, difficulties in social interaction, and a challenge to the meaning of life” (Aho et al., 2011, p. 880). Bereaved parents may also experience depression, anxiety and a sense of loss of control over life (Walsh & McGoldrick, 1991). Many parents who have experienced the death of a child continue to search for reasons for the child’s death, to develop a belief system that confirms whether they will ever see their child again, and/or to determine whether they are to blame for the child’s death (Miller & Ober, 1999). Bereaved parents must also continue living their lives on a day-to-day basis, including meeting the needs of their other children, continuing their marital relationship, and remaining employed. As a result, on the surface, some bereaved parents may seem to live their lives as if nothing significant has happened.

It is understandable that there is a great deal of trauma associated with the death of a child. Following the death, bereaved parents typically try to settle into a new routine and establish a “new normal”. However, some parents may be left with an inability to express their grief, which may alienate them from their family members and support systems as others may

not know how to meet their needs (Miller & Ober, 1999). The result is that many bereaved parents become seriously physically and emotionally ill, sometimes irreversibly (Li et al., 2003). The lived experiences of bereaved fathers, especially racialized immigrant fathers, are not well understood. For this reason, ongoing research is needed to enhance understandings of their experiences because the death of a child affects the father as well as the entire family system (Cacciatore, 2010).

The death of a child may erode the marital relationships of bereaved parents (Walsh & McGoldrick, 1991). The death of a child often affects the couple's sexual bond (Martin & Doka, 2000) and may intensify pre-existing marital problems (Corr, Nabe, & Corr, 2009). In one study, a break or a decline in sexual intercourse was reported in heterosexual couples' relationships after their child had died (Hagemeister & Rosenblatt, 1997). Further, the death of a child can impact the marital relationship negatively resulting in high rates of divorce (Badenhorst, Riches, Turton, & Hughes, 2006; Hagemeister & Rosenblatt, 1997; Lang & Gottlieb, 1993; Murphy et al., 1998; Riches & Dawson, 1996; Wing, Burge-Callaway, Rose, & Armistead, 2001). Marital troubles can be especially challenging for immigrant fathers as in many instances they might not have other family members in the host country. However, Lang and Gottlieb (1993) described study results that suggest that the loss of a child could improve a marital relationship, specifically the physical closeness of the couple (Hagemeister & Rosenblatt, 1997; Lang & Gottlieb, 1993). As a result of this closeness many marriages can develop a stronger bond following parental bereavement (Wood & Milo, 2001).

Importance of communication and ensuring self-identity are important factors in maintaining a healthy marital relationship among bereaved parents (Riches & Dawson, 1996). There is no doubt that the death of a child has a severe effect on the well-being of both of the

parents and on their interactions as a couple. Coping with the death of a child is considered to be a lifelong process for many bereaved parents (Walsh & McGoldrick, 1991). Better understanding of the difficulties that parents experience when their child has died would help healthcare providers to offer grief and bereavement services that acknowledge the highly individualized nature of parental loss and grief.

An association between losing a child and increased probability of early mortality of the bereaved parents has been established in a large-scale follow-up study (Murphy, Johnson, & Lohan, 2003). Mothers and fathers both have high mortality rates after the death of a child. The study results indicated that the mothers included in this study had a higher rate of health issues, such as exhaustion and the stress of bereavement when compared to the fathers. The study also found that the mothers were more at risk of dying from natural causes but the fathers were more at risk of dying from unnatural causes such as suicide and car accidents. Following the death of a child, mothers experience increased mortality throughout their lifespan in comparison to mothers who have not experienced the death of a child. In comparison, after the death of a child, the mortality rate of fathers is higher in the first year when compared to fathers who have not experienced the death of a child (Murphy et al., 2003). According to Li et al. (2003) the stress associated with parental bereavement can directly impact parents' biological functioning. They explain, "stressful life events can affect the sympathetic nervous system, the hypothalamic-pituitary-adrenal axis, the neuroendocrine systems, and the immune systems, which could result in various diseases" (p. 363).

As noted in Chapter one, research conducted in the area of parental loss and grief has historically mostly involved mothers. This research has included investigation of mothers' experiences of prenatal and perinatal losses. In some instances, mothers who have experienced

the death of a child during childbirth prefer to leave the postpartum care area immediately while other mothers prefer to receive aftercare (Corr et al., 2009). It has been identified that men and women cope with grief differently because of general socialization pressures; in many instances, male griever are uncomfortable sharing their feelings and are less likely to seek grief support (Staudacher, 1991). However, further research is necessary to understand the experiences of bereaved fathers (Martin & Doka, 2000). Such research will help healthcare providers to build knowledge and understandings around the grief experiences of fathers that can be applied in practice (McCreight, 2004).

Societal expectations of how men should behave following the death of a family member and how men should behave in general as the leader, the protector, the fixer, and the “rock” of the family, causes all kinds of problems in how men are perceived, especially when grieving (Doka & Martin, 2002). A father’s role in shielding his wife and children from anything that could hurt them may become much more pronounced after he has suffered the death of a child (Staudacher, 1991). The protector role may have a negative effect on how a bereaved father grieves the death of his child based on the expectations associated with this role (Staudacher, 1991). On top of fulfilling his role as protector, there are societal expectations for how a father should mourn the death of a child (Doka, 1996; McCreight, 2004). These expectations depend on the cultural norms and values individuals abide by which also influence the grieving processes of both men and women (Doka, 1996).

In general, it is believed that gender influences how individuals react upon receiving the news of that a loved one has died (Koo, Fong Tin, Koo, & Lee, 2010). For example, women are said to be more likely to express what they are experiencing through verbal communication whereas men tend to respond to grief by expressing anger, keeping busy, and experiencing guilt

and aggression (Doka, 1996; Martin & Doka, 2000; McCreight, 2004). Wood and Milo (2001) noted that the bereaved fathers who participated in their study coped with their grief through activities and displayed stoicism instead of discussing their grief verbally or using social support. The activities that the grieving fathers engaged in included playing sports, reviewing of the medical literature relevant to their child's death, and attending their jobs (Wood & Milo). Paying attention to "men's unique voice of pain" (Pollack, 1998, p. 148) can be a way to gain insight into how men grieve and mourn. Although there is no evidence that men grieve less than women, it is clear that males and females have different patterns of grieving. To place the expectation on fathers to grieve the same way as mothers puts a lot of pressure on the fathers and distorts the roles and behaviours associated with men's grief (Zinner, 2000). There is a need for further studies examining the roles and behaviours of fathers whose child has died.

Culture, Death, and Dying

Williams and Spencer-Rodgers (2010) define culture "as a set of shared meanings and practices that are transmitted, communicated, and reinforced among members of a cultural group, and that, in turn, influence the values, beliefs, emotions, and behaviours of their members" (p. 591). Other authors described culture as "the integrated pattern of human behaviour including thought, communication, ways of interacting, roles and relationships, and expected behaviours, beliefs, values, practices, and customs" (Denboba, Bragdon, Epstein, Garthright, & Goldman, 1998, p. S47). As Canada continues to diversify ethnically and culturally, healthcare providers need to take into consideration cultural factors that could affect death, dying and bereavement experiences. Failure to embed cultural competency within bereavement service design and delivery hinders the process of grieving for patients and their families (Clements et al., 2003). One of the reasons the present study is being conducted is

because each person's experience of death and dying is uniquely multifaceted. In particular, the experience is influenced by an individual's cultural background (Martin & Doka, 2000).

Likewise, the experiences of racialized immigrant fathers after their child has died is modified and mediated by the fathers' cultural backgrounds and contexts. Their culturally informed perspectives on death and dying are different from conventional Western conceptualizations. Developing cross-cultural perspectives on death, dying and bereavement sheds new light on bereaved fathers' lived experiences and forces healthcare providers to take note of and if necessary, revise their own assumptions (Parkes, Laungani, & Young, 1997).

Cultural background and associated processes of socialization influence views on death and dying, including end-of-life processes, rituals and practices (Saiki-Graighill, 2001; Srivastava, 2007). Culture influences the meaning ascribed to illness, help-seeking behaviour, the language used to discuss illness and death, and the symbolic value placed on a child's death. Culture affects the lived experience of the pain and suffering associated with bereavement and mourning, as well as specific beliefs and practices related to the end of life (Pottinger, Perivolaris, & Howe, 2007). Cultural values and norms may further dictate the appropriate role of healthcare professionals and family members in preparing the body after death (Saiki-Graighill, 2001).

As established above, culture, in its many forms, influences peoples' perceptions of illness, suffering, and dying (Kagawa-Singer & Blackhall, 2001). However, due to cultural variations people from the same cultural background may not behave in the same ways following the death of a loved one (Lynch & Hanson, 2002). An individual's response to a death may be impacted by social, ethnic, religious, and philosophical values and beliefs, in addition to cultural values and norms (Rando, 1984). As culture is an important component of an individual's

character, special consideration should be provided when discussing death and dying with fathers from racialized backgrounds. According to Field and Berhman (2003), some families will experience cross-cultural misunderstandings when accessing healthcare services.

Cultural Competency

The present review of the literature reveals that considerable progress has been made in understanding the importance of cultural competency in healthcare and in end-of-life care for adult patients (Kagawa-Singer & Blackhall, 2001; Koenig & Davies, 2002). According to Denboba et al. (1998), cultural competency refers to:

An individual's and program's ability to honour and respect those beliefs, interpersonal styles, attitudes, and behaviours both of families who are clients and the multicultural staff providing services. In doing so, the program is able to incorporate these values at the levels of policy administration and practice. (p. 47)

In practice contexts, cultural competency is not limited to awareness building and sensitivity; it is a concept that includes knowledge creation and skill acquisition. Equally important in cultural competence is the relevance of self-awareness (Field & Berhman, 2003; Srivastava, 2007). It is crucial to help healthcare providers reflect on their biases, stereotypes, and racist attitudes in order to understand that to work effectively with racialized families, they need to acquire and use certain skillsets. Field and Berhman (2003) stated that when healthcare professionals incorporate a family's cultural, ethnic, and religious beliefs about death and dying into the services being provided, the family is better able to cope with the loss of a child.

There is evidence that many bereaved parents from racialized backgrounds do not access mental health support when needed, including grief and bereavement services (Clements et al., 2003; Shapiro, 1996). Lack of culturally competent care negatively affects families from

culturally diverse backgrounds who have experienced the death of a child (Clements et al., 2003; Davies, Contro, Larson, & Widger, 2011; Hebert, 1998; Srivastava, 2007). Healthcare providers should have a deeper understanding of the cultural and social circumstances affecting the grief experience in order to effectively support bereaved parents (Shapiro, 1996). In addition, healthcare providers need to self-evaluate their perceptions regarding death and dying and the influence of these perceptions on the care they provide. Furthermore, they also need to assess their assumptions and biases regarding bereavement in cross-cultural contexts (Clements et al., 2003; Parkes, 1997; Srivastava, 2007). Developing cultural competency is a lifelong journey. Based on my experiences with addressing cultural competency over the past 20 years I recognize that it takes individual and organizational commitment, planning, dedication and inclusion.

Culturally Informed Customs and Rituals Associated with Death, Dying and Bereavement

Culturally and ethnically diverse groups may observe numerous customs, traditions, and rituals when an individual dies. These rituals and traditions share many common features. Belonging to one particular group does not mean that an individual will observe the same rituals as everyone else within their group, as there is diversity within the groups and subgroups associated with each culture. Some individuals wail loudly, others may wear black, white, or blue only during the funeral. Crying in public is sometimes allowed although, in the case of men, it is not accepted among all cultures (Clements et al., 2003). For some groups, their cultural beliefs are closely aligned with spiritual or religious beliefs in rebirth, Karma, God, or Allah's will (Hebert, 1998). These spiritual or religious beliefs can help individuals to manage their grief and add meaning to the experience of grief and loss. Following the death, cleansing and preparing the body for burial is highly regarded by some groups, as is the timing of the burial or cremation (Clements et al., 2003). Some cultural groups become very protective of the

bereaved mother following the death of a child and they may ask that she does not attend the child's funeral (Hebert, 1998). There are specific observations of grief days in different cultural communities (Firth, 1997; Gatrad, 1994), as this supports the survivors in their grief processes. One of the important points in the present study is that the different responses to grief that are grounded in culture are not well understood in Canadian society in general, or the healthcare system in particular.

Although many cross-cultural rituals and traditions could be described, it would not be beneficial or possible to list them all here. The keys to understanding how to provide culturally competent services for healthcare providers are: (a) to know what questions to ask each individual; and (b) to approach each person as a unique entity. To improve end-of-life and bereavement care services, further research in the areas of clinical, cultural, and organizational practices related to end-of-life and bereavement care should be conducted (Field & Berhman, 2003; Gatrad & Sheikh, 2002; Koenig & Davies, 2002). Recommendations to conduct research on the experiences of fathers and mothers from diverse cultural and religious backgrounds when a child is dying or has died have been made elsewhere (Davies et al., 2004; Saiki-Graighill, 2001). For example, Davies et al. (2004) recommend that: "future research should explore the experience of fathers of varying backgrounds with regard to race, ethnicity, sexual orientation, marital status, whether the father lives with the child, geographic areas, and experiences with varying end-of-life care programs" (p. 133). Given these critically important multidimensional elements, it is essential that healthcare providers, in particular those who work in palliative and end-of-life care settings, understand racialized fathers' lived experiences of bereavement and the effects on their health status when their children die.

Understanding the Death of a Child in Cultural Context

Emerging research on the experiences of bereaved parents from different cultures is available from the United States, Denmark, Japan, Australia, and Finland. Studies conducted in the United States cover the experiences of White Americans and African Americans (Davies et al., 2004) as well as Mexican Americans and Chinese Americans (Davies et al., 2011). In one study Davies et al. (2011) interviewed 10 Chinese Americans and 26 Mexican Americans who had lost a child through death six months to five years prior to the study. The study results showed that language, healthcare providers' lack of experience in palliative care, focus on cure, and discomforts in discussing dying were barriers to receiving effective and culturally competent healthcare. Language and cultural barriers, particularly regarding different types of information-sharing by healthcare professionals, spiritual care staff, and other parents, were perceived as challenges in receiving and providing end-of-life care. When there was insufficient information sharing, the parents experienced frustration, resentment, and sorrow long after the death of their child (Davies et al., 2011).

In another study, Davies et al. (2004) interviewed eight fathers who were either racially White or African American, who had experienced the death of a child no more than three years and no less than one year prior to the study. A retrospective grounded theory method was used in the study. The researchers noted that the fathers referred to their experiences of losing a child as "one living in the dragon's shadow" (p. 118). According to the fathers, dragons are perceived as creatures that attack heroes and these fathers felt they had to battle the dragons for their children. The findings illustrate that although the fathers had experience in accessing bereavement services, "interactions between fathers and professionals were not always smooth and pleasant" (p. 131).

As Canada and many other parts of the world continue to diversify through immigration, healthcare providers should consider the beliefs, rituals, and customs of each family that they work with (Rice, 2000; Srivastava, 2007). This strategy is important during bereavement because each of the above factors may affect the grievers' experience after the death of a loved one (Clements et al., 2003; Rice, 2000; Srivastava, 2007).

Several examples from various cultural groups illustrate between-group differences in regard to grief and bereavement processes. The following paragraphs will illustrate some of the differences by presenting the processes generally associated with select cultural groups, including Chinese, Japanese, Korean, Vietnamese and Hindu cultures.

Death is usually perceived as a prohibited subject in Chinese culture and is not to be discussed (Chan & Chow, 2010). In Chinese culture, discussing a child's death is discouraged because it is perceived as bad luck (Braun & Nichols, 1997). When a child dies before the parents do, some Chinese people believe that the death is caused by evil spirits or is a form of punishment (Braun & Nichols, 1997; Woo, 1999). Grief in the Chinese culture is kept within the family (Braun & Nichols, 1997) and many people refrain from expressing emotion; they would rather keep emotional distress to themselves (Woo, 1999). Many Chinese families will not seek professional grief and counseling services (Braun & Nichols, 1997; Woo, 1999).

A research study in Japan examined families who had lost a child to cancer; 13 Japanese families who had lost a child in the previous three years were interviewed (Saiki, Martinson, & Inano, 1994). Japanese families wanted to be included in the treatment options and discussions about their child's illness (Saiki, Martinson, & Inano, 1994). In Japanese culture, a diagnosis such as cancer may not be accepted as the cause of death due to the stigma associated with the disease (Davis, Konish, & Mitoh, 2002). As in Chinese culture, researchers noted that Japanese

families prefer not to engage in conversations about grief (Miyaji, 1994).

In the Korean culture, if a parent or spouse dies, they are buried but it is believed that when a child dies the child is buried in the heart of the parents (Martinson, Lee, & Kim, 2000). In the Filipino culture, they believe that when a child dies he or she goes to heaven, as a child is without sin (Parry & Ryan, 1995). Similarly, many Muslims believe that the soul of a child ascends straight to paradise because all children are innocent (Gatrad & Sheikh, 2002). The father or another family member performs the bathing ceremony of the deceased child, but not the mother (Gatrad & Sheikh, 2002). The age of the child, including loss of young children even in utero loss does not change the fact that bereaved parents grieve their dead children. In this case the sense of grief and loss is no different from that of parents who have lost an older child (Hebert, 1998).

Karma, the spiritual belief in the rebirth of an individual, is adhered to within Vietnamese culture and it strongly influences perceptions of the death of a child (Braun & Nichols, 1997). It is believed that the child's cause of death is due to the past lives of the family or the child's own misdeeds (Braun & Nichols, 1997). The same belief exists in the Hindu culture (Laungani, 1996). The death of a male child in the Hindu culture is considered a greater loss compared to the illness or death of a female child (McGoldrick & Walsh, 1991).

Overall, Field and Berhman (2003) stated that when healthcare professionals incorporate the family's cultural, ethnic, and religious beliefs about death and dying into their practice, whatever those beliefs may be, the family is better able to cope with the loss of a child. The above section provides several examples of cultural beliefs and expectations associated with child death. Across cultures, there are both similarities and differences in how fathers grieve their child's death and how the death of a child is perceived. Since culture is just one aspect of

the way an individual expresses grief, it is important to be aware of all the other aspects effecting grief when conducting qualitative research. In regard to the present study, the lived experiences of racialized immigrant fathers should be viewed in the context of the fathers' cultural values and beliefs.

Equity and Social Justice in Healthcare Services

In this section of the chapter the following topics will be discussed: equity, social justice, barriers to accessing healthcare services, healthy immigrant effect, and health research on racialized immigrant fathers. Some evidence has shown that immigrants experience equity issues in accessing healthcare services (McGibbon & Etowa, 2009; Srivastava, 2007). Braveman (2013) noted that the presence of health equity in healthcare is equivalent to social justice in healthcare. Social justice in healthcare means that individuals experience no systemic health disparities (Braveman & Gruskin, 2003). In order to address health equity and health disparity, a clear definition of health equity is required. Accordingly, health equity can be defined as:

The principle or goal that motivates efforts to eliminate disparities in health between groups of people who are economically or socially worse off and their better off counterparts such as different racial/ethnic or socio-economic group or groups defined by disability status, sexual orientation, or gender identity by making special efforts to improve the health of those who are economically or socially disadvantaged. (Braveman, 2013, p. 1)

Through the measurement of health disparities, researchers are able to measure whether or not health equity is improving for communities. Health inequities experienced by racialized communities in Canada include: cardiovascular disease, cancers, occupational and environmental

illnesses, diabetes, mental health, HIV/AIDS, intimate partner violence and domestic abuse, tuberculosis, liver transplantation, and female genital cutting (Nestel, 2012).

Due to health disparities linked to race and ethnicity, many individuals who already experience marginalization are placed in a position of having compound disenfranchisement in their life. When an individual has equity in health, that person has the same opportunity as everyone else to be healthy. This is possible when everyone has access to resources that are dispersed equitably (Braveman & Gruskin, 2003). The general theme here is that racialized groups experience barriers in accessing healthcare and that racism, discrimination, and other settlement issues continue compound these barriers. It is also important to note that equitable services are not the same as equal services. Equitable services mean providing services to everyone based on diverse needs to address unequal barriers that individuals face (Patyчук, 2011). Social justice is an important aspect of Canada's commitment to eliminating health disparities and providing equitable healthcare services. In order to achieve equity in healthcare there has to be awareness of the disparities, the root causes of marginalization, and ways to solve the problem at a structural level rather than on a case-by-case basis (Peter, 2001). This awareness will certainly support social workers to pursue social justice in healthcare especially because they will understand the manifestation of health inequities and different ways to address this issue.

Professionals and researchers frequently use health equity and health disparity measures to advance specific arguments and provide rationale for health funding decisions. The reasons that health inequity persists are manifold, including racial biases and stereotypes that perpetuate inequities in healthcare organizations (Nestel, 2012) as well as the impact of racism on individuals and groups more generally (Smedley, Stith, & Nelson, 2003). The literature suggests

that structural racism and White privilege produce and perpetuate health disparity for racialized individuals (Patyckuk, 2011). Effectively, racism is a major cause of poor health outcomes for people from racialized backgrounds (Brondolo, Gallo, & Myers, 2009; Chae, Nuru-Jeter, Lincoln, & Francis, 2011). For example, among immigrant women racial discrimination can alter “their hormonal, immune responses, making some immigrant women more vulnerable to pre-term labour and low birth weight” (Reitmanova & Gustafson, 2007, p. 102). Other studies point to adverse consequences related to the physical health and mental health of racialized populations (Neighbors, Neighbors, & Jackson, 2003; Rutter & Tienda, 2005). Harding (2005) stated that racism has the greatest effect on the mental health status of immigrant women. Waldron (2005) identified racism as the most important mental health issue affecting the lives of people of colour. Racism is frequently experienced at the personal and institutional levels, including when seeking employment, when new immigrants want to apply their educational skills in Canada, and with injustices in salaries (Canadian Race Relations Foundation, 2008).

Experiences of racism may result in social trauma, negative physiological and psychological effects, and insufficient access to healthcare services, along with insensitive clinical support (Nestel, 2012). A racialized immigrant father who has experienced racism and then suffered the loss of a child may be compared to what Cook (1988) refers to as someone experiencing a “double bind”. This means that this father not only has to address his trauma related to encountering racism but also thinking about the added stress of coping with his loss and grief related to the death of his child. In such cases fathers’ levels of trust towards healthcare providers might be impacted by negative experiences, including institutional racism, resulting in fathers not accessing bereavement support services or following through with other care recommendations.

Canada espouses human rights as an important value, yet a study by the Association for Canadian Studies published in 2013 found that over one-quarter (28%) of Canadians say that they have personally felt discriminated against or harassed for their ethnicity, age, or sexual orientation. In this same study, 41% of individuals in the study reported having witnessed discrimination. Veenstra (2009) noted that the inequality in power associated with racialization affects the health of individuals. Health researchers are, therefore, encouraged to engage racialized individuals in ongoing health research by including them as research participants and co-investigators.

Barriers to Accessing Healthcare Services

Ethnic, cultural and socio-economic backgrounds may affect how individuals perceive the content and accessibility of healthcare services. For instance, in some North American studies, ethnicity has been found to explain low rates of access to preventative healthcare services among some groups such as African Americans, foreign-born Black fathers, and Muslim women (Doyle et al., 2012; Sharif et al., 2000). When health resources do not work from a culturally competent perspective, users are less likely to access these services, and even if they do, the services may not be effective (Clements et al., 2003; Hebert, 1998; Parkes, 1997; Rice, 2000; Srivastava, 2007).

Cultural barriers to accessing healthcare services may include attitude towards suffering, etiology of illness, distrust of Western medicine, unfamiliarity with Western medical methods, cross-cultural communication, healthcare professionals' cultural ignorance, lack of knowledge of available health resources, and misinterpreting side effects of medication (Uba, 1992). Cultural barriers to accessing healthcare services often arise from differing worldviews on health and illness and lack of understanding of the cultural content and context of available resources

(Sharif, Dar, & Amaratunga, 2000). Barriers to accessing healthcare services will continue to exist when families have a different understanding of health and illness than does their healthcare provider. The area of paediatric death and dying provides a poignant example. Healthcare providers in this service area have said that many barriers exist for families to access bereavement services. The barriers occur in particular for racialized immigrant fathers who are grieving the loss of a child and experiencing changes in their own health status. Barriers to accessing services thus indicate increased disparity in health for marginalized individuals including racialized parents, especially fathers (Solas, 2008).

Limited knowledge of the Canadian healthcare system most often causes disappointment with services received by racialized immigrant families based on their expectations of what type of services should be provided (Donnelly & McKellin, 2007; Liu, So, & Quan, 2007; Zhang & Verhoef, 2002). This limited knowledge is related to a lack of awareness of the types of services available and the different roles of healthcare providers on an inter-professional healthcare team.

Healthy Immigrants upon Arrival

Opposition to Canada's liberal immigration policies is based on the perception that immigration places great pressure on healthcare and social welfare systems. However, this perception does not take into account the "healthy immigrant" effect (Srivastava, 2007; Wu & Schimmele, 2005). A growing body of literature describes this effect. Essentially, first-generation immigrants are often healthier than (a) Canadian-born individuals who share similar ethnic or racial backgrounds, or (b) their White counterparts (De Maio & Kemp, 2010; Fennelly, 2007; Hyman, 2007; McDonald & Kennedy, 2004; Srivastava, 2007). The healthy immigrant phenomenon has been observed in Canada, Australia, the United States, and the United Kingdom (Kobayashi & Prus, 2012).

Hyman (2007) and Ali, McDermott, and Gravel (2004) have conducted extensive reviews of the literature on immigration and health. They concluded that new immigrants to Canada, especially from non-European countries, have better health compared to Canadian-born racialized groups. However, the immigrant health advantage diminishes dramatically with each successive generation especially in the areas of self-reported health (Newbold & Danforth, 2003; Ng, Wilkins, Gendron, & Berthelot, 2005), mortality (Wilkins, Tjepkema, Mustard, & Choinere, 2008), self-reported disability (Chen, Ng, & Wilkins, 1996), and self-reported chronic disease (McDonald & Kennedy, 2004). It has been reported that the manner in which immigrants are selected to come to Canada, which is based on educational attainment and excellent physical health, are the biggest contributing factors to the healthy immigrant effect (Wu & Schimmele, 2005).

As part of Canadian immigration policies, individuals who wish to move permanently to Canada have to undergo a rigorous medical examination (Gushulak, 2007). The subsequent decline in health post-migration is related to changes in diet, lack of physical exercise, increased weight, and use of substances such as alcohol and tobacco. Although many studies have indicated that immigrants arrive healthy in their host country because they are screened prior to immigration, their health often declines after approximately ten years (Srivastava, 2007; Wu & Schimmele, 2005). Despite this finding, there is no public health agenda to keep immigrants healthy (Kobayashi & Prus, 2012). According to Gushulak (2007), more research is needed in this area to help racialized immigrants remain healthy in the host country.

Health Research on Immigrant Fathers

As discussed earlier, the lack of fathers' inclusion in bereavement research is well documented. Most of the relevant research has been on women rather than men (Bartlett, 2004;

Cooper-Patrick et al., 2002). Even when some studies have stated that the focus of the study is on both parents, in reality the focus has often ended up being placed on mothers (Hebert, 1998). Bartlett (2004) stated that little is known about the physical and psychological health of fathers in general since many studies over the past 80 years have dealt only with the health experiences of mothers. Barclay and Lupton (1999) noted that this is a sign of health disparity and it presents a major gap in family research. However, research is now extending to fathers and their involvement in the well-being of their families (Plantin, Mansson, & Kearney, 2003). For example, fathers have been included in studies examining issues of male parenting pertaining to their relationship with work, sports, violence, and sexuality (Lupton & Barclay, 1997). While little research incorporates the voice of fathers in general and racialized immigrant fathers in particular (Davies et al., 2004), some researchers have attempted to identify the benefits of including fathers as participants in their studies.

A study conducted by (Roer-Strier, Strier, Este, Shimoni, & Clark, 2005) examined the systemic barriers and obstacles that immigrant fathers experience in the host country (Canada and Israel) and the numerous possibilities and advantages resulting from immigration. This qualitative study consisted of 54 interviews examining the involvement of immigrant fathers with their children while experiencing difficulties in settling in their new country. The study results may help service providers and health and human service organizations to create services that will benefit immigrant families. The first American study to provide national estimates of mental disorders among ethnic populations of Black fathers concluded that US-born Caribbean Black fathers had a higher rate of mental disorders and less access to mental health services than African American fathers and foreign-born Caribbean Black fathers (Doyle et al., 2012). The findings of this study offer healthcare providers much-needed information regarding how to

include fathers when making decisions about mental health services. This study recommended that further research is needed to gain understanding of the help-seeking behaviours of ethnically diverse fathers.

Este and Tachble (2011) conducted a study with Sudanese and Russian immigrant men in Calgary, Alberta exploring the relationship between fatherhood experiences and their health and well-being. The gender expectations of fathers in Canada (including the issues of gender roles, unemployment/underemployment, racism, discrimination, lack of social support, and low self-esteem) were noted as eroding the fathers' health and well-being. If not addressed, a combination of these issues has been reported to cause mental health problems, marginalization, and isolation.

A study related to racialized fathers' experiences of grieving a child was conducted in Australia among Maori men. The researchers investigated the participants' experiences of grief when losing their child to sudden infant death syndrome (Edwards, McCreanor, Ormsby, Tuwhangai, & Tipene-Leach, 2009). These studies indicated that it is important for fathers to grieve and that men have their own ways of grieving. Notably, all of the remaining studies reviewed were conducted with White men as participants and dealt with fathers' grief over either perinatal deaths (Badenhorst, Riches, Turton, & Hughes, 2007; Worth, 1997); deaths of children with disabilities (Wood & Milo, 2001); or deaths of children experiencing cancer (Chesler & Parry, 2001; Cook, 1988; Neil-Urban & Jones, 2011). Although it is presumably acceptable for men to show their feelings publicly, the socialization for men in regard to expressions of grief still favours the masculine manner of grieving which limits emotionality. This socialization is informed by traditional gender roles and stereotypes (Cook, 1988; Wolfelt, 1990). Research suggests that it is difficult for many men to conform to these social roles when it comes to

grieving losses (Doka, 2009; 2016). When men cannot mourn or grieve in the way they want or need, they also cannot heal.

Summary

The literature provides a foundation for (a) examining the lived experience of parents when their child has died, and (b) culturally informed values, beliefs and practices regarding paediatric death and dying. There are differing values, beliefs and practices related to a child's death across cultures. Enhanced understanding of how culture and gender intersect in regard to grief is needed, particularly regarding fathers' experiences. While some studies have included fathers' perspectives, they have not included racialized immigrant fathers nor examined the effects of bereavement on their health status when their child has died.

Through qualitative research, such as in the present study, racialized immigrant fathers will be able to express their experiences in a detailed manner so that society, particularly the healthcare system and healthcare providers, can build greater awareness regarding the needs of fathers and the societal beliefs and expectations of men in general when it comes to grieving. One such belief discussed above is that fathers are expected to be the strong one in their family, just as society expects a stoical, masculine mode of grief from men. This expectation marginalizes many men by disenfranchising their experiences of loss and grief. The literature shows that grief is an individual experience and placing any expectation on how people should grieve has the potential to cause harm (Doka, 2009; Hooyman & Kramer, 2006). Racialized immigrant fathers are already marginalized as newcomers who face barriers related to working in their field of expertise, language, adaptation to culture and weather, racism and racialization, and learning to navigate the healthcare and social services systems in their new country. It can be overwhelming and devastating when a father's grief is ignored or disenfranchised. All of these

factors make grieving the loss of a child unnecessarily complicated for racialized immigrant fathers. Other relevant subjects discussed in Chapter three included culture, death, dying; cultural competency; customs and rituals at time of death; social justice and access to healthcare services. Next, Chapter four focuses on constructivist grounded theory, the research methodology used in completing my research.

CHAPTER IV: RESEARCH METHODS

Qualitative research is especially well suited for studying phenomena where little is known about the subject (Schreiber, 2001; Streubert & Carpenter, 2007). Research methods extend and magnify the researcher's perspective of what is being studied, which in turn provides a deeper level of understanding of the phenomena (Charmaz, 2010). Using qualitative approaches improves insight into the lived experiences of research participants. According to Denzin and Lincoln (2003), employing a qualitative research approach allows researchers to gain understandings regarding the manner in which meaning is socially constructed. The purpose of qualitative methods is:

To stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry . . . they seek answers to questions that stress how social experience is created and given meaning. (Denzin & Lincoln, 2003, p. 13)

All qualitative studies need to be centred on building understanding of the particular phenomenon being investigated. The study participants, the stakeholders who requested the study, the readers, and the researchers are secondary to understanding the phenomenon itself (Creswell, 2007). Qualitative researchers must recognize and challenge their own experiences, biases and stereotypes and ensure these factors are accounted for within the study.

The current study adopted Charmaz's constructivist grounded theory methodology (Charmaz, 2009; 2010; 2011) to inquire into the experience of racialized immigrant fathers who have experienced the death of their child. This study generated a detailed, contextual description of the experiences and the health statuses of racialized immigrant fathers following a child's death. The process of reviewing the experiences of participants, and informed by the literature

and utilization of constructivist grounded theory as a tool, I was able to develop a theoretical explanation of the death of a child of racialized immigrant fathers. The theory that emerged is: Hollow from the inside - the death of a child served as a reinforcing process for ongoing loss linked to racialized immigrant fathers' experience of immigration. This research aided in creating greater awareness and insight of the complex processes related to racialized immigrant fathers' experiences when a child has died.

Constructivist grounded theory is a research methodology that evolved from classical grounded theory (Glaser & Strauss, 1967). A description and history of the grounded theory methodology is presented next.

The History of Grounded Theory Methodology

The Traditions of Grounded Theory

According to Glaser and Strauss (1965), grounded theory is a perspective-based methodology that recognized the uniqueness of each individual's perspective. In grounded theory studies, the researcher tries to conceptualize the varying perspectives of participants in an abstract manner in order to identify a different viewpoint (Glaser, 2002). The goal of grounded theory inquiry is to develop theoretical concepts that describe a specific action or phenomenon within the social context being studied (Stern, 1980). Grounded theory approaches aid in generating a theory that is grounded in the data gathered through the data collection phase of the study (Denzin & Lincoln, 2005). Essentially, grounded theory is based on the systematic generation of theory from data. Thus, grounded theory method offers a rigorous, orderly guide to theory development that is closely integrated with the broader methodology of social research at each stage of the research process. Indeed, conducting social research and developing theory are considered to be two aspects of one process (Glaser, 1978). In the classical grounded theory

approach, the theory is systematically developed from the data that was gathered according to a series of rigidly defined steps (Dey, 2010).

Grounded theory helps us to comprehend the world we live in while generating theories (Strauss & Corbin, 1998). In grounded theory “researchers are encouraged to remain close to their studied worlds and to develop an integrated set of theoretical concepts from their empirical materials that not only synthesize and interpret them but also show a processual relationship” (Denzin & Lincoln, 2005, p. 508). In other words, context is an important consideration in grounded theory research. A grounded theory researcher attempts to understand what is happening within the context where the study is conducted, as well as to study participants’ ways of life within that context (Strauss & Corbin, 1998).

The four main criteria for evaluating the quality of grounded theory research are credibility, originality, resonance, and usefulness (Glaser & Strauss, 1967). Credibility refers to believability of the study. There needs to be enough data presented in order for third parties to form their own opinion. Originality refers to the type of new information this study contributes, while resonance refers to data that is taken for granted and the way in which respondents view this data. Finally, usefulness encompasses social justice and anti-oppressive practice issues as well as opportunities for further research (Denzin & Lincoln, 2005). These four evaluative concepts will be discussed in more detail later in this chapter.

Historical Context and Methodologies of Grounded Theory

Grounded theory methodology was first introduced in the book, *Awareness of Dying* by Barney G. Glaser and Anselm L. Strauss (Bryant & Charmaz, 2007; Charmaz, 2010; Glaser & Strauss, 1965). This book was followed by a second publication by the same authors (Glaser & Strauss), titled *The Discovery of Grounded Theory* in 1967 (Bryant & Charmaz, 2007). These

books outlined a new social research methodology based on a conceptual understanding of social behaviour whereby the theory is developed from the core category that emerges directly from the data (Charmaz, 2005). The two founding methodologists of grounded theory, Glaser and Strauss, felt that the principles used in some studies were usually unsuitable for research participants. When Glaser and Strauss (1967) were developing the classic grounded theory methodology, they contrasted it with flexible research methodology, stating:

The change of emphasis in sociology toward verification of theory, which has been linked with the growth of rigorous quantitative research, has had the unfortunate consequence of discrediting the generation of theory through flexible qualitative and quantitative research. The qualitative research is generally labelled “unsystematic,” “impressionistic,” or “exploratory,” and the flexible quantitative research “sloppy” or “unsophisticated.” These critics, in their zeal for careful verification and for a degree of accuracy they never achieve, have forgotten both the generation of theory and the need for carefully appraising the different degrees of plausibility necessary for sociology’s diverse tasks. (p. 223)

Although Glaser and Strauss developed grounded theory methodology, they went their separate ways after a disagreement on the evolution of the research approach (Creswell, 2007). According to Glaser (1992), Strauss’s way of conducting research using grounded theory was too prescriptive and organized. Strauss went on to develop his own approach to conducting grounded theory research, with his new methodological collaborator, Juliet Corbin, who was formerly his student. Strauss’s approach to grounded theory is often referred to as Straussian grounded theory. As grounded theory continued to develop and its use extended to various academic disciplines, many novice researchers around the world began to apply Strauss and

Corbin's approach of grounded theory within their studies (Creswell, 2007). In 1987, Strauss published a book on grounded theory to clarify his conceptualization and approach to using grounded theory methodology. Strauss also published another book co-authored by Corbin, in which he appeared to separate himself from his former co-author Glaser and some of the tenets of their approach to grounded theory detailed in *Discovery of Grounded Theory* (Strauss & Corbin, 1990). This launched a longstanding debate over various approaches to conducting grounded theory research in which Glaser and Strauss disagreed in their methodological approach, specifically, in relation to Corbin and Strauss' approach to coding and labelling data (Strauss & Corbin, 1990). Strauss and Corbin's grounded theory method is more intricate than Glaser's in terms of research procedures and processes. One benefit of using Straussian grounded theory methodology is that it guarantees a solid understanding of the research process and procedures because it is highly structured and has clearly identified boundaries. However, a theory clarifying the phenomenon under study involving the research participants might not be resolved. Strauss and Corbin examined axial coding that explains situations and the scope of a problem. This research methodology offers a concise philosophical viewpoint for developing theory about the research that is being conducted. In Straussian grounded theory, coding occurs in three stages: (a) open, (b) axial, and (c) selective (Denzin & Lincoln, 2005; Strauss & Corbin, 1990). This is referred to as the constant comparative method and data collection and data analysis occur concurrently in this approach.

Glaser and Strauss have held their methodological differences for decades, yet their publications; both those written together and separately, have propelled grounded theory to become a well-regarded legitimate research methodology (Charmaz, 2010). A distinguishing accomplishment of grounded theory methodology is that it has moved "qualitative inquiry

beyond descriptive studies into the realm of explanatory theoretical frameworks” (Charmaz, 2010, p. 6). A past student of Glaser and Strauss, Charmaz (2006) later developed constructivist grounded theory as a variant of grounded theory methodology. Constructivist grounded theory is the research methodology employed in the present study and is discussed in detail below.

In grounded theory studies, a series of specific procedures guide researchers in gathering and analysing data. Following these methods allows the researcher to be constantly aware of his/her emerging analysis grounded in the data. Grounded theory permits the researcher to investigate processes and explicate what is evolving in the research setting while developing original theories (Glaser & Strauss, 1967). In the end, grounded theory facilitates the development of novel conceptual understandings of social behaviour through identification of a core category or conceptualization (Glaser, 2002). Hallberg (2009) identifies the core category of Glaser and Strauss’ approach as constant comparison. According to Glaser (2002), the core category is an important aspect of grounded theory because it is central to informing the theory that is developed.

In the Glaser and Strauss approach to grounded theory the methodology dictates specific procedures for data collection and data analysis. First, the collected data is coded and these codes are then systematically examined to validate a suggested proposition. Second, the researchers review the data to see whether categories could be allocated to the coded data. In addition, the researchers complete memo writing throughout the research process in order to aid the ongoing analysis and support the development of a clear understanding of the data and the development of theory. To further increase the effectiveness of the data analysis in grounded theory Glaser and Strauss (1967) added the constant comparison method which involves

comparing new data collected in the research interviews with data that had been collected earlier which can support theory development.

After preliminary data collection and data analysis, the beginning of the theory emerges during the merging of codes into concepts and then concepts into categories or themes (Glaser, 1978; 1998; Glaser & Strauss, 1967). In the coding process, the researcher assigns labels to sections of the data. The label must aptly describe each section of data in a few words or a short phrase (Glaser & Strauss, 1967). From the outset, coding helps the researcher to cluster, categorize, and combine the data. During coding, the researcher moves backwards and forwards in the process, analysing the data through constant comparison and generating new areas to find more data, known as theoretical sampling. Through this process of merging and categorizing the data are theorized. During theorizing the most substantive categories are used to create a hypothesis and eventually a theory (Walker & Myrick, 2006).

The historical context was provided to share my understanding of the development of grounded theory and in particular, constructivist grounded theory. A discussion of constructivist grounded theory methodology is presented in the next section of this chapter.

Constructivist Grounded Theory

Kathy Charmaz (2010) utilized Glaser's classical grounded theory to inform the development of constructivist grounded theory. I adopted this methodology in the present study to inquire about the experiences of racialized immigrant fathers and their health status when their child has died. I prefer this methodology because of its methodological flexibility and its acknowledgement of the multiple standpoints, positions, and situations of the researcher and the participants who are viewed as being engaged in a joint research process. As a research paradigm, constructivism denies the existence of an objective reality, "asserting instead that

realities are social constructions of the mind, and that there exist as many such constructions as there are individuals (although clearly many constructions will be shared)” (Guba & Lincoln, 1989, p. 43).

In contrast to earlier grounded theory methods, the outcome of constructivist grounded theory research does not have to be the construction of a theory per se (Charmaz, 2014). This important distinction of constructivist grounded theory is attributed to Charmaz’s acknowledgement that research may be conducted that falls short of theory generation and nonetheless the theoretical narrative that results may be valuable and meaningful. Applying a constructivist grounded theory approach to exploring the narratives of participants can also meaningfully contribute to theory development by enriching our understandings of participants’ lived experiences. In the present study, the constructivist grounded theory approach has been applied to developing rich understandings of the lived experiences of racialized immigrant fathers who have experienced the death of a child.

Epistemologically, constructivism is positioned between postmodernism and positivism. Constructivism asserts that reality is subjective rather than objective. According to constructivist grounded theory methodology, theories are perceived of as being constructed instead of “discovered” and they are grounded in an “interpretative portrayal of the studied world, not an exact picture of it” (Charmaz, 2006, p. 10). This methodology is suited to studying “how” and “why” individuals shape “meanings” and “actions” in particular situations (Charmaz, 2006).

According to Creswell (2007), constructivist grounded theory emphasizes “the views, values, beliefs, feelings, assumptions and ideologies” (p. 65) of the research participants. This methodology places emphasis on the phenomenon under study rather than on the methods involved in studying the phenomenon (Charmaz, 2010). The relativity of multiple realities is a

concept that Charmaz (2006) emphasizes. In accordance with this principle, the results of constructivist grounded theory studies incorporate and reflect multiple truths and multiple participants' perspectives, instead of one main concern or core category. Constructivist grounded theory represents a way to "give voice" to research participants in rendering their lived experiences (Charmaz, 2006). The researcher role requires deep engagement and exploration as explained by Charmaz as this is critical to constructing meaning and interpretation of lived experiences. Pertaining to this study, I, as the researcher, and the participant's co-created knowledge and assigned meaning to experiences. The interpretive role of the researcher is integral to the outcome of constructivist grounded theory research. Essentially, the researcher is considered to be a part of what is being studied rather than being detached from the experience and process. Later in this chapter I will provide more detail regarding my background and positionality as a researcher.

According to Charmaz (2005), researchers need to be mindful of perceptions and biases, e.g., equity, oppression, exclusion, social hierarchy, and class, which can materialize during any research process. In this particular study, the participants expressed themselves through words and through non-verbal cues in order to communicate their experiences regarding the death of their child and their health status. Constructivist grounded theory principles were useful to me in ensuring that I paid attention to the fathers' worldviews, how their worlds are constructed, the underlying factors that influence different issues they experienced, and how these factors combine to shape their lived experiences.

Comparison of Constructivist (Charmaz) and Classical (Glaserian) Grounded Theory Approaches

Although constructivist grounded theory by Charmaz (2006) adopts strategies from classical grounded theory as developed by Glaser, there are notable differences between the two approaches. First, data collection through classical grounded theory could include interviewing as many as 20 to 60 individuals in comparison to constructivist grounded theory where 10 to 12 participants could be interviewed based on theoretical sampling and saturation (Creswell, 2007). Charmaz (2010) identifies saturation as reaching that point through constant comparison of the data, where no new areas or insights are developed. Second, grounded theory stems from a positivist paradigm and constructivist grounded theory assumes a relativist epistemology (Charmaz, 2010). According to classical grounded theory methodology, a researcher that employs grounded theory believes in discovering a theory through the process of data analysis (Glaser, 1978). In contrast, a constructivist grounded theorist believes in co-construction of meaning through completing the data analysis together with the participants (Charmaz, 2010). Third, in classical grounded theory the research methods are prescribed and rather formulaic. In contrast, constructivist grounded theory offers researchers more flexible guidelines. Fourth, co-construction is a concept that is particular to constructivist grounded theory (Charmaz, 2010). Co-construction assigns the researcher the responsibility of ensuring that the voices and experiences of the research participants are kept intact in the data analysis process, especially regarding how participants understand and make meaning of their worlds (Mills et al., 2006).

I am using constructivist grounded theory because it is a well-suited conceptual and methodological approach for my dissertation topic for several reasons. First, constructivist grounded theory recognizes the importance of the phenomena and the participants' lived

experiences in regard to it, not just the importance of the research methods employed to complete the study (Charmaz, 2006). Constructivist grounded theory recognizes various “local” worlds and the diverse realities of the study participants (Charmaz, 2006). Second, the steps involved to complete the research are flexible (Charmaz, 2006). This methodological flexibility facilitates exploration of participants’ ways of life and their interactions with their environments, locally and globally (Charmaz, 2006). Third, constructivist grounded theory methodology is fitting for my research because, according to constructivist grounded theory, the researcher and participants co-construct meanings (Charmaz, 2006). I align with the statement that a constructivist grounded theory researcher starts his/her study “by being open to what is happening in the studied scene and interview statements so that they might learn about their research participants’ lives” (Charmaz, 2010, p. 3).

I selected constructivist grounded theory to support collecting data about racialized immigrant fathers’ lived experiences and the meaning they associate with these experiences and with their health status when their child has died. It is important to note that although a constructivist approach emerges from within the participants’ world, it is impossible for the researcher to imitate or replicate what the participants have experienced (Charmaz, 2006). In order to address the differences in lived experiences between the participants and myself as the researcher, I designed the study to involve ongoing data collection through which I would be able to connect with the fathers to collect additional detailed information as the data analysis proceeded so that I could enhance my understandings and check emerging conceptual categorizations (Denzin & Lincoln, 2005).

In my doctoral study, constructivist grounded theory supported a number of research considerations during data collection and data analysis. First, as an array of opportunities were

created for the participants to express themselves and share with me about their experiences through one-on-one interviews. I met the participants at a location where they felt comfortable. The participants were aware that they could opt-out of the interview at any time during the interview, and they could choose to reschedule the interview if they felt distressed. Second, the interview approach allowed the fathers the flexibility to engage in the conversation regarding their experiences in an unstructured manner. In this way, the fathers had the ability to focus on their experiences and not so much on the data that I needed to collect. Third, the questions that guided each interview were refined based on the one that had been completed previously, resulting in an interview instrument that was shaped by the experiences and emerging meanings significant for the participants. Fourth, the study resulted in the co-construction of a narrative through the integration of categories that were developed and refined by exploring, clarifying, checking and interpreting the participants' lived experiences.

Researcher Background and Positionality

My research interests are based on the manner in which immigration status and racism have affected the experience of individuals accessing health services. My curiosity grew when I began employment in the field of healthcare services in 2001 with the former Calgary Health Region, now Alberta Health Services. Alberta Health Services is responsible for health care service delivery in the province and is government funded. I have worked within the healthcare organization and in the community with stakeholders to build capacity regarding accessibility of healthcare services for racialized children, youth, and their families. My work has included brokering services for interpretation and translation services to minimize language barriers for healthcare staff and families. Throughout my career in healthcare and through my social work education, I have been exposed to theories of anti-oppression, cultural competency, social

justice, White privilege, and anti-racism. These experiences have contributed to the development of my understanding of the importance of addressing barriers for racialized people in the healthcare system.

Although both qualitative and quantitative research methodologies have their own strengths and limitations, I prefer qualitative methods for investigating my dissertation topic. Qualitative methods are a natural fit with my thoughts on epistemology (theory of knowledge) and ontology (theory of being). It is important to discuss these two aspects of a research project and to relate them to the researcher's positionality because they affect the ways that individuals are motivated to engage in research and select a research topic and method.

Each person's ontological assumptions are grounded in his or her historical and communal social location. I was born and raised in Suriname, an ethno-culturally diverse country. My parents are descendants of the Maroon community. As a descendant of Maroons, I was raised to be proud of who I am and to fight oppression in every aspect of my personal and professional life. The Maroon community in Suriname has been oppressed for many years and to this day the people are treated very poorly.

My lifestyle and experiences as a Maroon were different from my Maroon peers. Because I was born and raised in the city and my formal education took place in the city, my upbringing was different and privileged. I was exposed to multiculturalism at a very young age and in my country, I grew up with people from diverse ethnic backgrounds who were part of the fabric of my community. This contributed to a deeper understanding of diversity, ethnicity and multilingualism. I spoke Dutch fluently and, according to societal expectations in Suriname, without a Maroon accent. My experiences were different because my father worked for a bauxite company and was able to provide well for his family. My father learned his professional

skills from co-workers who originated from the United States. Growing up I lived a particular type of lifestyle that was seemingly different from other Maroon families. I had privileges provided by my parents because of their access to income and resources. At a very young age I was exposed to travelling to foreign countries and I was also engaged in leadership in a variety of institutions, providing support to those less fortunate than myself. I saw how other Maroon families struggled around us and how they were made fun of because of the manner in which they spoke and dressed, or the food they ate. After graduating from university, I was the co-founder of a Maroon students' association. This association was called Boston Bendt, named after the first free slave who journeyed from Jamaica to Suriname by foot to tell people about the freedom from slavery in Jamaica. The association continued for many years after I left. The Boston Bendt association was created to provide a platform for high school and university students from Maroon backgrounds to come together and talk about problems faced by their community. It is not surprising to me that even now living in North America and away from Suriname for over 23 years I co-founded the YEEPI Foundation Inc., a Calgary based not-for-profit organization that provides aid to Maroons living in Suriname.

Epistemology

Mason (2002) defined epistemology as a theory of knowledge that is related to the way we come to know things. Harding (1991) elaborated on the term epistemology as a theory of knowledge that poses the question of who can be a knower, and recognizes that there is a test that beliefs must pass in order to be considered legitimate knowledge. In short, epistemology is about the way we know what we know. I know about oppression from firsthand experience and I understand issues of marginalization as a social worker in healthcare and as a first-generation immigrant woman. As a researcher, I am well positioned to understand the lived experiences of

oppression based on my own lived experiences, particularly my firsthand knowledge from the inside as a Maroon, as an immigrant and as a social worker. I am a doctoral student, a healthcare professional, a mother, and a wife. All of my experiences have positioned me in certain ways that align with my approach to research using constructivist grounded theory methodology. I chose this research methodology because it fit well with my professional and personal experiences in addressing oppression. I understand issues of marginalization as a social worker in healthcare and as a first-generation immigrant woman. In addition, I hold anti-oppressive practice and solving issues of marginalization in high regard, especially when conducting research and developing new programs for patients and families.

The main issue driving my doctoral research is my concern that fathers are excluded from research projects conducted around grief and loss issues and experiences. I realized that, in many instances, immigrant fathers were excluded from various aspects of healthcare in relation to paediatrics. As the experience of a father losing a child through death is perceived as an emotionally devastating event (Aho et al., 2011), it is important to conduct research with fathers in this situation to fill in the existing gaps in knowledge and services. I sought to better understand the effects of losing a child from the fathers' perspectives. I recognized that this topic required exploration and attention in order to increase access to quality bereavement services for immigrant fathers, and challenge systemic barriers within the healthcare system for racialized fathers. I recognized that taking up this research would not be an easy process and that many systemic issues could have potentially hindered my progress, however I kept in my mind my goal of seeing the development of valuable bereavement care services for racialized immigrant fathers and their families.

Reflexivity

In choosing this research topic for my doctoral studies, I had to think about how my background, epistemology and lived experiences and the ways in which these factors influenced my choice of research topic and methodology. In qualitative research, this is referred to as “reflexivity” (Hesse-Biber, 2010). A reflexive researcher always takes into account personal ontological and epistemological assumptions. Reflexivity contributes to coming to terms with the different identities of our “selves” in the study environment and with respect to the research participants and the research itself (Hesse-Biber, 2010). Charmaz (2010) defined reflexivity as:

The researcher’s scrutiny of his or her research experience, decisions, and interpretations in ways that bring the researcher into the process and allow the reader to assess how and to what extent the researcher’s interests, positions, and assumptions influenced inquiry. A reflexive stance informs how the researcher conducts his or her research, relates to the research participants, and represents them in written reports. (pp. 188-189)

Much qualitative research acknowledges the importance of recognizing and addressing bias on the part of the researcher because no qualitative research is completely value-free (Ritchie & Lewis, 2003). I am a Black female, a mother who has lost two children through death, and a social worker who has worked in healthcare for a number of years. Based on this background and lived experience, as a researcher I have to be very careful about my biases, not only those associated with my own experiences in losing two children, but also the biases from my experiences in accessing health services for myself, my children, and my husband.

I entered the research process with awareness that I may hold a bias regarding the experiences of the participants in accessing the healthcare system. Specifically, I was working

under the supposition that the participants may have experienced racism within the healthcare system. At the same time, I was aware that some participants may not have experienced racism within the healthcare system. Another bias I had was the belief that some of the fathers who participated in my study might not be willing to openly talk about their values and beliefs about death and dying, even when asked by a healthcare provider. In addition, I realized that my experiences as a Maroon might affect the way in which I collected and analysed the data as I engaged in conducting research using constructivist grounded theory, a Western research methodology.

During the data analysis, I interpreted that some of the experiences that the fathers had were somewhat similar to the experiences of Maroons in Suriname. As previously identified, Maroons from Suriname have experienced oppression over many years. One of their survival strategies has been to use their voices and their experiences to combat oppression. Surinamese Maroons also use the tools that are either provided to them or that they acquire in order to improve their life circumstances. As a Maroon woman, I came to view constructivist grounded theory, not as a Western research methodology, but rather, as a tool that could be used to make meaning of the experiences of the fathers who participated in the study and to co-construct meaning with them.

For example, when the fathers used analogies and metaphors it was easy for me to relate to their style of communication because from a cultural perspective and within constructivist grounded theory, these responses are deeply appreciated for their meaning. As a woman from Suriname, as well as a person with a clear understanding of the process of racialization based on lived experience, I realized that in many cultures metaphors are used to address all kinds of issues that are hard to put into words. For example, in Suriname, metaphors are also used to

deflect pain and/or to convey joy. At times, metaphors are used to share a message that otherwise would cause great distress to the individual or to others. Listeners are then required to make meaning of what the sharer is trying to convey. In employing constructivist grounded theory as a research methodology, I was able to make meaning of what the participants were sharing through their metaphors. My use of constructivist grounded theory in my doctoral research is reflective of my belief in the importance of recognizing ways to use and adapt Western tools, methodologies, practices and clinical interventions for the benefit of oppressed individuals and of society as a whole. I also realized that collecting high-quality self-reported material could be a challenge based on first-language issues, location of the interview, or the fathers' emotional states at the time of the interviews. I was also aware of potential challenges with technical difficulties so I brought a second tape recorder to ensure there was no need to meet for a second interview and avoid overtaxing research participants.

Research Participants

Eight first-generation racialized immigrant fathers who had experienced the loss of a child participated in the study. At the time of the interviews the participants were all living in Calgary, Alberta. The research participants included a variety of religious, socio-economic, ethnic background, countries of origin, language, and immigration status. The inclusion criteria included the following:

- A current or former client served by Palliative Care and Grief Support Services at Alberta Children's Hospital.
- A father of a child who passed away no less than 12 months and no more than five years prior to the time of the study.

- A racialized immigrant (for the purpose of this research racialized immigrant refers to a visible minority person who immigrated to Canada as an adult).
- A father born outside Canada who has come to Canada as an immigrant (self-reported) with attention to variation in participants in terms of stage of settlement and time in Canada.
- A father able to communicate with the interviewer and able to conduct the interview in English as an interpreter will not be provided because of financial constraints.

Participant Recruitment

Participants were recruited with the help of the Palliative Care and Grief Support Services Coordinator and staff at the Alberta Children's Hospital. The main reason for recruiting through this program is that the staff provide bereavement services to parents and siblings in families that have experienced the loss of a child under the age of 18 in Calgary. Even when bereavement services are not accessed, this service area is aware of all the children who have died at the Alberta Children's Hospital. In order to initiate participant recruitment, I met with two social workers at the Rotary Flames House Grief and Palliative Care Support Program to discuss the study.

Based on the inclusion criteria of the study, the decision was made to send the recruitment letter to all immigrant fathers who have accessed services from this program between January 2008 and August 2012. The letters were sent to 46 fathers in the first week of August 2013. Three letters were returned because the parents had moved and the Grief and Palliative Program did not have a current address in their files. Fathers who expressed interest in participating in the study called me to set up a date and time to complete a research interview, provided that they passed a screening to ensure they met the inclusion criteria. The screening

was completed over the phone. Two fathers contacted me within two weeks and both met the inclusion criteria. Two other fathers contacted me to set up an interview and the remaining four fathers became involved through snowball sampling and either called me directly or provided verbal consent for me to call them after leaving their phone number with the individual who recruited them. I paid close attention to the demographic profiles of the participants. Fathers from different racial, ethnic and cultural backgrounds with different lived experiences were chosen to be part of the study in order to ensure that a mixture of diverse experiences were represented.

Data Collection

The interviews were conducted individually and face-to-face. Each interview lasted for approximately 90 to 120 minutes. This is a method that is more commonly used for data collection in constructivist grounded research (Denzin & Lincoln, 2005). Each participant chose an interview location where he was comfortable. Some of the participants chose to be interviewed in their home and others at the Alberta Children's Hospital. At each interview, I reviewed the purpose of the study, my role as a doctoral candidate and researcher, confidentiality, rights to withdraw at any time during the interview, and follow-up information. Informed consent was obtained via signature and all interviews were audio-recorded.

The interviews flexibly followed an interview guide (see Appendix G). The interview guide was used to initiate conversation which then flowed in various directions with each participant. The interview guide included questions about the fathers' experiences, values, beliefs, perceptions of losing a child, experiences in the healthcare system, and impact on their individual health status. This method of gathering data allowed the fathers to be the experts when sharing their experiences and created a comfortable environment to freely express their

thoughts, beliefs, and experiences (Denzin & Lincoln, 2005). I explored lived experiences, self-reported health statuses, experiences within the healthcare system, and personal insights into how racialized immigrant fathers experienced living without their child following death, with the participants.

During the data collection process, I positioned myself to listen, to observe with sensitivity, and to encourage the participant to respond and be the person who talks the most during the interview (Charmaz, 2006). The interview approach that I employed proved to be an effective way to listen to and generate detailed understandings of the complexities of participants' experiences of loss and grief. This manner of having a conversation with the fathers supports the notion of the importance of developing empathetic understanding among researchers and participants as a means of gaining knowledge and insight into a phenomenon (Ritchie & Lewis, 2003). The goal of this type of interview was to comprehend underlying assumptions and to make meaning of lived experiences rather than just take information from the participants for my own purposes (Charmaz, 2011; Mills et al., 2006). Exploratory questions were used in the interviews, to probe for details while moving from general to more specific questions and topics of discussion (Creswell, 2007; Norton, 1999; Schreiber, 2001). Some of the exploratory questions included:

- Please explain what it means to you to go through the loss of your child.
- Please describe this experience for you in the healthcare system.
- In general, please describe your health status and how the death of your child has affected your health status.

These questions centred on each father's personal experience in the hope that new information would emerge, including but not limited to their cultural values about death and dying,

expectations when grieving their child, and their roles after their child died. Data on the health statuses of the fathers was gathered for assessment; and the fathers were asked to report their health perceptions in the areas of health, coping, and physical and emotional well-being.

This type of interview allowed the participants' values and beliefs about their experience of loss and their health status to surface instead of being biased by the researcher's preconceptions and ways of thinking. As such, research participants guided the conversations as they were sharing their experiences. The interview process aligned with the assertion that grounded theory interviews can be perceived as an unfolding story or theoretical narrative created by the researcher and participants (Charmaz & Belgrave, 2012). The story that is created is not just based on individual experiences; the narrative that ensues captures the collective experience. As the study progressed, the interview guide was adapted to reflect the issues arising in earlier interviews that might not have been included previously. The interview questions were designed to be general enough to elicit narrative stories and in turn, gather useful data, but detailed enough to inquire about the individual fathers' lived experiences in relation to specific areas that were identified as being relevant to the emerging analysis (Charmaz & Belgrave, 2012). The interview guide also included questions to gather demographic information and immigration histories.

Each father brought multiple layers of experience arising from his country of origin, culture, language, immigration history, worldview, emotions, feelings, and everyday life experience in Canada. These experiences related to his experience of losing his child and the effect of the loss on his health status. Through this study I was able to work with the participants to peel back these layers and capture the experience of a bereaved father's loss and his respective health status. My involvement in the co-construction process included asking questions,

outlining the research objectives and processes, and interpreting the data. This process was closely linked to my pre-existing experience with and knowledge on the topic under study. As discussed above, I was reflexive regarding my personal experiences and awareness and this reflexivity added to the depth of understanding of the phenomenon that I developed (Charmaz, 2005).

Throughout my engagement with the participants I remained sensitive to the participants' expressed desires to end the interview if they felt they had shared everything they needed to share. If the interview was incomplete or interrupted due to emotional distress of the participant or other unforeseen circumstances, I set up another one-hour interview with the participant with their consent. When the fathers showed signs of distress, time and space was made for them to cry, get up, and/or drink some water. I also offered them support through empathic listening. When signs of emotional distress became apparent I would reassure the fathers that they could end the interview at any time. In addition, each participant was given my contact information as well as a list of organizations they could contact for grief counselling.

Ethical Considerations

Confidentiality and informed consent were the two primary ethical considerations associated with my doctoral study. Strict adherence to confidentiality is very important in conducting qualitative research (Charmaz, 2011; Creswell, 2005). At the beginning of each interview, the concept of confidentiality was discussed with each participant. All participants were told that their information would not be shared with anyone except for my thesis advisor and even in that regard identifying information would not be mentioned. In some instances, some of the fathers had a question or two regarding confidentiality but there was never an incident when they refused to participate based on fear of breach of confidentiality. Some

participants asked questions about how the results would be used, who would have access to the information, and how many other fathers would be interviewed. The research materials, including audio-taped interviews, interview transcripts, memos, field notes, participants' contact information, and data analysis were placed in a securely locked cabinet in my home, to which I have sole access. My personal laptop was also used for data storage. The laptop is protected by a password that only I know and for added security the password is updated on a regular basis. I backed my data on a USB. The laptop also has anti-virus software in accordance with instructions from the Conjoint Faculties Research Ethics Board and data management guidelines at the University of Calgary. All data management guidelines will followed after completion and publication of the thesis. Disposing of the research material after this time will be in accordance with the proper disposal of confidential research information (Charmaz, 2006) consistent with current university guidelines.

In addition to confidentiality, I also discussed informed consent with each of the participants. I explained to the fathers that providing consent implied that they had adequate information regarding the goals, purpose, and objectives of the study and that they were willing voluntary participants. This discussion took place at the beginning of the interview and sometimes even at initial contact during participant screening, which was completed by phone preceding the face-to-face interview. All participants were informed that they could stop the interview at any time and that they could also request for the tape recorder to stop taping in case they did not want a particular aspect of the interview to be recorded. I assured the participants that, in case they decided not to continue with participation in the research, it would not be held against them or have any negative consequences. In particular, since I am employed by Alberta

Health Services I assured the participants that their participation would not impact their access to healthcare services, for them or their family members, at any time.

I signed the consent form together with the participants. The consent form (Appendix G) consisted of my name and phone number, my advisor's name and phone number, the title of the research study being conducted, information regarding the University of Calgary's Conjoint Faculties Research Ethics Board, the purpose of the research, and other general information regarding consent and confidentiality. A copy of the consent form stayed with the fathers and I retained the other copy for filing. All of the fathers signed the consent form without hesitation. At the end of the interview, I debriefed the fathers to review their understanding of the purpose of the research and check on their emotional well-being. The participants were given a list of community bereavement support services in case they required support after the interview ended. They were reminded of my phone number in case they had additional questions or comments or wished to follow up with me concerning the study.

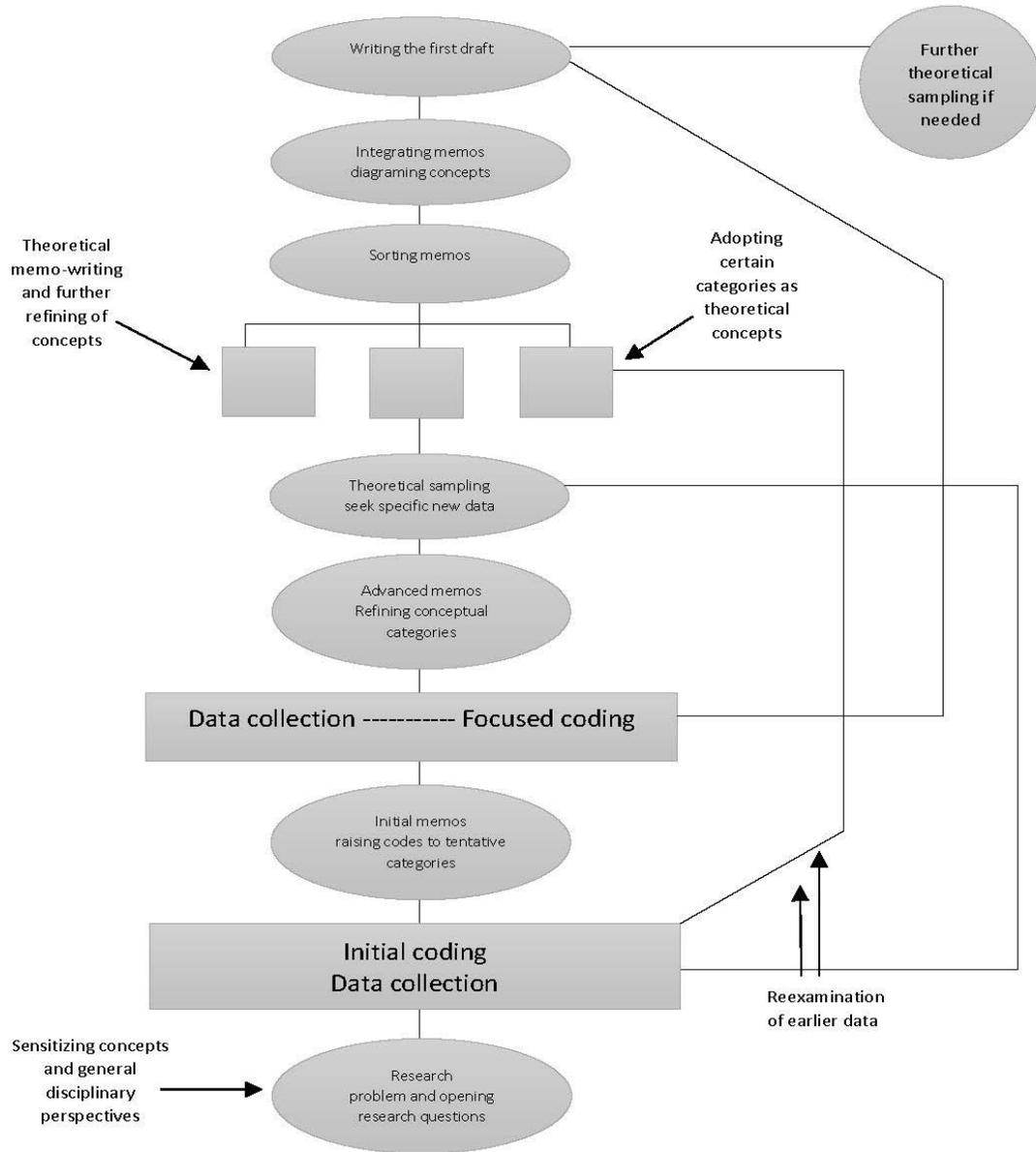
Data Analysis

This study used a constant comparative approach during data analysis (Charmaz, 2011). This approach meant that the initial codes were constantly compared with new, subsequently gathered data. The analysis of the data was completed over time and in several steps, which required several iterations of data analysis as data was being collected and integrated into the emerging analysis following each interview (Charmaz, 2011). Figure 2 included below is a graphic representation of the grounded theory process developed by Charmaz utilized as a tool for constructivist grounded theory. Data collected from the participants about their lived experiences and the meanings associated to them was used to understand, refine, and check the emerging conceptual categories by seeking more information from successive participant

interviews (Denzin & Lincoln, 2005). Analysis of the data arose from my subjective interpretations of the information that was collected (Charmaz, 2010; Denzin & Lincoln, 2005).

I used my laptop computer to personally transcribe and analyze the data in a systematic manner. I created my own framework using Microsoft Office Word to organize the data and emerging conceptualizations. Microsoft Word was utilized also to develop the visual representation of my constructivist grounded theory found in Figure 2. I found that handling the data in this manner helped me to be focused, stay closer to the data and refine constructions of the data as I became more familiar with it. My comparative coding process involved colour coding sections, quotes and words that were either similar or very contrasting. This led to the development of my codebook. Through additional sifting and sorting of the data based on the concepts that emerged I developed the diagram included in this thesis (see Figure 2). The development of codes, codes and categories is discussed further in the next section of this chapter. As this is a qualitative research study, the criteria of credibility, transferability, dependability, and confirmability were used (Creswell, 2007).

Figure 2: The grounded theory process



Source: Charmaz, K. (2010). p. 11.

Coding Process

Initial coding involved labelling segments of the collected data into descriptive concepts and then moving into more analytical conceptions and ideas. Through the coding process I was able to scrutinize and interact with the data (Thornberg & Charmaz, 2011) and develop greater insight developing an understanding of what the fathers were telling me. The coding process supported me to formulate additional research questions, if and when needed for greater depth and clarity in the interviews. I shared the codes with my supervisor for verification and to ensure that data reliability was maintained.

According to Charmaz (2006), the following questions support the process of initial coding:

- What do the data suggest and from whose point of view?
- What do actions and statements in the data take for granted?
- What processes are at issue here?
- How can I define it?
- How does this process develop and under which conditions does this process develop?
- How do the research participants think, feel, and act while involved in this process?
- When, why, and how does the process change?
- What are the consequences of the process? (pp. 47-51)

Coding helped in viewing the information in a completely different way and supported knowledge acquisition. It helped in recognizing and refraining from assumptions and ideas or efforts to place the data in a preconceived “box” before the study.

After the process of initial coding or open coding, where I used short, simple, precise, and active codes to interpret the data, I then used focused coding. In focused coding, the researcher continues to work through the different initial codes to get to one core category that

captures the essence of important repeated information or often-used codes. Focused coding is more directed, selective and conceptual, when compared to initial or open coding (Charmaz, 2014). Coding is a method of organizing the text of the transcripts and discovering patterns in their organizational structure. According to Charmaz (2013), the purpose of coding is to develop explanatory schemes, concepts, and relationships as well as address the research question and capture the logic of discovery. The goal is to develop patterns that show what information emerging from the data. In a sense, the codes are a reflection of highlights that stand out in the data. These highlights might be something significant and meaningful that one person said or a topic that arises frequently across quotes, or that has a clear relationship to other quotes.

Glaser (1978; 1998; 2005) developed the term “theoretical coding”. He perceived of theoretical coding as a tool that explains the relationship between categories and codes and how to incorporate them as part of a theory. Charmaz (2010) proposes that focused coding is the precursor to theoretical coding. After reviewing the first interviews, an initial coding or open coding framework was developed. The transcripts were coded line-by-line and the codes identified were analysed from father to father (on a case-by-case basis) as well as across fathers for comparison. These codes were then placed into codes and categories. By defining the data and conceptually grouping the data into codes, patterns in the data began to emerge, supporting the development of new insights – an iterative process that comes to a close with saturation.

In developing the codes for this research, I focused on three key things, i.e., the context, action, and consequences that the codes reflect:

1. What is the context of racialized immigrant fathers when their child has died?
2. What are the consequences of their experience and the death of their child?
3. What is the action they took in grieving their child?

All in all, to arrive at the codes, I asked myself one fundamental question: What is the lived experience of the participants?

A specific technique that I employed while coding was using gerunds (Charmaz, 2010). A gerund is a noun derived from a verb (Charmaz & Belgrave, 2012). Gerunds involved using -ing words or codes, that describe what the participants are doing and experiencing. Using gerunds in the coding process identifies actions and allows the researcher to describe a particular situation or part of the research process (Charmaz, 2011). Through the use of gerunds, researchers are able to show links between codes and ensure that their data analysis remains emergent. This process, when completed line-by-line as suggested by (Charmaz, 2011), allows the researcher to refine, compare the data, and identify emergent codes to explore further through the constant comparative process. In this research, gerunds were used when possible throughout the coding process.

Codes and Categories

The focused coding process as identified by Charmaz (2006; 2010) supports the development of categories and codes. The codes are placed in groups based on commonalities, which form themes known as categories (Charmaz, 2006; 2010). Through the formation of codes and categories, further development of the data supported the construction of a constructivist grounded theory. The constructivist grounded theory and the theoretical narrative summarized what I, as the researcher, have learned about the participants' experiences. In creating the constructivist grounded theory and the theoretical narrative, I used the fathers' words as much as possible in order to remain close to the data.

Theoretical Sampling and Saturation

The goal of theoretical sampling is “conceptual development” to construct theory (Thornberg & Charmaz, 2011). Theoretical sampling occurs when researchers search for and gather relevant information to enhance groupings of the research concepts into theoretical constructs (Charmaz, 2010). “Theoretical sampling involves starting with data, constructing tentative ideas about the data, and then examining these ideas through further empirical inquiry” (Charmaz, 2010, p. 102). It means (a) identifying the categories that are being developed, (b) refining the theoretical categories, and (c) detecting discrepancies and inconsistencies. The advantage of theoretical sampling is that, as the categories are being developed, the researcher can use questions to engage the data or involve new participants to strengthen categories. Categories can also be made more robust by going back and asking more detailed questions of the categories. Sometimes, it is essential to go back and talk to more research participants; however, in many cases, if the information is in your data when you go back and review, there is no need to interview more participants.

Theoretical saturation occurs when the researcher identifies that no new theoretical concepts and insights related to the identified categories are emerging as interviews are being completed. According to Charmaz (2010), theoretical saturation is the “point at which gathering more data about a theoretical category reveals no new properties or yields any further theoretical insights about the emerging grounded theory” (p. 189). In the present study, a variety of codes, categories, and codes emerged early in the interviews. I was then able to ask more questions of subsequent participants to get clarification on information developing in the analysis (Corbin & Strauss, 2008). Theoretical sampling allowed me to determine when no new information was emerging in the data collection process and the codes were saturated to a certain level. As with

any study continuing to gather data, one can always bring in a new perspective, hence making it difficult to claim that complete saturation was achieved (Charmaz, 2010).

When all eight of the participants had been interviewed, I felt confident that rich data was gathered for this study. By following Charmaz' (2010) process of interviewing, completing analysis, following-up with the analysed data then completing more interviews my research process was consistent with the constructivist grounded theory methodology. While completing this process I constantly checked my own biases to reduce their influence on the analysis. This process is detailed in the section on reflexivity presented earlier in this chapter.

Memo Writing

Memo writing is an important part of grounded theory research. Memo writing helps the researcher to reflect on the data and to start writing about issues that arise during interviews (Mihas, 2013). In addition, in memos, researchers may include observations that catch their attention or questions that come up after an interview. Through memo writing, the researcher is able to reflect on their thought processes (Morse & Richards, 2002). Memos can be thought of as a way to record ideas however, they may also signify a move towards the development of codes, categories and associated linkages and insights that emerge from the data. Memos are intended to be for the researchers' use in developing their analysis and writing. As the research process progresses memos typically evolve from being merely descriptive to being more conceptual and theoretical. Memos can be quite elaborate and as long as (or longer) than participants' quotes. In the memo-writing process, the researcher wrestles with what is happening until the logic of the experience and the hidden assumptions of participants are constructed. The memo writing process is a way of making sense of what the participants are saying in the interviews and also of uncovering the researcher's biases and assumptions.

Ultimately, through memo writing, the researcher connects parts of the data with the whole of the analysis. Memos are considered to be critical data (Clarke, 2005) because they support data collection and data analysis by enabling reflective comparisons of interviews which might be neglected until much later in the analytic process if memo writing is not completed.

In general, memos aid in completing a thesis because codes and categories cannot be the only source of information for the thesis-writing process (Charmaz, 2006; 2010). It is critical that each memo has a title and that these titles are derived from the codes (Mihás, 2013). While completing my doctoral study memo writing supported me in building greater understanding of what I was thinking when developing the codes. Through memo writing I was able to ask reflective questions about the experiences of the fathers and explore how particular concepts and categories fit together. In short, memo writing facilitated my analysis of the data. I have provided some of examples of my memos in Appendix E.

Rigour and Trustworthiness

To achieve rigour and trustworthiness in qualitative research it is necessary to establish credibility, transferability, dependability, and confirmability (Charmaz, 2011; Corbin & Strauss, 2008; Lincoln & Guba, 1985). These criteria are better suited to evaluating qualitative research (Creswell, 2007).

Credibility

Just like reliability, credibility ensures that the researcher followed certain steps to ensure that the theory and the data were linked (Charmaz, 2006). For example, this includes ensuring that memos were written after each interview (Bryant, 2009), that all interviews were audio-taped and transcribed (Creswell, 2005), and that during the interview the researcher used active listening skills and engaged in meaningful conversation with the participant on the research topic

(Bryant, 2009). As a qualitative researcher, part of my data collection process was to audiotape and transcribe all interviews conducted with the participants. Due to the sensitive nature of the study, it was important to be sensitive to the fact that the fathers were still grieving the death of their child. To ensure credibility, I had to put aside all beliefs and values about the death of a child (Charmaz, 2006). To achieve credibility in this research, I completed the following:

- I attended qualitative research courses in and outside of Canada to compare information on constructivist grounded theory and how to develop codes and categories;
- I continually referred to my memos, transcription notes and demographic information on the racialized immigrant fathers along with the written profiles on each father during data analysis;
- I continually discussed the emerging codes and categories with my supervisor;
- I reviewed numerous studies on fathers' experiences with death and dying; and
- I repeatedly listened to each taped interview while comparing my memos with what the father had said during the interview.

Transferability

Transferability implies that the study findings are applicable to other contexts. A useful technique to ensure transferability is “thick description” (Lincoln & Guba, 1985). This technique encourages transferability to other groups in society, in other situations related to the topic, and in other geographic locations. To support thick description I collected demographic details about the participants related to the socio-cultural relationships and contexts of the fathers including their ages, immigration status, and employment information, experiences in losing a child, the number of living and deceased children, marital status, and social supports. Collecting this information facilitated reporting rich, detailed, and comprehensive information about the racialized immigrant fathers. Qualitative research studies can be utilized to influence program development (Charmaz, 2011; Creswell, 2005). The way this research becomes known is through dissemination via publications which is intended once the thesis is completed.

Dependability

It is important to ensure that the research findings are dependable and reflect the voices of participants. This required my openness to discuss the data collected, the technique used for gathering data, and the way in which the data analysis was completed with my PhD supervisor and other researchers. These discussions aided in evaluating whether the interpretation and recommendations arising from the data analysis and results reflected the experiences of participants. I was able to discuss preliminary codes and categories with my supervisor in-depth. These discussions helped me to engage in critical reflection which in turn ensured that my interpretations emerged from the fathers’ experiences and were not solely derived from my personal perspective.

Confirmability

With confirmability, it is understood that the study's findings are based on the information shared by the fathers and not shaped by the researcher's bias, motivation, and interests (Lincoln & Guba, 1985). In other words, there must be sufficient reason to believe that there is neutrality from the perspective of the researcher and the researcher is cognizant of personal biases (Malterud, 2001). There are numerous techniques to evaluate confirmability in qualitative research including reflexivity, triangulation, and conducting an audit trail (Lincoln & Guba, 1985). Reflexivity in my research included writing memos in a journal to support identifying any potential bias that could have affected the study. This particular journal was used for the purpose of reflective writing and memos and potential inclusion in future publications. Triangulation, in this context, means ensuring that the data-gathering method contributes to comprehensive, detailed, and valuable information regarding the experiences of racialized immigrant fathers who were the focus of this study (Mays & Pope, 2000; Patton, 2001). An audit trail means that all the steps the researcher incorporated in the study are accounted for. In terms of this study, my steps include memo writing, reflexive note-taking and journaling, the coding process, the development of codes and categories, and finally the report-writing process (Lincoln & Guba, 1985).

Summary

Many researchers in different disciplines employ qualitative research approaches in general, and grounded theory methodology in particular, as a research methodology. Chapter four provided an overview of qualitative research and explanation of why this approach was best suited for my doctoral research. A discussion of grounded theory methodology was provided

with a specific focus on constructivist grounded theory, the methodology chosen to conduct my research. Constructivist grounded theory was deemed to be best suited for my study because it values participants' lived experiences and supports meaning making. Next, the research findings are presented in Chapter five.

CHAPTER V: RESULTS

The purpose of the current qualitative study was to explore the lived experiences of racialized immigrant fathers who experienced the death of their child and the effect this had on their health status. One of the goals of this study was to present an analysis of the fathers' stories. I interviewed eight racialized immigrant fathers. Through interpretation and analysis according to constructivist grounded theory methodology, I was able to construct a detailed, contextually grounded description of the fathers' lived experiences.

This chapter includes presentation of the following: (a) the demographic information regarding the profiles of the participants; (b) description of the participants' lived experiences; and (c) the analytical findings of the study including codes and categories. Finally, an integration of the findings into a theoretical explanation of the experience of the death of a child for racialized immigrant fathers is included in this chapter.

Demographic Profile of the Participants

This section contains demographic information on the racialized immigrant fathers that participated in this research (see Table 1). The fathers ranged in age between 30 and 54 years old. All of the fathers were married to the mother of the deceased child at the time of the interview. The countries of origin of the fathers included Ghana, Malaysia, Sri Lanka, Cambodia, Cameroon, Iran, Fiji and St. Lucia. In discussing countries of origin with the participants, I found it interesting that in some cases the participant would mention their country of origin and then provided additional information regarding their tribe, without my prompting. This description opened the door to further discussions about how their cultural background affected their ways of grieving. All of the fathers were fluent in English and they also spoke a range of other languages including Twi, Sengalese, Tamil, Chinese, Cambodian, French Farsi,

Azari, Creole, Ga, Hindi and Fijian. Four of the participants experienced the loss of one child. Two fathers had lost two children and one father had lost three children. Collectively, the participants were fathers to 12 children who had died. Four of the deceased children were females and eight were males. At the time of interviews, the period of time that had passed since the deaths of the children ranged from two to five years. The ages of the deceased children ranged between six months gestational to ten years of age. Of the eight fathers interviewed, four had surviving children. Three of the fathers had one surviving child each, one father had two surviving children, and one father was the stepfather of three surviving children. Three of the fathers had no surviving children. Four of the fathers were employed in their field of expertise, while the other four fathers took any available employment to be able to take care of their families. Four out of the eight fathers lived in another province prior to moving to Calgary.

Descriptions of Participants

An overview of each participant's demographic profile and lived experience of bereavement following the death(s) of one or more of their children is described below.

Participant 1

Participant 1 is 58 and he was born in Malaysia. His ethnic background is Chinese Malaysian. He is married to the mother of his deceased child. Together they also have another daughter who is an older sibling of the deceased child. Currently this father is employed as an interior designer. He is university educated. At the time that we met for the interview it had been five years since this participant's daughter had died. During the interview, the participant became emotional and expressed feelings of guilt and self-blame in relation to his daughter's death. The father was crying and was consoled several times by his wife who was nearby, but not engaged in the interview. In order to accommodate this in the interview process recording and

conversation was stopped to provide time and space for the father to just cry. We picked up the interview when the father expressed that he was ready to do so.

According to this father, he should have “done more” and should not have been so negative when discussing the conditions and options of his child’s illness and prognosis with her healthcare providers. He reported that he asked many questions while his daughter was in the hospital and he was able to have regular conversations with the members of the healthcare team. He also searched online for information that would help him to have a better understanding of his daughter’s condition.

During the interview, this father offered descriptions about the meaning of his daughters’ name, specifically, how it was understood within Chinese culture. We also discussed beliefs and processes associated with death, dying, grief and bereavement in Chinese culture.

Participant 1 was educated in Malaysia in an English-language institution. He compared his educational experience with that of some of his siblings that had received their education in a traditional Chinese institution. According to him, his siblings who were educated in the traditional Chinese institution were focused more on the traditional way of living according to Chinese cultural values, in comparison with his own way of life. He reported that one of the cultural values he had learned from his mother had helped him to focus on his child’s death more closely and address his grief. He expressed a belief that he had to “let his daughter go” otherwise, she could not die. What this mean is that he had to give her permission to die. He described to me how he gave his daughter this permission by telling her that she should stop holding on to life and that it was time for her to go. Participant 1 also shared his perception that his daughter’s death would have been perceived differently within his ethnic community, if she had been male. He expressed understanding of the impact of culture in the healthcare system,

particularly regarding challenges and barriers in accessing services. He mentioned that he had witnessed other families experiencing challenges in the healthcare system but also that he did not experience any of these challenges personally.

Participant 2

Participant 2 was 45 years old at the time of our interview. He was born in Sri Lanka and he speaks English, Tamil and Sengalese. His religion is Islam. He arrived in Canada in 1997 and he is married with three children. He has a university degree in computer science. At the time of our interview, it had been two years since his son died. His son died seven days after birth and had been diagnosed with Thanatophoric Dysplasia Dwarfism (TDD). Participant 2 appeared to be knowledgeable about his child's diagnosis and the Canadian healthcare system. We discussed his strong sense of responsibility as a father of a healthcare patient. During the interview, the father expressed anger and disappointment in the healthcare system. I interpreted that this participant appeared to be angry at the healthcare system and that participating in my research project provided him with a platform to discuss his frustration. He expressed his perception that the healthcare professionals "killed my [his] child". During the interview, much of what we discussed was focused on how the healthcare system and, more specifically, some of the professionals involved in his son's care, had wronged him and hurt his child. Participant 2 had a particular mistrust of the social workers involved with his son's care. He implied that social workers are not supposed to know much about medical care of children. Participant 2 stated that he did not experience racism and discrimination within the healthcare system. However, he expressed that those people who do experience racism and discrimination are at fault for being subjected to such treatment because everybody has responsibility for cultural integration.

Participant 2 reported that he was informed of the TDD diagnosis during his wife's pregnancy. Following becoming informed of the diagnosis, he reported that he sought advice from his Imam who also connected with other Imams regarding the situation. Participant 2 reported that while the Imams did not see anything wrong with an abortion in this case, the parents chose to continue with the pregnancy. In contrast with some of the other participants, this father was less engaging regarding discussion of memories of his child, his support system and extended family, or his cultural or religious beliefs surrounding the death of his child.

Participant 3

Participant 3 was a 51-year-old father from Cambodia who immigrated to Canada in 1985. He had lived in Kamloops, British Columbia for three years prior to moving to Calgary. At the time of our interview, he had been married to a woman of Cambodian origin for five years. This participant identified that he is Buddhist and since arriving in Calgary he had converted to Christianity, specifically that he was a Seventh Day Adventist. Participant 3 and his wife lived separately for the first four years of their marriage due to the length of time it took for their immigration paper work to be completed. His wife lived in Cambodia until the paperwork was completed and then they reunited. This couple experienced the deaths of two daughters. The couple's first daughter died several hours after birth in 2011 in Cambodia. According to Participant 3, his wife had contracted rubella and the fluid retention associated with this illness was the cause of their daughter's death. Their second daughter was born in 2013 in Calgary and she died three weeks later. He also shared with me that his wife blames him for the deaths of their two daughters.

During the interview, Participant 3 provided a detailed description of the deaths of his daughters and offered comparisons between what happened in the healthcare system in

Cambodia, and what happened in the Canadian healthcare system in Calgary, surrounding the deaths. The father expressed his belief that the healthcare services received in Calgary were of better quality compared to those provided to the family in Cambodia. He believed that although both of his daughters had the same health condition, the second one was able to live for three weeks compared with the first living for just a few hours because the healthcare provided in Calgary was superior to that provided in Cambodia.

Participant 3 expressed appreciation for the time he had had with his second daughter before she died, which was spent taking pictures and completing clay hand and foot print molds. During our interview, he described every detail of the three weeks that he and his wife had spent with their daughter before she died, as well as the seizure that ended her life.

Participant 3 was very specific in identifying the people who supported him in his grief process. Specifically, he has a brother and a sister who also live in Calgary. His sister had been helpful in accompanying his wife to the hospital when their daughter was there before she died. He expressed that he was not interested in receiving bereavement counseling due to his belief that grief is a private and personal matter.

To honour the memory of his first daughter, Participant 3 named his second daughter after her. Participant 3 reported that he spent considerable time thinking about how to honour the life and the death of his second daughter. Eventually, he spoke to a colleague who told him that the funeral home could provide him a locket in the form of a heart with some of his daughter's ashes in it. He ordered one and provided it to his wife as a surprise gift that he said she was grateful to receive. The rest of the ashes of their second daughter are currently in their bedroom.

In discussing the death of both of his daughters, Participant 3 informed me that his first daughter was buried and that his second daughter was cremated. The rationale that he provided for this was that in Cambodia children's deaths are not considered as being a deeply concerning matter, as is the case in Canada. In Cambodia, bereaved parents are advised to forget the child and to "move on" as quickly as possible. In turn, having a funeral for a child was frowned upon socially. In the case of the death of the first daughter, Participant 3's extended family and in-laws suggested that she be cremated with all the other people that died at the hospital or be cremated with all the other children to suppress cost. This was unacceptable for the father as this was his first child and he did not want the memories of his child to be tarnished by treating her body in such a manner after death. The couple obtained support from the government for a cheap burial plot but at the time of the interview, they had been unable to mark the site with a gravestone.

In discussing his grief associated with the death of his first daughter, Participant 3 explained that for a long period of time he was unable to look at pictures of her. He shared that when he finally looked at the pictures he felt heartbroken.

Although Participant 3 reported that he was very satisfied with the healthcare services received during the death of his second child in Calgary, he also identified a perception that the death of his child had affected his own health. He explained that he carries a lot of pain in his heart and experiences heart palpitations and other forms of physical pain that cannot be explained medically. He informed me that he has seen several doctors but he has not yet received a clear diagnosis that explains his health concerns. He expressed he was at a standstill regarding further action he could take to address his health issues. In terms of extended family, the participant's siblings take him to his doctor's appointments.

Participant 4

Participant 4 was a 42-year-old father from Cameroon, Africa who immigrated to Canada in 2003. He had lived in Winnipeg for a very short period after landing in Canada, prior to moving to Calgary. At present, this family consists of the father and mother, as well as a seven-year-old daughter and a three-year-old son. Participant 4 speaks French and English fluently. He left Cameroon at the age of 20 to pursue his dreams. During his travels, he met his wife who is Canadian, leading them to eventually settle in Canada. Participant 3 is a devout Christian.

In discussing the death of his son at five days of age, I observed that he spoke of the death as if it had occurred quite recently even though it had been four years since the interview. He explained that he had never cried so much as during the five days of his child's life. He felt that his child died due to human error. According to this participant, his wife had gestational diabetes with her first pregnancy and her physician prescribed her insulin. However, during her second pregnancy, the same physician never mentioned any concerns about gestational diabetes and insulin was not prescribed. When their son was born, all of his organs were failing, including his heart. He was unable to urinate, each day he stayed alive he was on intravenous treatment, and he continued to swell. A physician at the hospital told Participant 4 that his son was seriously ill, that the cause was untreated gestational diabetes, and that the child had no chance of survival. This participant expressed that he was extremely sad but also furious with the healthcare system – particularly because a prior diagnosis of gestational diabetes should have informed the healthcare his wife received during her second pregnancy. He stated that the healthcare system should not be trusted. In discussing the death of his son, he shared that he had chosen a name for his son that represented a lack of justice within the healthcare system as a way for the memory of his son to remind him to continue to create and support a just world.

Participant 5

Participant 5 was 48 years old and was born in Iran. He speaks English, Farsi and Azari. He arrived in Calgary in 1989. He is an engineer and frequently works out of town. He is often away from home for a week or more, as his work required extensive travel. Participant 5 reported feeling guilty for not being home and spending more time with his family. At the same time, he takes pride in providing financially for his family.

Participant 5 lost his first son, eldest child, in 2010. His son died at the age of nine. He has a second child, another son, who is six years old. The first son was born with a genetic disorder, had a seizure disorder and was chronically ill. From the start of the interview, I noted that Participant 5 appeared guarded. However, as the interview progressed this father became noticeably more comfortable and openly shared his experiences. He expressed that since his son died he had lost his faith in God and has not been back to his religious place of worship. He explained his perception that there was a lack of support through his religious community and he indicated that he felt alone in his grief. During the interview, he recalled the last days and hours of his son's life. He explained how he felt as if his son was asking his permission to die during his final days.

While the family had experienced many health crises during their son's illness, Participant 5 recalled that the last time his wife called him at work regarding their son's health he noticed a new urgency in her voice and it was at that point he realized his son would die. Upon receiving that phone call, he immediately left work and went home. He expressed feeling guilty about leaving his son home to go to work and provide for his family. When he got home his son looked at him and it was at this point the father recognized that he needed to tell his son it was okay for him to die and shortly afterwards his son died.

I perceived that Participant 5 and his wife had been actively engaged in caring for their son. They were both firm advocates for equitable healthcare services and supports. Participant 5 indicated to me that he had witnessed inequities in the healthcare system with other racialized families. He explained his perception that his race had influenced the care and resources provided to his family in the healthcare system. Specifically, he described a perception that healthcare providers withheld information regarding resources from him and his wife that could have supported them in caring for their child. In short, he expressed that he felt discriminated against.

Concerning his participation in the present study, Participant 5 identified that initially he did not want to complete the interview but that his wife convinced him to consent to participation by telling him that he needed to participate because he “keeps everything bottled up”. I received assurance that he agreed to participate of his own volition.

Participant 6

Participant 6 was a 30-year-old immigrant from St. Lucia who landed in Canada in 2006 and settled in Calgary in 2008. He is married and his wife is from St. Lucia. He speaks English and Creole. He identifies as a Christian. Participant 6 has experienced the deaths of two sons, one in 2011 and the other in 2012. Both of his sons had been born prematurely.

I observed that Participant 6 laughed nervously throughout the interview. This was my first experience with a participant laughing throughout an interview. I was not sure if the laughter was attributed to nerves regarding completing the interview and talking with a stranger about his two children that died, or if this was an expression of grief. For me, this interview felt uncomfortable. I found Participant 6 more challenging to engage and converse with in comparison to the other fathers I had interviewed. From my perspective, he seemed guarded and

minimally engaged in the interview. This was also the shortest interview I had. Participant 6 provided only brief answers to my questions. Nonetheless, he provided some informative insights about what he thinks fathers from immigrant backgrounds need in order to address their grief following the death of a child. For example, he suggested that the bereaved fathers be brought together to talk about their experiences.

Participant 7

This father was a 40-year-old male originally from Ghana. He arrived in Canada in 1987 and lived for 14 years in Montreal before moving to Calgary in 2004. He is Ashanti from the Akan tribe and married to a woman from Ghana. He speaks English, Gha and Twi (both Ghanaian languages). He has a master's degree in social work and holds a position in healthcare. His wife has three children from a previous marriage, two girls (22 and 20 and a 17-year-old son) and as a couple they had one child, his only son who died at birth in 2008. This father told me that it took him five years after the death of his child to look at photographs of his son. He explained to me that he left the room before his wife gave birth because he was unable to look at his son as they had been informed that the child would not survive. He did not make funeral arrangements and a mass funeral was organized by the healthcare system. This father indicated that they would not like to try again to have more children as doctors informed them this would endanger the life of his wife due to a health condition. He indicated that, although many people believe that a couple needs to have children to stay together and have a strong marriage; this was not a choice for him and his wife.

This father shared with me that he did not cry when his son died but he had cried when his mom died. He explained that in his culture the child belongs to the mother and her side of the family. If his son was alive, although he would have an important role as a father, his culture

dictates a belief that the child belongs to the mother and her family. He further indicated that the reason he experienced so much grief and cried when his mother died is because he suffered a great loss, particularly the sense of belonging to his mother. In a similar way, a mother who loses her child suffers greatly because the child belongs to the mother and the family and their future are bound in having a healthy child who will grow to adulthood and take care of the mother. He also expressed that crying for a dead child would cause evil to kill the subsequent children born, especially if the child that died was a first-born, therefore crying and mourning the loss of children up to 18 years old was not permitted.

Participant 8

This father was a 42-year-old from a Hindu background. He speaks English, Hindi and Fijian. He arrived in Canada from Fiji in 1990 and came straight to Calgary. He is married to a woman who is also from a Hindu background. This family has the maternal grandmother living with them but no other family members close by in the city. The wife's sister visits from time to time from Fiji. The father is a city worker driving snowplows and clearing snow in the city during snowstorms. This father had four children and three of them are deceased. Two children, a two-year-old boy, and a six-year-old girl both died just weeks apart in 2013. He also had a son who passed away in 2006.

The father told me his first son was diagnosed with cancer at age nine in 2004 and he died when he was 11-years-old. In 2013 two of his other children became suddenly ill and died within a very short period – only a few weeks. The six-year-old daughter was hospitalized due to illness and was awaiting test results to obtain a diagnosis. The family went back and forth to the hospital and the mother stayed in the hospital with the daughter. The father then took primary care of their two other children, the two-year old boy and a 12-year-old girl. They often

ate on the road due to traveling to and from the hospital. While on a trip to the hospital, they stopped at a drive-thru for food and the two-year-old boy choked on his food. Subsequently he was taken to the hospital emergency department for medical attention. This boy was also hospitalized and the family now had two children at the same hospital at the same time. Both children were diagnosed with cancer and they died not long after.

Genetic testing was completed on both of the parents. It was discovered that both the father and the mother have a condition that makes their children more susceptible to cancer. When the father spoke about the loss of his sons, there was a smile on his face as he spoke about how muscular and strong his sons were. He expressed his memories of his sons with great pride. The father appeared to be distraught when he was talking about his daughter. It was difficult for him to contain his emotions and the interview was paused several times to provide a break. It was clear that this father was emotional regarding the death of his daughter. He explained that she was his “princess”. He told me how she was the one among his children who would run to meet him every day after work and he always looked forward to seeing her every day.

Both Participant 8 and his wife worked very hard to provide for all of the children. He said that he felt “hopeless” seeing three of them die. When we discussed religion, he reported that he feels faithless, as if there is no God. He explained that he has prayed to all of his gods and that he converted to Christianity to have all the prayers possible to help his children. He expressed that nothing worked. He said that no amount of prayers or his belief in God had helped to cure or bring back his children. He seemed very bitter and angry. He mentioned uncertainty about attending church because he lost his faith and felt that his God had abandoned him.

Participant 8 showed dedication and commitment to parenting his daughter and only surviving child. This child was the only one that had not been diagnosed with the same genetic disorder that led to the death of his other three children and during the interview, his daughter walked into the room and appeared to console her father briefly, and then left the room. My observation is that she seemed to take on the role of parenting her father in some ways. This father also expressed a desire to have more children.

Table 1: Participant Demographics

Participant	Country of Origin	Age	Religious Belief	Profession	Languages Spoken	# Children Lost	Age of Child at Time of death	Gender of Child	# of Surviving Children
1	Malaysia	54	none	Interior Design	English/Chinese	1	10 years	female	1
2	Sri Lanka	45	Muslim	Computer design	English /Tamil/ Sinhalese	1	7 days	male	3
3	Cambodia	51	Buddhism/ Christianity (Seventh Day Adventist)	Customer Service	Cambodian/ English/	2	One Day; seven Days	2 females	0
4	Cameroon	43	Christianity	Counsellor	French/ English	1	5 Days	male	2
5	Iran	48	Muslim	Engineer	English/ Farsi/Azari	1	9 Years	male	1
6	St. Lucia	30	Christianity	Construction worker	English/ Creole	2	5 months and 6 months Gestational	Both males	0
7	Ghana	40	Christianity (Baptist)	Social Worker	English/ Twi/Ga	1	6 Months Gestational	male	0
8	Fiji	42	Hinduism	Truck Driver	English/ Hindi/Fijian	3	9 years; 2years & 6 months; 6 Years	2 males and 1 female	1

Codes and Categories

First level coding or initial coding was completed after reviewing the first two interviews, and then, conceptually grouping of the coding was conducted in order to start to move the codes into categories. After the first level coding was completed, I interpreted that managing one's emotions and managing one's health status were two unique codes and this emerged fairly early in the data analysis process. During the second level or focused coding, some of the codes were regrouped and renamed and represent the experiences of the fathers in a more succinct manner. As a novice constructivist grounded theory, I used clustering as a tool to analyze the data in this research. Clustering is described by Charmaz (2010), as a means to visually represent, "understand and organize your material" (p. 86).

Grieving in a cultural context also emerged as a category early in the data analysis and fathers described experienced grieving within a Canadian culture and grieving according to their own cultural values. I labeled this category bicultural grieving. Another relevant category was objectification of fathers in the healthcare system. The analysis consists of 57 codes that reflected ideas, repeatedly offered within the participants' narratives and related to the research question (Charmaz, 2006). The list of codes evolved and emerged over time based on ongoing data analysis. The iterative coding process ensured that I was not fitting interview data into pre-existing categories. Through this process, eighteen codes emerged and six categories were developed.

Research Questions and Fathers Multiple Lived Experiences

One overarching question and two sub questions were developed for this study. Below I present each research question and relevant findings.

Research Question 1

What are the lived experiences of racialized immigrant fathers when their child dies? According to my analysis, the fathers felt that the death of their child negatively affected their lives and they had many challenges in expressing their grief. Many of the fathers who experienced the loss of multiple children were similarly affected in the same manner as fathers who had lost one child. The fathers appeared to display different emotions including sadness, anger, devastation, vulnerability, guilt, and desperation. Many of the fathers expressed that they could not grieve the death of their deceased child in a manner they wanted because of perceived pressure from their spouses, culture, family members, and cultural expectations that fathers were expected to be stoic and reserved.

Research Question 1a

What are the lived experiences of racialized immigrant fathers in their interactions with the healthcare system when their child dies? Based on the data analysis it was evident that the fathers underwent a mix of positive and negative experiences in relation to the services provided by the healthcare system. Some of these experiences affected them significantly with lasting emotions that they discussed in detail. This category addressed the lived experiences of the fathers regarding their perceived health statuses.

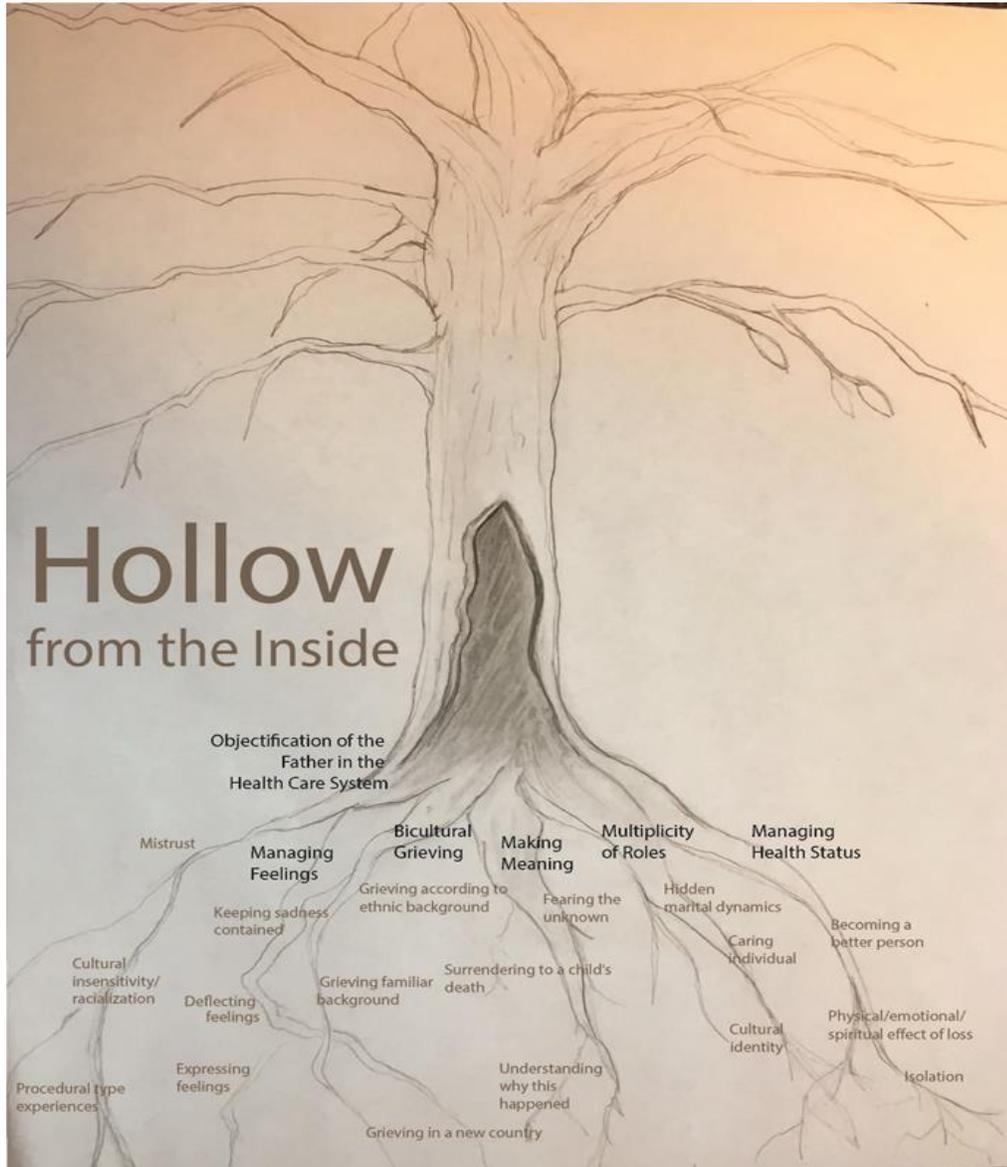
Research Question 1b

How do racialized immigrant fathers understand the impact of the death of their child and the impact of their experiences in the healthcare system on their health? All of the fathers shared negative experiences regarding the impact of the death of their child and the impact of the experiences in the healthcare system on their health. Additionally, the fathers came to realize during the interview that the death of their child had an impact on their health. The data analysis

also suggested that the fathers did not recognize the link between their own health statuses in relation to the death of their child. For example, some of the fathers expressed that the death of their child along with their experiences in accessing healthcare services seemed to have a negative influence on their health

Specific to the overarching research question and the two sub-questions six categories were identified; objectification of fathers in the healthcare system, managing feelings, bicultural grieving, making meaning, multiplicity of immigrant fathers' roles, and managing health status. A description of all six categories and their corresponding codes are depicted below in the Figure 3 graphic, and each category is then described in detail.

Figure 3: Hollow from the Inside - Categories and Codes Rooted in Racialized Immigrant Fathers Experience of the Death of a Child



Caption

There are six tree roots that represent the major categories of this research and the codes are embedded below in secondary roots that are supposed to bring nutrients and life to the trunk and the leaves.

Objectification of the Fathers' Experiences in the Healthcare System

The first category in this research is *objectification of the fathers' experiences in the healthcare system*, which addresses how the fathers perceive the healthcare system. The fathers felt as if healthcare professionals were treating them as objects while accessing services in the healthcare system. It made them feel as if they were less than human, and worthless. In this study, I have seen how some of the fathers felt they were treated in accessing services either for themselves or for their children and or spouse. In seeking services for their children, the fathers felt powerless and did not feel like there was anything they could do to help address their children's situation. The fathers did not feel as if they could change anything on their children's behalf. They felt crippled by the system, crippled by the choices they did and did not have. The fathers expressed feelings of anger because of their perceived loss of self-worth and blamed themselves.

The fathers' experiences in the healthcare system were very diverse with both positive and negative experiences. Interestingly, the procedural type of experiences was perceived as positive compared to the interactions with healthcare professionals. In this context, the procedural type of experiences refers to the physical supplies and the medical services received that involved acute care machines, different medical equipment, processes to address illnesses, and medications. The fathers expressed that receiving these services were positive in comparison to their interactions with the health care providers, which was perceived as very superficial. The procedural type of experiences helped to address the physical needs of their child and addressed some of the medical issues that their children were enduring. In some instances, through the procedural type of experiences signified that there was hope for the fathers in terms of the health of their child and even when the child passed away the fathers felt that through the physical supplies their children's needs were somewhat addressed.

It was interesting to see the different points of view as some of the fathers expressed that they witnessed other individuals being treated differently but not them. When the fathers would share their positive experiences, they would also say what went wrong with other people of different ethnic backgrounds. When then asked if they thought this had to do with discrimination or racism they said no. Sometimes the fathers did share about their own negative encounters with healthcare professionals but some of them did not name it racism or racialization. *Mistrust*, *cultural insensitivity*, and *procedural type of experiences* were the three main codes that supported in constructing this category. The participants' experiences were as if the healthcare system had a crippling effect on them with no possibility to act, behave, and speak about the healthcare journey as they felt fit.

Mistrust expressed by the participants was related to a feeling of being treated different because of cultural beliefs in health and illness and expression of different world-views. The perception of differential treatment was grounded in the belief that fathers felt they were being treated differently for expressing cultural views on illness, death and dying. Some of the fathers felt intimidated to share their real thoughts on how they thought they were being treated or how their child should be treated. Some fathers did not know how the information would be used against them as they had witnessed how others were treated when trying to discuss with healthcare professionals some of their concerns. They did not feel listened to when trying to explain how their culture influenced their decisions, which in some cases caused the mistrust as well. Cultural beliefs according to the fathers affected their access in healthcare in many ways. Based on the fathers' perception of being treated differently, they expressed mistrust of both the healthcare system and in the healthcare providers. The fathers also reported feeling that they were not heard in the system. There were times when the fathers felt that they were

dehumanized: “The doctors’ office is like a processing factory” (Participant 4). “Look at your patients as humans”. (Participant 2 and Participant 4)

Having the feeling that your child died because mistakes were made can be very daunting for fathers and addressing grief while mistrusting the healthcare system that is supposed to support you can be very complicated. As one father shared: “We paid a huge price because of human error”. (Participant 4)

Sadly, some fathers felt that the healthcare system wanted their child to be discharged because of lack of beds in the hospital or shortage of other resources. One father described his experiences:

I think there was some push to get our child out of the Intensive Care Unit, for some reasons, which I mentioned before, costs and availability of beds and what not? Which caused/expedited the process. Because death, death was coming to him, so they kind of expedited it. (Participant 2, lost one son)

The lack of resources was not just present in the hospital setting but also in physician offices. This experience was compared across provinces with Calgary not fairing favorably in one father’s insight:

I strongly believe that if my wife were in Quebec, things would have been different because, first of all, for many months, she couldn’t find a gynecologist. So, we were just, you know, going to the family doctor and there was no proper care, she actually, was sent to go to the lab and do some tests. And then the doctor received the tests, that, the baby kind of not doing well. And we did not get the results of the tests until the very day that she kind of went to see another doctor or something like that, she went for another test and then they said that, you know what, the baby is gone. And then we realized that, you

know, the first test has showed that the baby may not survive and they have already sent a report to the family doctor and the family doctor didn't have the time or somehow missed that information or something like that. So, there's a whole kind of, difficulties in, the waiting period, to see a specialist and those kinds of things. So, I think that's also contributed to the loss. (Participant 7, lost one son)

Some fathers felt visiting physicians did not provide them with the full scope of services and time that their family required. In the case of the spouse of one of the fathers interviewed, they felt like there were alternate options:

But my wife, saw the doctor but he was busy all the time, you know, only spoke to my wife each time, maybe 3 or 4 minutes, and then he was gone—you know to see another patient. But she was concerned that maybe she doesn't get the help she needed you know, she didn't feel like she was being looked after. So, she changed to another family doctor. (Participant 3, lost two daughters)

Fathers' mistrust of the healthcare system tended to be focused on how health information was shared with fathers. Some fathers felt like they did not have the full scope of information to make decisions for the well-being of their children. After the loss of three children, to then hear that it was related to genetics, led one father to be completely aghast with the healthcare system. This father could not understand the possibility of losing three children in Calgary in the hospital and not having known earlier that it was genetically related until he lost his third child. This father expressed the following:

When our third child passed away, then I know, the doctor tells me I got a genetic problem. Then I am worried, why didn't the doctor tell me before? We don't have our children anymore. Why we suffer right now, painful, all my life still. Then the medical

professionals told my wife and I that it is because the doctor made mistake and doctors make mistakes too. And, right now because of this, like I'm not blaming them but if these doctors know what happened, and that one of the other children would be next, why didn't they tell me first when my first son died there at the hospital? We would have stopped it, we don't want to keep suffering. These all my life I am suffering right now.

(Participant 8, lost 3 children)

Mistrust was also perceived as broken promises as another father shared his experiences when his son passed away and his desire to seek retribution for the death of his child.

They pretty much killed the baby. That's what I would say, you know? The thing is, that's how I feel about it. You're asking my experience, so that's how I feel it. And because we don't know what happened behind the scene. If I was there they wouldn't have removed him from oxygen from seven o'clock to until, until when he was moved to another hospital, like twelve o'clock. So, that's about four to five hours, and we know the consequences of removing the oxygen. And, so. I would say not to trust medical professionals on whatever they say. Because you can't trust them, because they broke the promises in the sense whatever they agreed. This is the problem with the hospital system. You have to sue them to get certain things done. But we didn't want to go that far we wanted to correct the system, and we had few discussions with the medical team.

(Participant 2, lost one son)

Cultural insensitivity relates to how the fathers were treated by healthcare providers or what they witnessed in terms of how others were being treated differently because of their racial background. Racialization was experienced by some of the fathers as well. Fathers who encountered racialization in accessing healthcare services may not be aware of being racialized

as even at the interview they did not name their experiences racialization. Many of the fathers used terminologies such as insensitivity and discrimination. In some instances, the fathers expressed witnessing other patients and their families being racialized or experiencing racism. Although the fathers expressed anger, fear and helplessness as they were going through racialization or witnessing the act of racialization they also felt as if the healthcare providers could not help it.

Particular aspects, relevant to this code were cultural competency, racialization of healthcare experiences, understanding diversity in grieving, and receiving bad news from the perception of the fathers. Additionally, a few of the services (e.g., counseling and palliative care) that were offered in support of the fathers did not really reflect their cultural context. The fathers did not feel that the services considered their cultural and religious beliefs when offered. There was little communication between the fathers and the healthcare team to clearly identify some of the barriers and pressures that the fathers felt to comply with some healthcare decisions. As such, accessing some of these services was not an option for the fathers to follow through on. One of these healthcare decisions for example was taking a child off life support. The fathers felt pressured to take a child off life support and expressed not having had the opportunity to fully discuss and explain the impact this decision had on them culturally and or spiritually. According to the father's discussions surrounding this topic, this caused great anguish for them. Making the decision to take your child off life support is comparable to murdering your child in some cultures. One father said:

And, like I said, we had the neonatal chief talking to us. She is a chief in the sense that she is a main doctor in the department and, quite a few doctors, came and spoke to us and educated us on this issue and that's when they were talking about, terminating the

pregnancy and everything. So, they did their part, and I would say that there was a little bit of pressure to make decision. (Participant 2, lost one son)

Sometimes discussing the fact that the child will not live was very difficult for the fathers no matter how it was communicated by the healthcare providers. Allowing that conversation to happen meant that as a father they gave up, sentenced their child to death and might as well have been the one killing their child, from their perspective as grieving parents. Culturally, some of the fathers could not have this conversation with the medical team as they felt caught between their culture and the Western world. One father described his interaction with the healthcare team looking after his son:

So, Neonatal Intensive Care room over there at the hospital, the doctors are working on it, so then this doctor comes in, and he says, you know, we need to talk. I say, okay, talk. Yeah, I don't believe your son is going to make it, and I guarantee that he's not going to be released from here, we can make it easy, you know, give him, some medication, so that he slowly, you know, pass away, you know, he'll be in peace, and you guys too. And I say, you know what, I don't, think so, if he lives, he lives. I don't have a problem with that. But I'm not going to let you euthanize him. (Participant 5, lost one son)

In some interviews, accessing formal support such as counseling support for grieving fathers was discussed. Not all the fathers were in favour of accessing formal support to address their grief experiences. The fathers interviewed felt that their specific cultural needs and perspectives on death and dying may not be well understood in the talk therapy. Others expressed a belief that grief support was best delivered through family members, parents or elders in the respective communities of the fathers.

Accessing formal grief support outside one's own community might be frowned upon, according to the fathers. Seeking support especially emotional support was a sign of weakness and shows that the fathers are unable to cope, which goes against their beliefs. One father explained:

Because if you look at counselling, in my language, we don't even have a word for counselling. But we have a word for advice. So, I would have gone to my mother for advice if she was alive. And then she will tell me exactly what to do and provide words of encouragement. Secondly, too, if I were to go see a counsellor, if somebody would have told me that, you know, you need to see a counsellor, whatever, I wouldn't have gone because I need somebody who understands my culture. And, I, don't think it will help me to see a counsellor a Canadian counsellor who doesn't understand anything about my culture, especially when it comes to grieving and those kinds of things. Right, so no, it never occurs to me that I have to see a counsellor or, even I wanted to see a counsellor. No. (Participant 7, lost one son)

Every father approached the topic of formal support or talk therapy differently. This father shared his experiences with having a social worker provide support to him and his spouse:

The same social worker came to do the counseling. I can't say if we feel better but when she left after a while, we always feel like getting back to our feelings, to that kind of feeling of sadness, depressed—and then, whenever I see my wife cry she would be talking about the baby, about the happy times, you know, while our daughter was still in her womb and everything was happy there. We always try to think about the happy times, but still, you know. They told me, maybe, try to think about, how much happy time you spent with her, she will die, and maybe she is still a part of us. But my wife, she

was crying and I was crying too but crying inside, not to let her know. (Participant 3, two daughters)

As counseling is an individual choice some fathers felt that support should come from their immediate family. One father explained his understanding of accessing formal support:

I don't believe I need counseling. I have some private memories that I want to keep for myself, that I loved my child and that is part of my life, it comes and goes, and so you know, for that reason you know, I can usually get support from my brother, dad, and other people they help me to keep my son close to me for a while, I don't really get used to the new normal. (Participant 5, lost one son)

For one father, information-sharing regarding resources was only for some patients and not for patients from ethnically diverse communities. This made him feel as if the healthcare system was discriminatory and privileged other families at the cost of immigrant families. This is how this father expressed his impression of what he experienced:

The first experience that I had in healthcare regarding discrimination was this —we pay our taxes as same as everybody else. We found out that we could have an aide, actually, because my wife was by our son's side, 24/7 at home without any help. Even our lovely social worker, was saying, there is no discrimination, but there is. Because they are always thinking of us as this immigrant. I feel like they are looking at us like outsider. I couldn't find a reason where the social worker couldn't tell us that the government could provide an aide but no one told us, for years until my wife found out from somebody else that she has three aids, 24 hours, and we don't have any. As a Middle Easterner, as a Muslim we experience discrimination constantly. They are saying no, there is no discrimination but that is totally not true. I never told anybody about my experiences.

Who am I going to tell? How are we going to settle? Then we will experience another problem. One of them is going to come out and say, prove it. (Participant 5, lost one son)

The *procedural type of experiences* code explores the different procedures that the children had to go through and how it made the fathers feel. Some of these procedures put the fathers in a very difficult position as they felt pressured to approve invasive and sometimes painful medical procedures and treatments for their children. Interestingly, however though, the procedural type of experiences was very positive for the fathers. The fathers felt that the healthcare system had the most up-to-date technology, drugs, medications, and diagnoses to support their children. Even when the child did not survive, the procedural type of experiences was a positive encounter for the fathers, compared to their interactions with the healthcare team. The hospitals were well equipped with treatment modalities and state of the art equipment and resources to care for the ill. For many of the fathers this showed that the healthcare system was well resourced to take care of their child, especially when they compared these resources to the hospital system in their country of origin. This is how one father described his experiences:

Yeah. You know, it was a shocker. You see, what happened was she was just a normal kid. She had bleeding nose, so sometimes she would come in, her pillows all bloodstained. And after that one day, she called in from school, and she had this nosebleed that refused to stop, and we took her to the clinic and the doctor tried to cauterize it, and it did not stop and the doctor freaked out. He said to send her to the hospital. And I said okay when I was growing up as a kid, a nosebleed is nothing, you know? In Chinese culture, we believe that if you are under the sun too long you have what you call, maybe what's the word in Chinese like your body become too hot and you bleed. So, all you do you just sprinkle some water on the forehead and cool down and

you know? It goes away. But it didn't go away, so they went in they usually do a full check-up and blood check-up and then the doctors came back and they said, we think she has leukemia. (Participant 1, lost one daughter)

Each individual, each patient has to be perceived as someone unique accessing health services. For this to happen healthcare providers have to look after each patient as a unique individual and put the resources in place that can support this patient in getting optimal health. Incorporating the best resources for this individual will provide opportunities to detect health risks that fathers and their families might be experiencing. One father communicated his experiences in this regard:

Take every case, I mean, look at every case as a special case, probably that's what I'll say. The healthcare providers have to consider every case as an important case, not to overlook things, look for the detailed information probably that's what I will say. But I think is whoever made that first mistake it was not an intentional mistake it's something that probably was unfortunate because that person overlooked some information, and like I said, my wife was told initially that because she has some defect in her womb, you know this is not the time for her to get pregnant, or it's not a good idea for her to get pregnant. (Participant 7, lost one son)

Some participants felt that in caring for their child their needs, their well-being, and their concerns needed to be taken into consideration as well by healthcare providers. They expressed that the practical needs of the child while suffering were attended to compared with the day to day emotional support that they needed as well. The healthcare providers show great intelligence and experience in providing medical care, which did not translate in what the fathers felt they needed as well. Although the knowledge base of the healthcare provider was to par, the

fathers' feelings were not sufficiently taken into account. Availability of the up-to-date information and pristine equipment does not qualify for optimal healthcare. Both the attitude of the healthcare providers towards the families and the most state of the art medical equipment have to be used to provide healthcare for patients and their families. One father shared:

Our doctor is an amazing doctor, very bright. But, I just couldn't understand why, I guess he didn't understand the emotional side. So, we were there for almost a month, and they put a tube in our son's mouth. Under the respirator, basically, breathing. So, they said, we cannot take it out, if he doesn't breathe, and we can try one more time but after second time, we're not going to do it. (Participant 5, lost one son)

Ah I feel very sad about it, but I'm glad that it wasn't me, I'm glad that it's not my fault that he died, it's someone else's fault, right? So, I'm happy in that term, so that's how I make up my mind. So, I never had to make a decision to remove his CPAP, right? Then I would be suffering with stuff, with guilt the rest of my life, saying, I made that decision to remove his oxygen, or whatever. Sometimes things like that happen, sometimes people have to make difficult decisions. And it wasn't me. So, that way, I make it up on that point? (Participant 2, lost one son)

The issue of making healthcare decisions for racialized immigrant fathers was very challenging and in some cases the medical system made decisions that some parents could not. While parents were informed of circumstances it was clear that their inability to make healthcare decisions were based on their cultural or religious beliefs surrounding death, illness and life. Some examples of these decisions involved taking children off life support, ending a pregnancy prematurely, arranging the funeral, gathering mementos including lock of hair, handprints and

footprints, taking pictures of the deceased child and other difficult healthcare decisions. For some of the fathers, it was a relief when the healthcare team made the decision for them.

Managing Feelings

The manner in which the fathers managed what they were feeling after the death of their child emerged early on in the analysis of the research. A diversity of feelings was apparent and present during the interviews and, depending on the father, these feelings were either contained or expressed. I named this category *managing feelings* based on the codes that emerged from the data. The fathers expressed their perceptions of how they perceived society, their family, and their friends expected them to behave after their child has died. According to some of the fathers, they could not express how they really felt regarding the death of their child at the time of death. Fathers also conveyed that the interview process finally provided them an opportunity to openly express themselves and convey their feelings regarding their deceased child.

Some of the fathers still appeared to feel caught between trying to express their feelings and trying to impress their family with their ability to cope and carry on after the loss. At times during the interviews some of the fathers expressed their feelings through crying, however some would stop when their spouses walked in or when another child entered the room where the interview was occurring. Their spouses were aware that this interview was set up and they chose to be home during the interview. The interview took place in a separate room, however at times the wife would walk by the room and check in on the fathers. Depending on which route the fathers took to manage their feelings of grief, it was clear that the fathers chose different means to grieve in order to achieve specific goals and objectives. There were three codes derived in this category: *keeping sadness contained*, *deflecting feelings*, and *expressing feelings*.

Keeping sadness contained was the first major code in this category to describe the internalized grief of the fathers. The fathers showed great constraint and stoicism based on cultural, familial and societal expectations on how they are supposed to share their feelings after the loss of a child. The fathers in this study further identified that this act (containing sadness) was a means for them to cope with the death of their child. Initial coding of statements and words such as regretting, guilt of working long hours, inability to discuss pain, avoiding the feelings of grief, and feeling negative help to develop this code. For several fathers, just the mere fact that they were unable to express their pain to their spouses or anyone else worsened their experience. It might seem obvious that the fathers should have been able to express their sadness, but societal, spiritual and cultural pressure certainly dictated how these fathers should grieve (Betz & Thorngren, 2006; Doka, 2009).

I come back to the hospital and I walk back to the room that my wife stayed in. I think that the first couple of days, she cried all the time. And for me you know, with the culture that I was brought up, a man is not supposed to cry. Even though, in that situation, I didn't cry. I didn't cry at all. I tried to stay but some time, in front of her, I tried to be very calm, tried to be calm, compose myself, try not to break down, because I don't want her to see me in that kind of position. That we all really like that? So, all the hurt, all the sadness, is inside. With her, with my wife, when she was crying I was crying too, crying inside, not to let her know. And now she still complains sometimes. Because I can't cry. Something inside me, that just doesn't want me to go talk to people and let people see me cry because sometimes, I'm an emotional guy too, sometimes I can cry easily too. (Participant 3, lost two daughters)

I could not handle seeing my son die, even though, like you know, yeah, it's hurting me inside, but like you know, yeah, I can't, I cannot show it to the wife, you know.

(Participant 5, lost two sons)

Fathers also found it difficult to show how much they were affected but continuing to internalize the pain: "It's hurting me inside but I can't stop, and show it" (Participant 6, lost two sons). In internalizing the pain, a father felt that it was best not to say anything at all as everything that he communicated about the death of his child was perceived as off-putting and pessimistic: "I feel really guilty for being negative" (Participant 5, lost one son).

In internalizing the grief one father felt it was better to just think of having other children with his wife as that's what he was being encouraged to do by friends and family: "I don't talk too much about the child I will have another child" (Participant 2, lost one son).

In trying to keep their sadness contained some fathers chose to avoid discussing the topic of the death of his son altogether. This strategy was what worked for him to continue living and taking care of his surviving children and spouse:

Uh [*laughs*] yeah, the first one, you know you just know you just kind of feel it, you know you lose, something you love a lot, you know? Yeah, but to show the expression, you know, I can't show the expression but I can feel it in my heart, you know? Yeah. To show it. I'll never, come and cry and do that thing, you know? You do it inside, you know? That's the way I feel it, you know. Yeah. You know, something you really love, just you lose something that you love so very much. Yeah, you just feel broken-hearted, you know? Yeah. Ah, come out and cry is not good for me [*laughs*]. (Participant 6, lost two sons)

Identifying how one feels after a child has died is not easy as shared by this father.

But once in a while, it's my wife that will bring it up, you know, like few weeks ago, she mentioned, we would have had a 5-year old boy, screaming around the house. I say, Okay, [*laughs*] let's talk about something else. Yeah. I tried to avoid the conversation, probably because I feel like it's not necessary? I can talk about it now, without causing any emotional harm to me, but it's just, I think, okay, it's past event. (Participant 7, lost one son)

Some fathers used metaphors to highlight how much they were impacted by the death of their child. The metaphors helped the fathers illustrate the importance of their child's death, and in some instances, reframe or redefine the hurt they were experiencing while grieving. Through the metaphors the fathers found a way to talk about their experiences with the death of their child. However, even with the use of a metaphor it was still difficult for the fathers to express what they were feeling, how the loss of their beloved child affected them. While fathers used metaphors to explain their loss, this did not contribute to reducing the pain they experienced. While using metaphors as a way to express their feelings the metaphor did not take the pain away:

I mean, I compare the feelings of not being able to forget the loss of my son as entering a room with a smell. When you enter a room and there is some smell. You smell it, smell it but after 5 minutes, you don't smell it anymore. But that doesn't mean that the smell is not there. That's the same with the loss I suffered. So, this is my new normal, basically, it's a new normal. He's gone, and it's not going to be the same normal but it becomes normal. (Participant 5, lost one son)

So, and we have another saying that says, somebody stole another man's hat and the man went and sat in the graveyard, and they say, why are you sitting out here, and the guy

says, the guy who stole my hat someday he's going to show up over here. So, it's just, a matter of time. Because it's natural, everybody has to go, has to die and there's a God who wants him to go and for you to stay on earth, so that is why we are grieving for death, it is meaningless. Everybody has to go, when his time is up, he's gone. Even, if we all grieve a little bit, it mostly resolves in 7 days or something like that. Because it is part of the natural path. (Participant 8, lost two sons and one daughter)

The most profound metaphor that was shared came from a father who lost his son. He compared the feeling he had and not being able to express it while internalizing the grief as "a tree that was hollow from the inside" (Participant 1 lost one daughter).

With one father in particular, the regret he felt for working long hours and even sometimes working from home to make ends meet and providing for his family made the experience of losing his daughter so much more difficult to handle. According to the father, he was expected to be there and spend time with his child. There was a lot of regret in the manner in which the father expressed his experiences regarding the loss of his child. This father admitted that he wished he could get the opportunity to do things all in terms of spending time with his daughter. He wished he could turn the clock and be there with his child when she asked him to play with her:

I was kind of working away those days, you know, and so there are things I regret. I look back and think I should have spent more time with her. Because, when I worked, I kind of so focused on work, and I still remember a time when my daughter said, she comes up to me and she said, dad, can you have some time to play with me, and I kind of said I got to finish work, some other time. So, when this thing happens, when she died, it really kicks my butt, I say, gee, I could have dropped my work and get on and have times with

her. So, I always like, tell my friends with kids, it's good that you spend time with them.

Next thing you know, it's all gone. They may grow up, or they may just go, just die.

And that's hard to accept, but then, looking back, it's all sweet memories you have.

(Participant 1, lost one daughter)

Deflecting feelings is an approach that the fathers used to manage their feelings. This approach consisted of the use of self-blame. Through self-blame the fathers were able to find a different medium to internalize their grief. They did not have to deal with it or address it because they were to blame for what had happened. Deflecting their feelings through blame was not just about blaming themselves but also towards blaming God and other individuals. For the fathers, this was a great way to deflect what they were really feeling, without addressing their pain. They had a way, a medium, or something they could hold on to that they felt caused the death of their loved one. This was another way for some of the fathers to get through day to day life after the death of their child:

Obviously when she was sick, I didn't, you know, say my prayers, and it didn't happen you start to blame, you're not helping. But then after you go through the next stage, and then you say, no, it's not that, is he telling teaching you to learn what life is all about? Or whatever it is and then something happens, you blame, you know? But now, you're thinking shift again, you say, it happened for a reason. (Participant 1, lost one daughter)

Another father expressed the following:

I think they are in a better place. That's my comfort right now, because to me, and my wife, we know we are good people, we never do anything bad, never do anything wrong, we are peaceful good people. So, I think that is what helps me when I think of my daughter. You know, maybe my daughter is in a good place because we are both good

people, that's what I think, somehow, I take comfort in that thinking. (Participant 3, lost two daughters)

Expressing feelings emerged from the aspect the fathers felt safe to express how they really felt regarding losing a child. With no one in the room, some of the fathers openly wailed or cried, at times quietly, at other times uncontrollably. Some of the fathers simply had tears in their eyes, which they wiped away periodically or cried silently as they spoke about their child. Thinking of their children brought back many joyful but also painful memories for the fathers, especially when they spoke about how their child died, or in the event it was an illness and there was hospitalization involved. Included in the development of this code were words such as using time wisely (which was more a behavioral change for the fathers), not taking life for granted (addressing their memory of their child and making sure they took life as it was presented to them), feeling as if running out of time (ensuring that they lived their life), value life (not thinking that tomorrow will be granted, but the awareness that each moment is valuable and should be taken as such). Contrary to popular beliefs and societal and cultural expectations, the fathers were very detailed and expressive about their experiences. The level of detail in which the fathers shared their lived experiences was honest, detailed and very emotional.

One father described a rather heartfelt experience of when he first broke down and cried in front of his wife after the loss of his second child:

But on the way home, we were driving, and my wife started to talk about the baby. And that is the very first time that I cannot hold it all in anymore, and I cried, while we were driving, right there. And my wife said, oh, the first time she sees me, sees me cry. And I cried, I kind of let it out because it has been held back inside for so long. (Participant 3, lost two daughters)

A father who experienced the loss of one son had the following to share regarding how work-life balance could not stop him from reaching his son before he died. He also expressed how finally, after a long struggle with illness, his son seemed to be seeking permission to die. He described the grief he felt and his emotions:

So, I just drove back to Calgary, I was in Airdrie. As soon as I got the news, I know this is serious. We went through this, many times, but this time it is different, it feels different. I could feel it. Whenever my wife called, just my heart dropped. So, we come over to the house, and he was on the bed, in a very bad situation. He could not breathe. His lips were kind of bluish. Anyhow, the anesthetist told us that his heart is very, very strong. He might be in this situation for days, maybe weeks. Get prepared for it. So, the same day, I went to get some stuff in a store, so my wife called me and says, come home, right away and I knew. And the doctor was sitting over in the house with my wife at that moment, while our son was asleep. And he woke up, he woke up, and was waiting. So, they called me. As soon as I got in, I had only one chance to come and when he saw me he gives me a look, and he was gone. He was waiting for me to say goodbye. As soon as he saw me I gave him a kiss on his forehead and he was gone. But there are many, many nights that I cry. (Participant 5, lost one son)

The manner in which this father expressed the memories of the last day of his son was as if it was yesterday, which is indicative of the sense of ongoing loss expressed by many fathers.

Bicultural Grieving

The category *bicultural grieving* reflects the fathers' grieving experiences in a cultural context, more specifically as they grieve with respect to two different cultures. When a child dies, immigrant fathers have to think of how to honor their child's life, death, burial, and

memory in a manner that reflects their cultural and religious background. At the same time, however, immigrant fathers must also understand that the Canadian culture is their new culture as well, and the culture with which their child was possibly most familiar with. The participants felt that they were expected to grieve according to the culture they grew up in as well as they felt that there were expectations in grieving in a Canadian manner.

This category also focused on the fathers' perceptions of how they understood diversity in grieving and their own understanding of grief expectations in Canada. Codes that emerged within this category were *grieving according to ethnic background*, *grieving on familial background*, and *grieving in a new country*. Grieving according to ethnic background as a code highlighted how the fathers felt impacted by their cultural background in grieving the loss of their child. Expectations of how a father should grieve, cultural values of grieving, cultural beliefs after death, fathers' cultural understanding of illness, afterlife beliefs, fathers' perception of a child as a gift, gender roles in grieving, and gender of the deceased child were some of the codes that supported constructing theory. Sometimes fathers felt that their religious beliefs influenced their perception of life and death. Their understanding of how their child's death is perceived in terms of having no sins because they are a child and have not lived long enough to have a multitude of sins. As one father described his thoughts:

When, a child or, anyone dies, it's common, doesn't matter, right? So, we mourn for three days. Maximum, we're allowed to mourn for three days and that's it. And I don't remember even if we are screaming and crying because we know what death is all about do we? We know what the purpose of life is? Once you understand the purpose of life it is easy to make up your mind. So, that's how it is. So, pretty much I would say we learn a little bit more about our religion, out of all this [*laughs*]. Yes, well, we are here

temporarily in this world, right? So, whatever you do good, you will enjoy if you do bad, you will pay for it. So, that's the purpose of life, in being here on earth for a short life.

So, when our child dies, he pretty much has no sins, right. (Participant 2, lost one son)

Fathers also reported that they felt caught as the general beliefs and perception in terms of men expressing themselves through crying or being emotionally involved was not acceptable in some spiritual and religious beliefs (Doka, 2009). This was not just a perception because some fathers truly believed it and it impacted them in how they coped with the death of their child. One father shared his story:

Men don't cry. So, we don't cry. You know, that's why when my wife sees me cry, she said that's the first time she ever sees me cry, when we drive back home. Right now, I think right now, it is okay now. If you want to cry, you cry, I cry. I said that's why, after crying maybe I feel better. Right now, I cry sometimes. (Participant 3, lost two daughters)

Another father believed that crying publicly greatly affected his manhood and it was not allowed:

So, so yeah. She cried for many days, but cultural, I'm not supposed to cry [*laughs*] ah, because we believe that if your first child passed away, especially baby, not even first child, but if you have a baby and she passes away and then you cry, and you make a big deal out of it, and, you have a funeral, and those kinds of things it is likely that the second and the third child will also pass away. So, you just try to control yourself and maintain your emotion. Not to go to that extreme. Yeah. So, we believe that if you do that, you invite the rest of the future babies to also kind of go through the same agonies. So, if I cried, well, it means that I'm a weak, you know, it reduces my manhood. In the eyes of

people from, Ghana, we didn't actually tell people outside the family. (Participant 7, lost one son).

The same father shared that culturally the manner in which the death of a child under 18 is observed is not the same as grieving for an individual that is over the age of 18:

Ah normally, if he were to be a grown-up, like maybe, 18 years and above, then there'll be a huge funeral. In Ghana, grieving involves a lot of preparation. Sometimes, the body will be kept at the morgue for months. But under the age of 18, you try to kind of, minimize all these things, you don't go through all of that so, under that age of 18 years old, there isn't as much grieving that's supposed to go on, as I mentioned. It means, you are inviting your future children to go through the same process, so you don't go through any publicity, make an announcement, family, and close family members. When I say close, close family members would be your aunties, your cousins, and those people would be the one to gather. And then they would have a very brief moment for grieving and then after that, everything is done. No one is going to talk about it anymore. So, this would have been the process if we were to be in Ghana. But if you were to be 18 years and over, then the process would have been a very, very long process and preparation, publicity and a lot of, you know, activities involved. (Participant 7, lost one son)

Grieving based on familial background is a code that explained how the fathers grieved the loss of their child based on the medical knowledge of the child's condition. Some of the fathers educated themselves tremendously on the medical terminology, explanation, and nuances surrounding the death of their child. This knowledge seemed to help the fathers cope with the death of the child. In being able to explain the condition behind the death of their child, the fathers seemed to retain some power to address their grief, to keep them going, and

to reflect back on the fact that their child had a medical condition that caused the death. The development of the code *Grieving based on familial background* was within the context of fathers knowledge and awareness of illness, cultural understanding of death and dying and religious beliefs. Fathers who observed their religious beliefs in Canada away from their country of origin were impacted even in the host country.

Grieving in Canada did not mean putting aside religious beliefs but it seems that spirituality and religious beliefs became significant for the fathers when their child died. Some of the fathers started going back to their religious place of worship to reestablish a relationship with their faith. In certain situations, fathers would attend different churches with the hope that their prayers would be answered regarding the fate of their child, especially when the child was palliative. Through trying to strengthen their faith, some fathers felt that they were better able to cope with their grief. Some fathers completely walked away from their faith and did not want anything to do with their religion after the death of their child. These fathers felt abandoned by their beliefs and religion. “As I said, in our religion, it says, age is just a number, everybody has to go”. (Participant 5, lost one son)

Sometimes grieving in a way that fathers were accustomed to, meant keeping the death of their child a secret until they felt that it was the right time to share their loss:

Friends, we didn't tell friends and even friends didn't know she was pregnant, we kept it secret. Ah, it's also part of the belief. So, there's a whole lot of cultural belief that play part on how we handle the situation and everything, because when you are pregnant for the first few months, you don't announce it, you try to keep it a secret. Afraid that, you know, if there's a witch in the family, they might, kind of cause the baby to die, or, cast a spell on the baby or something like that. Yeah, so a lot of people didn't know about it,

so, we kept it secret and then after the baby passed away we kept it secret for a long time. Before we told a few friends that she was pregnant and the baby died. (Participant 7, lost one son)

Grieving in a new country (Canada) was linked to the pre-migration, migration and post-migration experiences of the fathers and how these impacted them to grieve the death of their child. The fathers' perception of grieving in Canada, their perception of death, and perception of illness were relevant to this code. For one father making the comparison between how men and women grieve and how acceptable it seems for women to express their grief was difficult to handle especially because he was living in a new country:

Oh, of course, the people everybody grieves, especially men, because the men, they don't want to show it, but probably they grieve inside and they never, express the bad. But. Mostly women cry and for days. It is not part of the culture, even the man grieves, the other one says, hey, what's this? They try to just stop it, it is like, everybody's going to go, and your grieving is just meaningless. (Participant 5, lost one son)

One father made a pilgrimage to Mecca after the death of his son and was amazed at how much he could not express himself here in Canada but strangely in his country of origin because of what he experienced during his spiritual journey:

Ah, sometimes. For example, we don't feel sadness, but you feel sad. I shouldn't say feel sad, but you feel about him. One time, usually for fathers it doesn't heal often, like mothers, right. This is probably your question, and this is probably what you are interested in. So, mothers they always think about their child who passed away, but even my wife she understands it very well. So, she doesn't cry like that, but sometimes she feels it. But for me it happened two years ago, the same year. I didn't feel it very much

but, because I'm kind of tough as well, I would say. I went to Mecca, and I saw somebody who died, and they take him for his burial, then I felt it, and that was the only time I felt the pain very much. (Participant 2, lost one son)

One father who suffered the loss of three children and all three losses in Calgary was figuratively speaking at a loss himself. He felt that he brought his family to Canada for a better life and his children found death in this country that was supposed to fulfill many promises. He chose Canada to provide a better life for his family and there was nothing that he could do to save his children from death:

I know, I feel guilty for whatever I did to cause my kids to die. I never saved them never do anything for them I don't know what I will tell them, I don't know. It's very hard. Sometimes I think what kind of a father am I, I never saved them. But then I ask why is this happening to me and my family all my family is so healthy, my mom's side, my dad's side, this never happened. Why did this happen to me? What kind of punishment did I get? (Participant 8, lost three children)

Making Meaning

The category *making meaning* emerged as an important category in the research because it was evident that the fathers were trying to figure out why their child died. The fathers were also trying to make meaning of what was happening to them, trying to understand how to continue living. This category also meant that the fathers were trying to make sense of the death of their child. Making meaning became important as the fathers expressed it in a variety of ways. *Understanding why this is happening, fearing the unknown, and surrendering to child's death* were the major codes that were identified in establishing this category.

The code *understanding why this is happening* had to do with the father's own realization that they needed to understand why the death of their child occurred. The fathers in the study were all trying to make sense of dying in general through the interview process. They were also by talking, however, coming to a sense of why their child died. There must have been a reason. It was impossible to suffer such a great loss without an obvious reason. The major issues associated to understanding why their child died were related to casting of spells, predestination of life, and something they deserved as parents because of something they did. In regards to making sense and understanding the death of their child some fathers expressed the following:

Because you know your destiny is written, right, so you have no choice. Because it is written, the day I was born, or the day I die. It is in someone else's hands. So, whoever decides that, decided for our son. And I can't change that. If I couldn't change my day of death, or the day I'm born, or the time I am born, then I can't change someone else's, right? So, there's no why, it's straightforward. (Participant 2, lost one son)

Making meaning of the loss of one child is difficult. Understanding and making sense of the loss of three children is just indescribable:

With my three kids is hard. There's a big problem right now, like, every day and night, I'm thinking. I forget when I come home and when I am alone, it is very painful. One kid I was deserving to lose, but three kids it, is not easy. Then it is more for me, nightmare. (Participant 8, lost 3 children)

Sometimes, making meaning of the death of a child meant the fathers expressed during the interview what they normally would not have shared with anyone out of fear of how they might be perceived. This father described how he saw his son smiling after he passed away. Initially right after death there was no smile but a day after there was:

When he died all night, he was angry. I could see it, his face was so angry, and after, he couldn't rest. So next day we took him, I gave him a good bath, cleaned him up, and we put him in white sheets, so after you put him in white sheets you put him in the coffin. And, and suddenly his face changed. He was smiling. So, I called his mom, I said, you have to see this. Usually after we put a child in a coffin, we don't let the mom see them. So, we put him in the mosque, after the prayer, and we put him in the front and everybody prays for him. He was in the coffin at the back, because they're segregated, ladies and men area. So, he was put in the men's area. So as soon as I opened the coffin, he was smiling. I mean, looking at him, he was smiling his face was so bright. And he looked peaceful, mom give him a kiss after prayer we took him to the graveyard. So, we buried him over there. Put him in the ground. Well is it denial? Over there, you don't want to do it. But I want to take him home. [*Crying*] I want to take him home.

(Participant 5, lost one son)

Understanding the loss of two children is really difficult especially when there are no surviving children and the prospect of having other children is very slim. This father described what he is feeling because the death of his two daughters were related to genetics and the chances of having children with his wife are highly unlikely. He is much older and there is fear based on what the physicians have shared with them that they might need alternative ways of having children which might put financial strains on this couple. Understanding his loss under these circumstances makes it so much harder:

Why did this happen twice? It happened one time, we suffer, now it happened two times, we suffer like this you know, and then, we don't have any children, maybe if we had another one we can take comfort, you know? Two children? But for us, it is nothing.

And then the prospect of us getting another child is almost none. My wife is getting so scared now, and I am getting scared too because for us, if we went through this kind of experience for the third time, I don't know what might happen. And for the first time, the suffering is not that much but the second time, it is so much. (Participant 3, lost two daughters)

All of the fathers used spirituality, faith and religion in different ways to cope with their grieving. The fathers' spirituality and faith also supported the grieving process, even when some of them were not devout prior to the death of their child. For some fathers, the short-lived life of their child on earth was perceived as temporary, merely in a world to test them for what is supposed to happen after death. Therefore, believing that their loss was the will of God supported them in coexisting on earth while waiting to be reunited with their child. Seeking spiritual comfort in their faith and or religion was therefore important to the fathers. Having great faith also helped create an understanding why the child passed away. The role of religion, faith and spirituality definitely evolved throughout the experience of losing a child. Some fathers used their faith or religion to get them through but some also turned away from the one faith they knew.

A couple of the fathers also believed in reincarnation or rebirth. This brought hope for them as they perceived the death of their child as a possibility to be reborn. The fathers' demeanor changed when talking about the reincarnation of their child. Especially in situations where there was a previous loss and the second child was from the same gender. In this case, the father believed that his first daughter was born again with the purpose to survive this time. According to the father, the purpose of the rebirth is to reveal the medical diagnosis, the reason why the first child passed away. Through the reincarnation and the

diagnosis, the physicians would be able to determine the cause for the loss of this fathers' first child. This was however not the case, as the physicians were unable to provide a diagnosis before their daughter passed away according to the father:

When she died, when our second daughter died, we think that maybe our first daughter came back. Our first daughter came back that's what me and my wife, thought one time. Our second daughter brought the same disease with her so that we know what really happened to our first daughter. Because, their condition is the same, the problem is the same. But then both of them met the same fate. (Participant 3, lost two daughters)

Another father described his experiences as follows:

Muslims believe in hell and paradise, right? So, my son will be in paradise because he has no sin. So, that way, it gives us comfort. Yeah, and, it's just a lottery for him. I mean you just got it without doing [laughs] anything really. So, without him being tested in this life. If you think that way, I'm just thinking that way. We will meet him in paradise, that's how we think. So, that way we are happy and we know that, that he will be in paradise, and we will meet him all my kids, they always say that, oh, we will meet him. They are very confident of it. And we will meet him and we will be reunited with him eventually. (Participant 2, lost one son)

Fearing the unknown as a code in this category was expressed by the fathers in different ways. It was either fear of having another child or fear of where their child might be or if they ever will meet their child again.

For one father not having a diagnosis is really walking into a situation without any guarantees:

So now we got a dilemma that we are scared to have another child. My wife, she said that, if there is no diagnosis of the death of my daughter then she doesn't want to go through another pregnancy for the third time. Maybe not at least not for now. We are looking for some kind of adoption. It is very hard to sponsor a baby. That's why we want to adopt, you know, a child from Cambodia, but I think that maybe it is not that easy to sponsor a child. And to adopt a child here is not that easy, it is even more difficult. It is even more difficult, that is why, my wife's doctor talked to her about a special kind of implant. To get another donor instead of me next time to get pregnant. But right now, everything is still not decided yet. They said that if they can figure out the problem, then they can help us to protect the baby and have a healthy baby. (Participant 3, lost two daughters)

Surrendering to a child's death described the feeling of powerlessness from the perspective of the father. The fathers felt like they were not able to do anything for their children to keep them alive. They were supposed to be the protector and solve problems for their children. These problems included health, illness, and dying. The process of surrendering to the death of their child was not an easy one; for some of the fathers had not reached that stage at all during the interview process.

For one father, it took five years to look at the pictures of his son and visit his grave: So, it was too painful for me. And I didn't want to see what he looks like and everything, and probably because I didn't have the guts to see what he looks like, and that was around the same time my mom passed away, so I mean, I was going through a lot. And within three months, having and losing a child, so, I didn't want to see him. But my wife brought the pictures, and everything the teddy bear, and everything else home. And she kept it.

And I know where she kept it. So, it's just a few months ago after five years, I was cleaning up and I say, okay, I should have the guts to see what this child looks like [laughs]. And so, I took out the everything [laughs]. I looked at the pictures, and finally did what I was supposed to do years before. (Participant 7, lost one child)

“Fathers are not supposed to bury their children.” (Participants 1, 2 and 4)

Surrendering in this context also meant that the fathers had elements of acceptance and non-acceptance of the death of a child. Although many of the fathers shared how they needed to surrender to the loss of their child they still felt that it was not an easy process. Being a father meant that your children had to outlive you. Many of the participants shared sentiments that implied that children are supposed to grow up, take care of their parents and live full adult lives. On the same hand, parents are supposed to grow old and be taken to their final resting places by their children when they die.

Multiplicity of Immigrant Fathers' Role

Multiplicity of immigrant fathers' role is an especially important category in this research. The fathers in this study had many aspects in their lives to balance while assuming different roles. These different roles signified the multiple identities that the fathers have in their family and in the community. These include the father's role not only as a grieving individual, but also his various roles in society, in his community, and in his family; he is an employer, employee, father of surviving siblings, a husband, an uncle, brother, son, member of faith community, the protector of his immediate family, and in some instances the main provider in the family. Clarity and expectations around these roles were difficult for the fathers at times as these roles predominantly impeded the ability of the fathers to grieve the way they wanted to. In some instances, society, family, and culture dictated how these roles should function. This

caused an additional layer of stress for the fathers, as they were yet experiencing another barrier to express how they really feel regarding grieving their children's death. Navigating the role of the multiple identities of the fathers caused some deep-rooted issues for the fathers in terms of understanding their self-identities and self-care needs and strategies.

Evolving marital relationships, caring individual, and cultural identity where all codes within this category. Evolving *marital status* addresses the issues that arise between the father and his wife after the loss of a child. There were both positive and negative experiences in the marriage after a child had died. These evolving aspects in the marriage of these parents were considered hidden as many of the fathers interviewed did not realize some of the issues in their marriage until the interview. During the interviews, the fathers came to realize how much the death of their child affected their relationships with their spouses. As such, many of the fathers never had an opportunity to discuss these issues, positive or negative, with their spouses. Some of the mothers, if present during the interviews, heard what the fathers shared for the first time. All of the fathers who were interviewed had a great sense of responsibility regarding supporting their spouses after the deaths of their children. They also felt that, as a husband, they were placed in their wives' lives as a protector to guide the mother through the mother's grief. In many instances, this meant that the fathers had to place their own needs and their own grief second to that of their spouses.

Although the fathers tried to support their spouses, at times there were frictions as the perceptions of how the mothers should grieve influenced the kind of support that the fathers could provide. In many cases the fathers could not provide the support that their spouse needed. Similarly, the manner in which the fathers should grieve affected the wife's understanding and

perception of the fathers' expressions of grief. The fathers expressed that their spouses felt that they were not grieving and not expressing their feelings. As one father stated:

And then I noticed a difference between me and my wife. Sometimes I look at a picture, I feel it's okay, I can see her, I look at her, I feel at least I can release a little bit. But for her, she cries. I think one day, we were fighting. I said, you look at the video, you cry and cry all the time. Stop looking at the video, because when she cries, is too much pressure on me. Even though I don't cry, but, but you know, deep down inside I'm going to burst, you know, in two pieces. Yeah. One day, I told her, stop watching that TV, I was so mad at her. But later on, I know, I shouldn't have said it like that, but because I have too much stress and too much sadness when I, see that she cries, non-stop like that whenever I see the video. But now, right now, she's okay now, we can look at the video, we can look at, we can, smile, we can be happy even when she sees our, our daughter taking a bath, or that stuff. So now, now I think it is okay now. (Participant 3, lost two daughters).

In regards to having a successful, divorce-free marriage, a father expressed the following:

Well my experience, was that, my wife and I were expecting, especially my wife, it is her dream that she has a child with me, even though she already has 3 children, because she believes that that's what will keep the marriage, strong. But, to me, it is not [*laughs*] I don't believe that having children will keep the marriage going. I tell my wife that, you know otherwise there wouldn't be single mothers [*laughs*]. So that's my belief. But she has higher expectation than I? And I don't know, it's because she is a female, and also culturally, back home, the tribe where I come from? When you have children, the children belong to the wife's side of the family. (Participant 7, lost one son)

For some participants supporting their spouse while being blamed for child's death was a challenging experience. One father shared how he felt:

So, in our culture, if a man cannot have children, the community looks very differently at this man. Not in a good way. The marriage is also not good. Right now, my wife is blaming me. Right now, she asked me to give her back her baby. Sometimes, she's even joking with me, sometimes, whenever she says that it hurts me but I never told her it hurt me. That's why, you know, I always wanted, a child. I really want a child. So, either, one day, maybe if we can have the courage, we might try again. (Participant 3, lost two daughters)

The dilemma always existed in ensuring that the spouse was physically and emotionally healthy and all the needs of the wife were addressed even before the father could take care of himself:

Yes, I had to support my wife in everything. Especially with children, because she knew the situation, right? So mentally she was not okay even though she's pregnant, but sometimes is a stress. (Participant 2, lost one son)

Some of the fathers did not share everything with their spouses including hiding their health condition from their spouses. One father described in particular how his own scare with a health condition did not matter as long as his wife did not know and she did not have to worry about it:

And then I worry about my wife, all the time, you know first, there is the baby problem, if she finds out that I have cancer, my wife cannot take it. On the way, there I told my sister that if the results come out that it is bad, just between me and my sister, the results should never be made known to my wife. (Participant 3, lost two daughters)

The code of *caring individual* portrays the participants as a father who shows support to surviving children. The fathers are in particular concerned in how the surviving children respond to the death of their sibling. I noticed that the fathers, when talking about how to support their surviving children, were still very detailed about the loss of the child that passed away. For me, this signifies how an individual that was grieving was still able to direct attention to different aspects as the role of a father. The fathers were attuned to their role as a supporter of their other children, also remaining conscientious of different ways to include the surviving sibling(s) in building memories of the deceased child. The participants observed the impact of the death on the siblings and they were able to express how they felt about this in detail.

The way in how the surviving children felt and experienced the death of their sibling and how they grieved had an impact on the fathers as at times they did not know what to do either. So, although they were aware that the surviving child needed support and needed answers, the fathers did not necessarily know what to do and how to provide the needed support for their remaining children. While worrying about their spouse and surviving children, however, the fathers consistently displayed their caring nature.

Surviving children had to be taken care of, as well, and the fathers needed tact in how to share the news with the rest of the family. Addressing the well-being of everyone in the family was important. Fathers had to consider all of this:

Yeah, that's right, so we had to prepare our children for the outcome, and, we had enough time to give them, educate them about life and death and train them how to deal with that.

(Participant 2, lost one son)

In supporting the children, the fathers had to fill in the gaps when the mother was unable to care for the family as she was submerged in her grief. Being strong, having people think that you can handle everything is a concept that was described by fathers:

No, because, you don't know, my wife is weak, so, I cannot be weak, too, I got to be strong, you know? (Participant 6, lost two sons)

The fathers felt that they had to be strong for the surviving children.

Being a caring individual had an impact on the fathers' employment situation as well.

When it came to employment issues, the fathers had to make choices that sometimes could cause them to lose their jobs. In a society where men are pushed to focus on climbing the corporate ladder or being the breadwinner at any cost, did not deter these fathers to forego their jobs and care for their loved ones. Balancing their jobs and caring for their wives or attending to their ill child was not an easy task for many of the fathers interviewed:

I was at the plant and I told them, I have to go. And we were in the middle of a project, and I said, I have to go. What do you mean you have to go? I said, I have to go. My kid is sick. And they didn't believe it actually, it doesn't matter if they believed it or not, I, had to go. So, I stopped the project basically. (Participant 5, lost one son)

Because that week was very tough in the sense, my wife was in the hospital, then I had to kind of work as well because we didn't know how long our son was going to be living or stay alive. (Participant 2, lost one son)

The *cultural identity* code emerged based on how the fathers' immigrant status, ethnic background, level of education, racialized father who survived a child's death affected their role as a father. Immigration status included the fathers' positive and or negative settlement experiences. Some of the fathers felt well connected with their country of origin but a few felt

no connection with their home country until the death of their child. Regardless of the circumstances of the death of the child's death or the length of stay in Canada, the fathers' reflected on how their ethnic background affected their grief. Additionally, the role of culture in grieving a male or female child influenced the fathers at times on how they thought but not in every instance. The fathers were more influenced by the fact that their parents or family in their country of origin might have something to say regarding the sex of the child and how they presumably should grieve:

Oh, man all our kids are all in my heart, it is not different or anything. My son or daughter, it is all same thing, in me. But before in the old days, my great-great-grandparents' days, a son is very important for this and that. Yeah, it is important to have a son, I know that. Because a son is going to take, our generation. The daughter is going to leave and things stop with her, and that's why they're thinking we need a son. But this moment, nothing is helping me out, what am I going to say, I'm going to throw my daughter away? No, is no, having boys or girls is all the same for me right now.

(Participant 8, lost three children)

Managing Health Status

The final and sixth category in this research study is *managing health status*. The particular focus of this category was centered on the fathers' expression of how the death of their child impacted their own health. Aspects such as how the fathers handled their own health, how fathers managed their physical, emotional, mental health and well-being after the loss of a child were also considered in the construction of this category. *Physical, emotional and spiritual impact of the loss, isolation and becoming a better person* were the major codes in this category.

Becoming a better person as a code had to do with the fathers' response on how the death of their child affected the fathers to grow into becoming a better person. As the loss of their child was a great distress on the fathers, the manner in which the fathers' grief affected their view of life also influenced the entire family. Subsequently, when the father was negative it had a great effect on the spouse and the surviving children. Realizing this, the father found ways to address their attitude in life and within their family. As one father said:

I have to be prepared for my death too, right? And I would say it has improved. Now I am constantly thinking about certain things like being a better person, so that's why this is the benefit of death sometimes it also brings good things into your life. This is one of the good things, you know, it should make you a better person. (Participant 2, lost one son)

The *physical, emotional, and spiritual impact of the loss* on the fathers was evident throughout the interview. It was interesting to see the emergence of this code especially because some of the fathers had not given it any thought. The fathers had also not put a link between their health, the death of their child and their experiences in the healthcare system. Through the manner in which the interview was conducted, the fathers had the opportunity to speak about their health with a focus on their physical, emotional, and spiritual well-being. Some of the fathers' expressions were also related to their health status, with metaphors being widely used: "The day he died my back was broken" (Participant 5, lost one son). "I got old the day he died" (Participant 2, lost one son). "A big chunk of me died with him that day". (Participant 1, lost one daughter)

The fathers faced significant emotional challenges that in turn had a physical impact on their health statuses. They often suffered from a lack of sleep that amplified the impact of the

circumstances and daily tasks often became too difficult to manage. One father shared that he experienced difficulties having to frequently travel back and forth to the hospital:

Sometimes I had to come home, to cook, to get stuff and to bring it back to the hospital and go back and forth, back and forth. In my heart, it's so hard for me by the time I have to leave. Sometimes I don't want to leave her alone by, by herself at the hospital. So, I think the first two or three days I just, you know, sleep, you know, sleep beside her bed in the chair, sit down on the chair, sleep like that. And sometimes I was so tired, I just go to sleep. She told me maybe I should try to sleep on the same bed with her, because, it seemed like I had no more energy, no more, it is too tough to go through this kind of ordeal now. (Participant 3, lost two daughters)

One father who had two seriously ill children who both died described having a problem with lack of sleep because two children were at the hospital at the same time was extremely difficult for one father to manage:

We're in a very tough time in our life. We struggled, me and my spouse, very much struggled we were walking, back and forth and how many days we never slept I know, it is very hard for us. (Participant 8, lost 3 children)

Several of the study participants experienced physical symptoms in conjunction with the grief that they were experiencing surrounding the death of their child:

I always have energy for things and stuff, but as soon as my son died I felt that I wasn't 44 years old, I was about 60. Well it takes so much of you it just takes a big chunk of me, a big chunk of me died with him, actually [*exhales*] my memory is not the same, since then. I just get so many other problems like [*exhales*] arthritis and stuff. And things will never be going to be the same. My memory is not the same. I mean, nothing

is the same. We have, a saying that the tree always, how I can translate this the tree always dies from inside, not outside. (Participant 5, lost one son)

The physical changes and effects when a child dies was described by one father as follows:

And then all those people, they see me, during you know, those times, they say, Oh, how come you look so old now? Your hair looks gray too fast. I say, that's how it happened, too much stress every day. Actually, I sleep one or two hours at most, at a time, because sometimes I tell my wife, maybe I come home to cook something, when I come home, sometimes I just go to bed to try and take a nap for 1 hour or 2. (Participant 3, lost two daughters)

Several of the participants said that their spiritual well-being was impacted by the death of their child:

Okay there's lots that has changed with me and there are some improvements as well, spiritual, I try to pass that on, because that's through my Muslim religion, right? So, the other thing is that I am constantly concerned about how others feel about things about anything. When you talk to people, I make sure that I don't hurt them. So, it is behavioral and emotional mostly. (Participant 2, lost one son)

Participants specifically expressed a loss of faith:

Why should I believe? I have no belief. I have nothing to belief in right now. Because when my kids sick, right? And praying, praying, praying but that time god is not listening. Praying, praying, praying, that my kids would be saved, save my kids. How many nights have we said that prayer, I went, to a big church, I went and talked to so many people and the priests said, don't eat meat. And for many days, we never eat meat

for more than five or six months, when, the kids were sick, and we believe all these things. How are we going to believe now? How? One kid dies okay, we can believe. Two kids, okay, but three kids, I don't think so. No parent deserves this one. So, at this moment I don't believe. I don't think about anything in my life. All the church people come and say a prayer, I said I'm going to go change my religion, whatever you think. But does not matter, it does not help me. (Participant 8, lost two sons and a daughter)

Several participants said that the experience of the death of a child had affected the emotional and mental well-being of some of the fathers.

The memory I get, you know, is like the second I held my son in my hand, I always get that back in my mind, it never comes out, I can never forget that moment. Oh, that made me feel so good inside, like I could have held my child for hours, without having to give him up. (Participant 5, lost two sons)

To experience hurt and pain that never leaves you for one minute is for some people who have never experienced the loss of a child unimaginable. For the fathers interviewed this was something they had to live with day-to-day. As one father put it:

Well, it is the pain, it never goes away. But, I guess I get used to it, that's how we explain it [*clears throat*]. Something that [*clears throat*] makes me really angry is that he got robbed from his childhood, that just really makes me angry. Yeah, but soon after that year, the pain is still there, but you just get used to it. (Participant 5, lost one son)

Isolation as a code emerged because of the fathers' experiences in highlighting the lack of formal and informal support. Although the fathers interviewed had access to formalized healthcare services their needs were not met due to a lack of cross-cultural understanding of providing bereavement care. This lack of support affected the mental wellbeing of the fathers

caused by isolation. However, isolation was not always based on lack of family support but rather, an artefact of immigration. The lack of extended family residing in Calgary or Canada contributed significantly to the fathers feeling of isolation. Isolation contributed to a lack fathers' possibility to openly discuss the loss of their child with a family member. The fathers felt that even when there was a family member to talk to the conversations were not helpful as there were expectations attached to the support that was provided. The fathers said that these conversations with family members were focused on how they are supposed to grieve based on cultural and familial traditions. The fathers felt that the conversations should have been focused on what they need rather than what their family expected of them. Some fathers went so far as to not tell their family the actual circumstances surrounding the death of their child. Here is how one father shared what he went through:

And, you know because she is by herself at the hospital, and I'm also by myself in our house, and I have no parent—I have a brother and a sister but, you know, it is not the same as having a parent. Because you know, when something happened, you need your parents to discuss it. (Participant 3, lost 2 daughters)

Integrating My Findings into a Theory

This research study on immigrant fathers who experienced the loss of their children followed a constructivist grounded theory approach developed by Charmaz (2006). This methodology opposes the existence of an objective reality, “asserting that realities are social constructions of the mind, and that there exists as many such constructions as there are individuals” (Guba & Lincoln, 1989, p. 43). This study shows that racialized immigrant fathers who experienced the loss of their child(ren) faced complex, diverse, and multiple issues in Calgary, and these are highlighted in the six key categories emerging from this study –

objectification of the fathers in the healthcare system, managing feelings, managing health status, bicultural grieving, making meaning and multiplicity of immigrant father's role. These issues are not isolated from each other but rather; reflect intersectionality amongst the experiences of fathers when their children have died. Each of these six categories was strongly connected to the father's status of being an immigrant.

The fathers described experiencing objectification in the healthcare system which was identified by the fathers as feeling that they were being treated as if their lives did not matter while accessing healthcare services either for themselves, their spouse, or their child. Because this made the fathers feel insignificant it added an extra layer of burden on them additional to already experiencing the loss of a child. Managing their grief while making meaning about everything that was happening to them, as well as addressing the needs of their spouses and surviving children, became at some point too much for some of these fathers to bear emotionally. As a consequence of these experiences, the health of the fathers was impacted and the fathers expressed having little to no awareness that this impact was occurring in connection to the death of their children. There are particular tasks associated with bicultural grieving in response to a loss and in respect of culture and tradition. The participants reported that they felt obliged to address everyone else's health and grief issues, while continuing to carry on their multiple responsibilities and obligations as racialized immigrant fathers. This affected their experience of grieving, essentially putting it on hold so that the fathers could take care of everyone else.

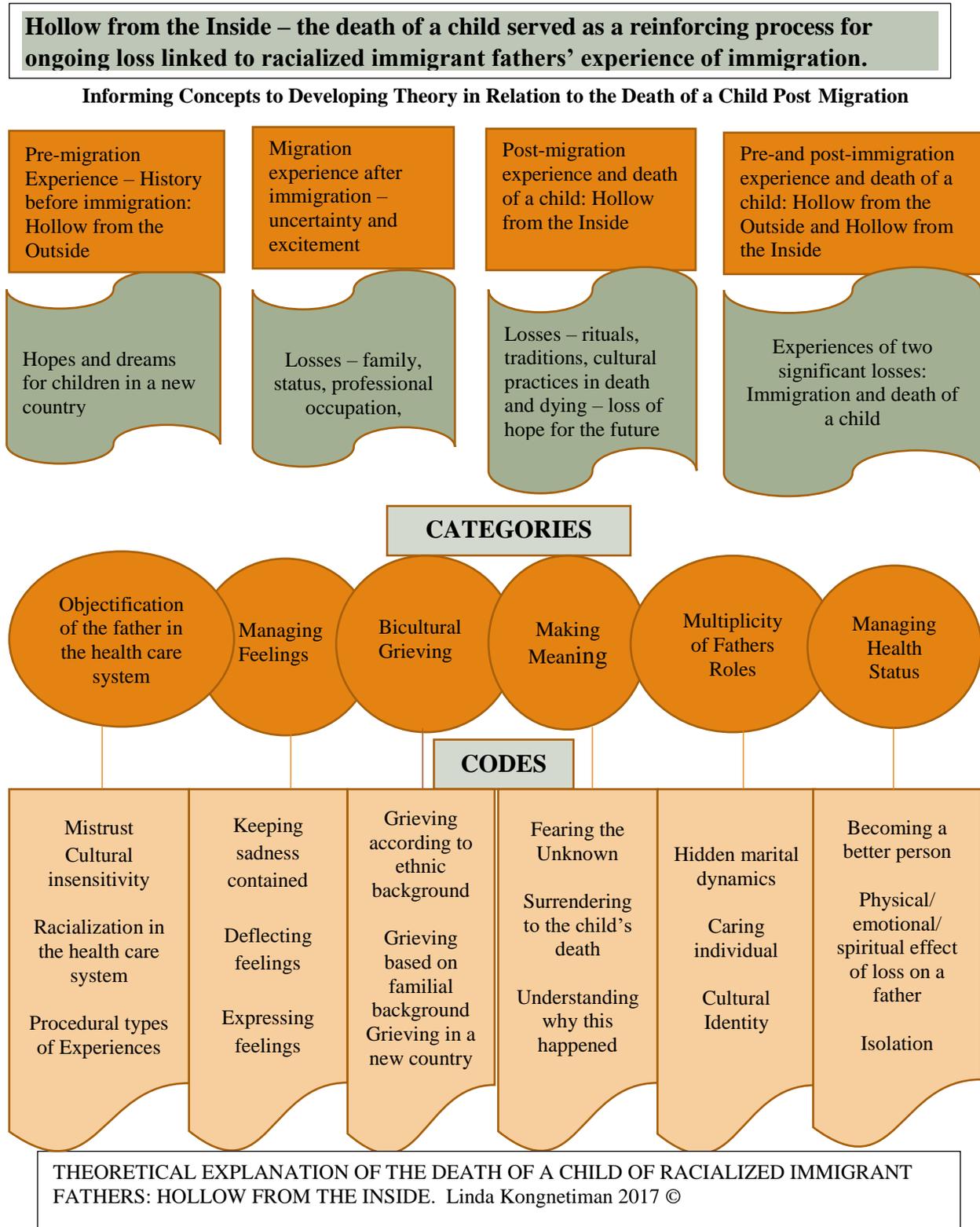
After many months of iterative review of the qualitative data the constructivist theory that emerged was *"hollow from the inside-the death of a child served as a reinforcing process for ongoing loss linked to racialized fathers experience of immigration"*. In other words, the racialized immigrant father's hope for the future is lost when a child dies.

In describing the phenomenon as experienced by the fathers, expressed through the interviews, and their metaphors, understanding of what it is like to be a father of a deceased child was constructed. The experiences of the fathers are very important, their feelings, emotions and their voice supported in constructing the grounded theory for this research. A major component of understanding what the fathers' experiences was linked to their migration experiences. As the fathers expressed through their own words the reason for moving to Canada it became evident that they were optimistic of making this change in their lives. This experience of migration and the losses associated to it are depicted in Figure 4. Pre-migration, migration and post-migration are perceived as consisting of many losses for the fathers. This migration experience and its associated losses, support the development of the theory for this study. To achieve theorizing, researchers must seek to move beyond the coding stage of analysis to raising main categories to concepts (Charmaz, 2006). Migration issues were embedded through all the codes and categories. According to Charmaz (2006) the most significant categories become concepts of the theory. Hence the inclusion of immigration experiences and the metaphor hollow from the inside. The other components that are equally important for the construction of the theory are the codes and categories. These themes and subthemes were developed as part of the analytical process and were found to constitute part of the framework for the theorizing that resulted from this study. This research has resulted in my own theorizing of the studied experience of the experiences of racialized immigrant fathers when their child has died and resulted in a substantive theory of the fathers' experiences.

To complete this research, I undertook the following activities with the fathers: constructed abstract understanding through face-to-face interviews, listened to their experiences, build understanding of the phenomenon under study, and made meaning of how the fathers felt

after the death of their child. In this research, I entered the racialized immigrant fathers' empirical world as much as I could and the substantive theory that was constructed is specific to the fathers that were part of this research. According to constructivist grounded theory the substantive theory constructed must come from what the participants have shared during the data collection. It is however also important to examine if there are other studies that supports this theory. I found one study that explained mental health issues of children to the impact of pre-migration, migration and post-migration.

Figure 4: Constructivist Grounded Theory on Racialized Immigrant Father’s Experience of the Death of a Child



The term *reinforcing* in this context means that all past experiences related to the process of immigration and coming to a new country for a better life for themselves, their children and family has shifted from a narrative of hope to one of loss. In this case pre-migration, migration, post-migration and the loss of a child had an effect on the immigration experience for a father in such a way that they experienced cumulative and ongoing losses. The fathers' viewpoint that their reasons for immigration centered on providing a better life for their children and family was altered following the death of a child. The death of a child signifies the loss of the dream upon which the process of migration was predicated upon, hope for the future.

It was clear through the interviews that what emerged, as key to the racialized fathers' experiences was their immigration story. In every interview completed, the fathers shared their pre-migration, migration and post-migration experiences that initially seemed unrelated to the death of their child. As I continued to review the data, I noticed how entrenched and connected their immigration story was to their experiences related to the death of their child.

Individuals who want a better future for their loved ones, particularly their children, undertake immigration. The fathers left their countries because they were missing something, they felt hollow from the outside because the hopes they had for the future for their children were not accessible in their home country. The immigration experience, in theory, will fill that hollowness by providing new experiences, new opportunities, and increased hope for the future. The fathers expressed the hope and dreams they had for the future of their children by taking a leap of faith and leaving everything familiar to come to a new country. The fathers moved to Canada to establish a better future for their children and themselves - to create a new life, much better than the one they had in their home country.

When they entered Canada, they had all kinds of dreams in which the future of their children was central to the reasons for immigration. They were moving from their country of origin because they wanted a better life for their children, they envisioned a hopeful future, with better opportunities on many levels. Hollow from the outside as a construction that came up during the analysis is similar to the push and pull factor of international migration discussed in research (Schoorl et al., 2000). Push and pull factors or forces are situations that make people move from their countries of origin. These factors could be related to socio-economic factor, poverty, religious freedom, education, and lifestyle changes. The push factor refers to forces that pushes people away from where they live and the pull factors relate to situations that are attractive in the country that individuals would like to move to.

The findings indicate that pre-migration, migration and post-migration experiences and the losses associated with those experiences are compounded when a child dies, as an immigrant's envisioned future is taken away. Some of the losses associated to immigration identified by the participants included: loss of language, culture, professional jobs, status, employment, education, economic, loss of family, loss of name, loss of cultural familiarity in new country, heritage, loss of role as a male provider in the family, loss of recognition, loss of role as the father, and impact on the role of being a husband. These losses stay with the father throughout their lives and new losses can trigger the experience of former losses. The death of a child necessarily taps into the meaning of the experience of immigration in unanticipated ways.

The death of a child signifies the loss of the dream upon which the process of immigration was largely predicated upon – hope for the future. The fathers were often left feeling that the purpose of immigrating to Canada has been lost through the death of their child. Losing a child cuts into the heart of the experience of immigration. The experience of the death

of a child leaves a father feeling hollow from the inside - an emptiness left where they are only left with the experiences of grief. With the death of a child comes the hollowness from the outside. It returns in a new way, in a cyclical fashion that links the experience of immigration and hope for the future with loss and grief, re-hollowing the father again. The fathers' belief is that they are not supposed to bury their children as they are burying their hope, dreams and their future, the entire reason that caused them to immigrate to Canada in the first place. This contributes to multiple layers of complexity. The difference is that the hollowness from the outside can be addressed in multiple ways; however, the hollowness from the inside is far more challenging to address. This is why it is important to uncover and understand the experience of the loss of a child on racialized immigrant fathers. In and of itself, the past and present complicates the process of living in the host country while addressing the loss.

As hopes and dreams impacted by the loss of a child are deeply tied to the experience of immigration, service responses have to consider the role of immigration and how critical this is in supporting racialized immigrant fathers in dealing with the death of their children. It is a much bigger picture than what is currently known in existing service responses and requires knowledge, education and training in order to effectively respond and help families.

Figure 4 is called Constructivist Grounded Theory on Racialized Immigrant Father's Experience of the Death of a Child. This figure provides a theoretical explanation of the death of a child of an immigrant father and offers a visual representation of the major categories and codes supportive of grounded theory development. These include immigration experiences and losses related to the constructivist theory of hollow from the inside immigration as a reinforcing process for racialized immigrant father's whose hope for the future is often lost when a child dies. I also discussed that fathers who experience loss of a child have a similar experience to other losses

associated to immigration. This experience, the loss, is highly compounded due to multiple experiences of loss prior to immigrating to Canada. The death of a child of an immigrant father represents a linkage to the immigration experience and all the losses associated with that process. Therefore, the experience is compounded by the personal history of the father and his past experiences of loss is amplified by the death of a child. Not being able to navigate the experience of their child's death as they would have liked in their home country, thus making it a new foreign experience that a father relates to from his experience as a racialized immigrant. This indicates that multiple parallels exist between immigration losses and the loss of a child in the country of migration.

Summary

In this chapter, I have explained the six categories identified: objectification of the father in the healthcare system, managing feelings, bicultural grieving, making meaning, multiplicity of fathers' roles and managing health status were central to the story of the fathers. I recognized how each individual father's experiences were important to the construction of their story. I have shown that consistent with constructivist grounded theory that there are multiple truths, multiple realities based on the fathers' experiences (Charmaz, 2010). I have also presented my constructivist grounded theory related to the fathers' experience. The discussions of the findings and their relationship to current literature will follow in Chapter six. I will review these categories in relation to salient literature and address how they relate to other studies on racialized immigrant father who experienced the loss of a child. I will also link the four social work concepts and theories described in Chapter three - anti-oppressive practice, critical race theory, intersectionality and racialization to the categories of this study. I will also offer my point of view on my experiences with social justice in relation to some of the categories

highlighted by the fathers. It is my hope that the results of this study may be relevant for bereavement program development for racialized immigrant fathers and their families.

CHAPTER VI: DISCUSSION AND RECOMMENDATIONS

In this final chapter, I will provide a summary of the findings including key categories, recommendations and conclusions are described in relation to the literature and research questions that guided the study. Additionally, the strengths and limitations of this research are outlined, along with suggestions for further research.

Research is generally informed by the literature. In grounded theory methodologists disagree about when and how to use the extant literature during the research process (Bryant & Charmaz, 2007; Dunne, 2011). In fact, Glaser and Strauss (1967) explicitly cautioned against using existing literature until completion of the data analysis. They believed that exposure to existing literature could bias the analytic process (Charmaz, 2006; Dunne, 2011; Glaser, 1998). As grounded theory is an evolving methodology the stance of when and how to use the literature has changed and evolved as well (Dunne, 2011). Each researcher chooses how they would like to present the results of their study to the readers, including when they introduce the literature review. While the literature was critical to informing this research, it was important that I remained open to the words of the fathers as a primary influence in completing this research. I attempted to remain neutral while reflecting on the literature that informed this research.

It is important to note that there is limited existing research on the topic of the present study. The available literature does not sufficiently account for the diverse experiences of racialized immigrant fathers living in Calgary, nor does it illuminate the lived experiences of the health statuses of the fathers when a child has died. Existing literature instead focused on the experiences of fathers who have lost a child either due to an illness or from a program perspective (Saiki et al., 1994; Doka, 2009, 2016). In most cases the existing studies have

approached their research from a White Eurocentric, or country specific perspective, revealing a gap on studies that are specific to the lived experiences of racialized individuals.

The existing literature identified that racialized immigrant fathers have a number of barriers to overcome when they arrive in Canada (McGibbon & Etowa, 2009; McGibbon et al, 2005; Srivastava, 2007). Some of these barriers include underemployment, unemployment (Jafari, Baharlou, & Mathias, 2010); English as a second language and housing (Jafari et al., 2010); healthy immigrant effect (De Maio & Kemp, 2010; Newbold, 2004); access to healthcare (Srivastava, 2007); and adjustment to Canadian culture including weather (Dossa, 2004; Jafari, Baharlou, & Mathias, 2010). Suffering the loss of a child compounds the challenges that these fathers experience and makes their lives harder. My approach to incorporating literature into the present study was to review relevant literature and interweave it in the latter part of my analysis in order to deepen my exploration and interpretation of how the voices of the fathers are positioned in relation to concepts such as social justice, healthcare accessibility, and racialization. The findings reveal some complex intersectional themes related to the experiences of racialized immigrant fathers after the loss of a child.

Categories

The findings provide new insights specifically on the experiences of racialized immigrant fathers who suffered the loss of a child and the impact this has had on their health statuses. The six categories identified through investigation of the research questions include objectification of fathers in the healthcare system, managing feelings, bicultural grieving, making meaning, multiplicity of immigrant fathers' role and managing health status.

The stories of the fathers illuminated their emptiness, their hollow feelings, their evolving marital issues, their fears, their relationships with the healthcare system and most of all the

devastation of their grief in losing a child. The research findings also unexpectedly illuminated that pre-migration, migration and post-migration experiences significantly impacted the fathers as their successful process of adaptation to life in Canada was cut short by the death of their children. Through interviewing the participants in the present study, they shared their narratives of their lived experiences and we co-constructed stories of meaning and purpose. The question informing this research is: What are the lived experiences of racialized immigrant fathers when their child dies? The two sub questions are posed as follows: (a) what are the lived experiences of racialized immigrant fathers in their interactions with the health care system when their child dies? And (b) how do racialized immigrant fathers understand the impact of the death of their child and the impact of their experiences in the health care system on their health?

At the beginning of this dissertation, in Chapter one, I discussed the importance of practicing social work within a social justice framework when working with marginalized populations. In Chapter two, I highlighted four key social work concepts and theories informing the study: anti-oppressive practice, critical race theory, intersectionality and racialization. These theories inform my understandings of oppression, racism, discrimination and racialization as experienced by fathers whose children have died. The six categories emerging from this research, presented in Chapter five, were viewed from a social justice lens. While fathers who participated in the study shared their individual experiences of the loss of a child, it became clear through the iterative process of reviewing all of the transcripts that common experiences were reflected. Recognizing that eight individual fathers expressed common experiences, it became clear that it was important to pay attention to intersectionality, as a critical theory informing this research. The key categories emerging from this research that were presented in Chapter five are discussed below and informed the core concept: **hollow from the inside - the death of a child**

served as a reinforcing process for ongoing loss linked to racialized immigrant fathers' experience of immigration.

In Chapter three, I reviewed existing literature that examined the experiences of parents when their child has died. In Chapter four, I provided an overview of the research methodology, namely, constructivist grounded theory. In Chapter five, I presented the results of the analysis of the lived experiences of racialized immigrant fathers when their child has died. Each of the chapters has served to inform the discussion of the categories below.

Objectification of Fathers in the Healthcare System

Researchers have completed significant studies on the impact of immigration on health and the barriers that many patients experience in accessing health services (Asanin & Wilson, 2008; Gagnon, 2002; McKeary & Newbold, 2010; Srivastava, 2007). However, there is a need to increase research that focuses on racism, racialization and discrimination and its impact on the health status of individuals (Pollock, Newbold, Lafreniere, & Edge, 2012). The fathers who participated in my doctoral research were vocal in identifying their experiences of racism, racialization, and discrimination and the theme developed in relation to this experience was objectification of the fathers in the health care system. They also expressed their perceptions of how other racialized individuals were treated by healthcare providers when accessing services. Talking about lived experiences discrimination, racism and racialization can be challenging. Defining racism and discrimination is hard for individuals who have had this experience, however there are multiple sources on which to draw definitions and understandings within the literature (Carrasco, Gillepsie, & Goodluck, 2009; Hyman, 2009). Some individuals who experience racism may not have the skills to address it at an individual level. In the present study, many of the fathers shared that they experienced racism and discrimination in the health

care system. Some of the fathers have never expressed what they went through emotionally when their child or children died prior to participating in an interview for this dissertation research. Talking about these incidents and identifying how racism and discrimination affected their lives was difficult for many of the participants, especially because it was in the healthcare setting where they expected to receive help and were disappointed. It is always difficult for patients and families to show how they were discriminated against (McGibbon & Etowa, 2009). In many instances discrimination occurs through subtle behaviors, processes in communications and in experiences that may be perceived as receiving inadequate services that contribute to making them feel like they are less (Beiser, Noh, Hou, Kaspar, & Rummens, 2001; Magoon, 2005; Pollock et al., 2012). My findings are consistent with other studies in reporting racialization and discrimination in healthcare.

Experiences of discrimination, racism and racialization in the healthcare system may contribute to ongoing marginalization in overall health outcomes for patients (Ng, Wilkins, Gendron, & Berthelot, 2005; Srivastava, 2007). As Peng et al. (2012) stated “understanding culture and its role in care is important for professionals providing end-of-life care since cultural perspectives influence attitude towards sickness, dying, death and grief” (p. 321). It is necessary to establish an agenda on how to address issues of cultural sensitivity and cultural competency in healthcare (McGibbon & Etowa, 2009), particularly when a child dies. Basic practice standards are required. Specific strategies need to be put in place to provide the comfort and support that grieving fathers’ need (Penget al., 2012). Past studies also suggest that even without the experiences of racialization fathers often do not feel supported by healthcare professionals and the lack of communication in these matters exaggerates the negative experience of losing a child (Davies et al., 2004, 2008; Peng et al., 2012). Fathers would like to have a relationship with

healthcare professionals that is characterized by caring, meaningful connections and supportive bonds with the medical staff (Davies, Baird, & Gudmundsdottir, 2013).

From a social justice lens, the experiences of racism, racialization and discrimination that the participants described, are important to consider, especially from a capabilities perspective (Nussbaum, 2000) that recognizes the worth and dignity of each person. In completing this study, I hoped that the voices of bereaved fathers might spur healthcare systems and providers into action in responding to the needs of racialized immigrant fathers who experience the death of a child. These actions may center on helping healthcare systems and providers recognize that services need to be developed with all individuals in mind no matter their countries of origin, languages spoken, or skin colour. From the perspectives offered of racialization, anti-oppressive practice and critical race theory, it is evident that the participants experienced racism. To respond to these lived experiences healthcare providers may consider the concerns of father's feelings of objectification in the healthcare system so that fathers can access services that they perceive to be free of bias, discrimination or racism. When a child dies and fathers are accessing bereavement care services, experiencing racialization, discrimination and racism should not be one of their worries.

Managing Feelings

The impact of a personal loss on the participants in this study clearly demonstrated that each father managed his feelings of loss in unique ways. Some fathers were expressive while some were stoic. Others were unable to communicate about their emotions and were lost for words during the interview. This experience is somewhat corroborated with Kracke (1981) and Davies et al. (2004) who suggested that fathers experience relief when they have the opportunity to express their grief. Wood and Milo (2001) indicated that fathers often express their grief less

intensely than mothers, which is also similar to the way some fathers in this study experienced their grief. Further, Davies et al. (2004) and Wood and Milo (2001) indicated that fathers often demonstrate and manage their feelings based on the expectations society has for men. O'Leary and Thorwick (2006) reported that according to societal beliefs fathers have to be the strong ones and are not supposed to express how they really feel about the death of their child. Based on my interviews with the fathers, the challenges they had in expressing their feelings in the period after their child died was identified as having a negative impact on their health. The notion of men having to be strong in the face of loss is what Chesler and Parry (2001) perceived as gender roles in grieving when a child dies. Managing feelings after the loss of a child was very hard work as it takes considerable effort to maintain one's health and ability to address self-care (Cook, 1988). This corroborates with what fathers in the current study have shared in relation to how they have expressed and managed their feelings.

Bicultural Grieving

In addition to immigrating to Canada, many of the fathers in this study had ties to their countries of birth, as well as with family members and friends from their home communities. Some of the issues that the fathers in the current study faced in terms of grieving are related to their cultural beliefs surrounding male mourning, namely that men are not supposed to cry after the death of a child. In many cultures, gender socialization dictates that men are supposed to be strong no matter what they are experiencing (Murphy et al., 1998). This inability to express their grief may have impacted the health status of the fathers in this study as mentioned in other studies when grief is not attended to (Murphy et al., 1998).

Some of the fathers expressed their grief openly during the interview, which was in contrast to the belief that males/fathers do not openly show their sadness. These fathers appeared

to feel that the interview provided them the opportunity to openly share their grief and discuss their experiences related to the death of their child, often for the first time. It was difficult to find literature on bicultural grieving so I had to extend my reading specifically in the area of racialized fathers who experienced the death of a child. I discovered the Kracke (1981) study that focused on the experiences of Kagwahiv Indians in Brazil. Kracke indicated that the participants in his study felt some type of relief from participating in the research, and it was actually very freeing to share their experiences as bereaved fathers – similar to what fathers shared with me. For the Kagwahiv, discussing the deceased is like opening up a wound that was never healed and speaking about their children after death was a challenge for many of the fathers in my study. Even so, Kracke was able to receive detailed descriptions of these fathers' experiences of the death of their child. This category reflects that fathers are hanging onto their grief for long periods of time without an outlet for emotional expression, reflecting a major gap in the process of supporting the grief for racialized fathers. With bicultural grieving fathers cannot completely grieve according to Canadian culture, nor can they grieve in relation to their own culture in a new country, and this poses significant challenges in the grieving experience.

Making Meaning

Some participants indicated in the interviews that in order for them to make meaning of the death of their child, they needed to understand the reasons why their child became ill. In some of the interviews the fathers went to great lengths to develop understanding of their child's condition. Davies et al. (2008) identified the importance of healthcare providers acknowledging that an "uncertain prognosis" (p. 287) is an obstacle for parents in accessing services when a child dies. Another study conducted by Davies, Contro, Larson and Widger (2010) with Mexican American and Chinese American fathers who experienced the loss of a child

highlighted that the lack of information regarding their child's condition impacted the fathers significantly. Fathers reported that they wanted factual information without embellishment (Wood & Milo, 2001). In the current study, the fathers reported that receiving adequate information supported their understandings of their child's prognosis equipped them to understand why their child died. It was identified that part of making meaning was being able to resume day-to-day activities and engage in family life. Depending on how affected the fathers were by their loss, they slowly allowed themselves to express interest in aspects of daily life (Neil-Urban & Jones, 2011), was considered important in moving forward in their life. Making meaning of the loss remained a challenge.

Multiplicity of Immigrant Fathers' Role

The fathers in the present study put their own grief responses and processes aside in order to be able to emotionally and financially support their spouses and surviving children, which was not always in their best interest. Davies et al. (2004) identified the concern of fathers not grieving and indicated that there are serious psychosocial consequences when feelings remain unexpressed. In the present study, while holding back their own grief, the fathers continued to show compassion for everyone around them. They were especially concerned about how their wife, the mothers of their children were coping, a finding that is similar to that of Wood and Milo (2001).

In the present study, the fathers' cultural identities were identified as becoming even stronger after the loss of a child. It seems as if the fathers had strong senses of identity and identification with what their cultures dictated in terms of behavioural responses times of loss and grief. In other words, culture informed the participants behaviours when their children died. This is consistent with the findings of Davies et al. (2004) in their seminal work on fathers'

grieving, *Living in the Dragon's Shadow*. Intersectionality (Dhamoon & Hankivsky, 2011; Rossiter & Morrow, 2011) is a key social work theory relevant to this research. It is recognized that racialized immigrant fathers' lives intersect in a variety of ways and that the multiplicity of immigrant father's roles contributes to challenges in their experience of grief and loss. When providing services, healthcare systems and providers have an opportunity to develop greater awareness on how the various roles of racialized immigrant fathers' lives may impact the fathers. Applying intersectionality theory in relation to the experiences of racialized immigrant fathers can support the development of quality bereavement services, particularly when it is recognized that immigrating to Canada has compounded the multiplicity of their roles, which is complicated by the death of their child.

Managing Health Status

Managing health status was an important theme as each father interviewed reported that at one level or another their emotional, physical or spiritual wellbeing was impacted by the death of their child. The fathers also reported that this experience influenced their thoughts about their own death, afterlife and mortality, which are consistent with other studies, such as one conducted by Davies et al. (2004). Aho et al. (2011) conducted a study in which they reported that stronger grief reactions were correlated with poor health outcomes among bereaved fathers. Similarly, in terms of poor health outcomes, some literature identified that fathers can be impacted emotionally, psychological and physically by the death of their child (Li et al., 2003, 2005; Samuelsson, Radestad, & Segesten, 2001). Murphy (1998) reports that "mental distress, posttraumatic stress symptoms, loss accommodation, and physical health" are also effects of the death of a child on bereaved fathers (p. 211).

In the present study, fathers expressed that the death of their child altered their spiritual and religious experiences. Some of the fathers became more involved and more engaged with their religion and/or spirituality while others refrained from practicing their faith. Some identified that changing religious or spiritual practices altogether worked best based on how they were affected by their grief. Grief in the context of culture was identified as a major factor in the health statuses of the fathers. The following section describes recommendations based on the findings of this research.

Implications for Social Workers and Social Justice in Healthcare

The results of this study may influence policy makers in healthcare, nursing, allied healthcare professionals, and frontline social workers. In Alberta, social workers are key advocates for patients and their families and could play a key role in the way the results of this study are considered in relation to healthcare policy and service delivery. The social work profession views support to people as a commitment to human rights as stated in Canadian law and maintained by the United Nations (National Association of Social Workers, 1996). Through a commitment to human rights, social workers should be able to support individuals and families no matter what their beliefs, background, or social status. Social workers assume the role of responding to social justice in healthcare. McLaughlin (2009) stated that there is doubt regarding the commitment to social justice by clinical social workers.

Many social workers employed in healthcare experience challenges in translating the social work values including social justice into practice. Social justice is a critical foundation in social work practice. For social workers, the profession's mission to promote social justice facilitates the infusion of a specific value-base into professional practice that includes belief in the equitable distribution of resources, fair treatment of all people in accordance with human

rights legislation, and proactively addressing the needs of marginalized individuals and communities (Constantine, Hage, Kindaichi, & Bryant, 2007; Messias et al., 2009). In the healthcare arena, Braveman and Gruskin (2003) acknowledge that equity in healthcare is equivalent to social justice in healthcare. Corresponding implications for clinical practice and implications in the area of social justice are presented below.

Clinical Practice Implications

Bereavement support is one of areas of healthcare service where social workers often engage directly with grieving families. In their roles as clinicians, managers, or researchers, social workers have the opportunity and potential to mitigate many of the issues currently experienced by racialized immigrant fathers when their child has died. Through collaborative practice in interprofessional teams, social workers are in a favourable position to be able to contribute to providing services that are appropriate for these fathers. It is hoped that the results of this research will contribute to social work's clinical practice knowledge base and educate both social workers and providers of other related health and human services through presenting the perspectives, needs and preferences of racialized immigrant fathers who have lost a child through death.

Social Justice Implications

Infusing social justice into healthcare is consistent with the ethical principles of the social work profession. There are two inter-related components of social justice: distributive justice perspective (Wakefield, 1988) and capabilities (Nussbaum, 2000). Within healthcare, distributive justice involves creating opportunities for patients to have access to social goods and is perceived as encompassing fairness to all individuals in society (Wakefield, 1988). From a capabilities perspective, social justice refers to the acknowledgement that each person in society

has self-worth and dignity (Nussbaum, 2000). The results of the study support the need for social justice for racialized immigrant fathers who participated in this study. For example, based on the research findings social workers could become involved in advocating for greater access to culturally appropriate bereavement care for racialized immigrant fathers. Dissemination of the findings will inform healthcare social workers and inter-professional teams about the effects of stereotypes, biases, and racism on bereavement services. The findings can inform social workers and inter-professional teams of (a) how bereaved racialized immigrant fathers are coping with child death, and (b) action steps to improve access to healthcare services for racialized immigrant fathers and immigrant communities more broadly.

Recommendations

As I make my recommendations, it is important to reflect on the fact that the population of Canada continues to change and many racialized immigrants continue to make Canada their home (Statistics Canada, 2011a, b). It is clear that racialized immigrants are in a disadvantaged position before they arrive in Canada, even when arriving healthy (DeMaio & Kemp, 2010; Newbold, 2004). Although the healthy immigrant effect explains the various reasons why racialized immigrants are healthier upon arrival in Canada, their health often drastically declines in the years following immigration (Kobayashi & Prus, 2012). Even with universal healthcare, racialized groups face bias, discrimination, stereotypes, and racism are experienced when racialized immigrants access healthcare services (Nestel, 2012). To address these issues consistent collection of race and ethnicity data in healthcare would be advisable. This information could serve as a platform to develop services and programs specifically targeting the issues of these individuals.

It is critical for healthcare service providers to have knowledge and understanding about how racism and racialization impacts immigrants' health, as this will better prepare them to provide the right type of services. Further, research needs to be developed that includes hearing racialized immigrants' voices (James et al., 2010; Patychuk, 2011) as a foundational value, thus supporting individuals and families to share their experiences, and be included in, the outcome of research. A commitment to action after completion of research involving racialized groups is important since there is often no follow-through with recommendations arising from such research (James et al., 2010). Knowledge mobilization could include knowledge translation documents as well as community-based meetings. In this research, the racialized immigrant fathers stand to reflect that their children were important to them, their children were the hope and dreams they had for immigrating to Canada and their loss was profound and impacted their future. The death of children of racialized immigrant fathers and their voices are the driver for the following recommendations.

Recommendation for Healthcare Organizations

Insights gained from this research suggest that there is more research needed in the area of how the death of a child impacts the health of fathers. All of the fathers interviewed have identified that losing their child has impacted them on a physical, spiritual and or emotional level. They have also expressed that they felt objectified in the healthcare system. They shared how the intersection and multiplicity of their many roles impact how they can address their own grief. The fathers have also shared that immigration combined with the death of their child amplified their experiences with losses – particularly in relation to losses associated with leaving their home country and losing their child in their new country. A research agenda to develop

specific services to address the concerns voiced by racialized immigrant fathers in this study will benefit these fathers, their families and their communities.

It would be of value to explore if access to culturally appropriate grief support for the fathers would have had a positive impact on their health statuses and health outcomes. Given the father's described experiences with racism, discrimination and racialization in healthcare, consideration of cultural needs is crucial. Culturally appropriate bereavement services with a focus on addressing racialization will ensure that all fathers from racialized backgrounds have access to services that makes them feel less objectified and more included. The fathers have also expressed that accessing bereavement services in the community or in their place of worship may be beneficial to them. Some of the fathers mentioned getting together in men's groups to discuss their experiences with the death of their child. Having a common immigration experience as well as the death of a child might support many of the fathers who access these community bereavement men's groups.

Communication seems to be an ongoing concern for the fathers. The participants expressed that mistrust and cultural insensitivity impacted cross-cultural communication with healthcare providers. When it came to medical care and procedures involving their child that involved machines, instruments and medications, the fathers expressed confidence in the Canadian healthcare system. However, communication with healthcare providers, on matters outside of these procedures was reported by fathers as challenging and stressful. Communicating with racialized patients and their families requires specific skills. Many healthcare providers even with the best intentions may not have the required skills to provide culturally competent bereavement services for racialized immigrant fathers. When we look at services available for bereaved fathers, it is critical to do so from a social justice framework and an anti-oppressive

lens – as this would encourage a more equitable approach to care in grief and bereavement services for racialized immigrant fathers

Recommendations for Social Work Practice

I propose that healthcare providers, especially social workers who are in leadership positions in healthcare, continue to address and to advocate discussing issues of racialization on policy, research and practice levels. Healthcare providers should also have an understanding of the destructive effect of institutional racism on the healthcare needs of individuals who are racialized (Patychuk, 2011). Being perceived of as “different” creates a powerful web of inequity in healthcare for many patients and this issue was discussed by the participants in the present study. The key to addressing this inequity is introducing new policies and implementation of practices that serve all individuals in the Canadian healthcare system. Grounding social work practice while consistently, addressing injustice, inequity and racialization in healthcare, would be advantageous for many communities experiencing these disadvantages. Social workers need to advocate for practices that infuse inclusiveness and confront racism in healthcare. It is recognized that individuals do experience discrimination and marginalization in healthcare (McGibbon & Etowa, 2009) and in my research, fathers clearly expressed experiences of feeling objectified within this system. If equity is the goal in healthcare for all then eliminating the barriers that racialized individuals face in healthcare is a priority.

The complexity of the words racialized and racialization contribute to increased challenges in addressing the experiences of individuals who are marginalized, as these terms are often misunderstood. Based on the research outcomes understanding racialization as well as the immigration experiences of racialized immigrant fathers is very important. Social workers and service providers need to become more confident and comfortable using terms such as racialized

and racialization, because racialized immigrant fathers have expressed that they experienced racism. Service providers should also continue to educate themselves regarding current research and language that addresses issues of oppression and racism in access to services – promoting anti-oppressive practice. Having this understanding will help create and advocate for services that considers the experiences of racialized immigrant fathers.

In light of the complexities and barriers to healthcare for racialized individuals, social workers in healthcare need to be at the forefront of addressing social justice issues. It is extremely difficult for social workers to address social justice issues as they themselves are currently disempowered and marginalized, as a result of healthcare restructuring in Canada. Social workers need to find meaningful ways to be part of the changes that healthcare organizations are experiencing and be a voice in their organizations. This can be accomplished through “(a) reflecting on changes and finding benefits; (b) self-assessment of skills and coping methods; (c) finding purpose and building new strengths; and (d) planning for positive change” (Globerman, White, Mullings, & Davies, 2003, p. 6). This will be possible when social workers use the social work theories Anti-Oppressive Practice, Critical Race Theories, Intersectionality and Racialization. These theories combined with the values that define social work as a profession that values the worth and dignity of each person may aid in achieving the goal of being the voice of marginalized population and place them in a position to engage in discussions to make the organizational changes beneficial for their profession. This means being proactive in redefining social work role clarity, incorporating flexible skills and knowledge, and staying current in terms of supervision and consultation by remaining connected with other social workers within and outside of healthcare.

Social workers do have the opportunity to provide great leadership in healthcare organizations in Canada (Globerman et al., 2003). This particular aspect of social work leadership in healthcare needs further research and development, as there is a scarcity of literature on this subject (Connolly, 2012). A social worker that advocates on behalf of families in a healthcare setting can be perceived as a troublemaker or a difficult professional (Miller, 2011). Balancing this advocacy role while being employed in the same healthcare organization can be difficult. Social workers need to understand that they might need to challenge their managers and leaders in healthcare when providing services to families within a social justice framework. Social work has always held a critical role of advocacy for clients. According to some of the fathers interviewed, social workers sometimes provided them with necessary support and in some other instances this was not the case.

Addressing social justice in healthcare for racialized immigrant fathers involves racialized immigrant fathers being provided with equal access to bereavement services that meet their cultural needs (Wakefield, 1988). I recommend that racialized groups be involved in each aspect of the development of new bereavement programs. In this manner, the services will be developed in true partnership. In turn, this will lead to best practices, follow-through in the healthcare system, and maintenance of ongoing relationships with healthcare professionals.

There are challenges associated with practicing social justice in healthcare. Some social workers use advocacy as a way to address social justice in healthcare. Understanding how to advocate on behalf of racialized immigrant fathers is not automatically understood by all social workers. Advocacy might have been taught in educational institutions but practicing advocacy in the workplace can pose challenges and might require guidance and support. These challenges

may spur social workers to become creative and address social justice in healthcare in a variety of ways when they have an understanding of racialization and its effect on immigrants.

By identifying the link between social justice and social work theory, specific skills and strategies of how to incorporate social justice in healthcare practice for social workers could be developed. One of the strategies social workers in healthcare can use is to connect the multiple intersections of the healthcare experiences of racialized families and help the families and other healthcare workers to reduce stressors that impact these families. It is important for social workers in healthcare to develop well-informed and current practice knowledge in working with families who are marginalized and being racialized. This will aid in providing healthcare services that are more consonant with what both racialized patients and the general public need. Social work claims to be established on the grounds of social justice and fairness and thus one could argue that social workers in healthcare system must reflect these values within their practice (Heinonen & Spearman, 2001; Mullaly, 1999). If the objective of social work in healthcare is to pursue social justice, this should be applied to both clinical practice and research studies, ensuring best practice and eradicating racialization, oppression and discrimination in healthcare.

Recommendations for Further Research on Grief and Loss

Recommendation 1: Research that focuses on racialized immigrant fathers' needs when a child dies.

It is recommended that healthcare providers and researchers focus on conducting research that focuses on racialized immigrant fathers' needs when a child has a life-limiting prognosis leading to the child's death. It is not only the death of a child, but the process and journey that takes place prior to the death that forms part of the struggle for fathers and their families. They

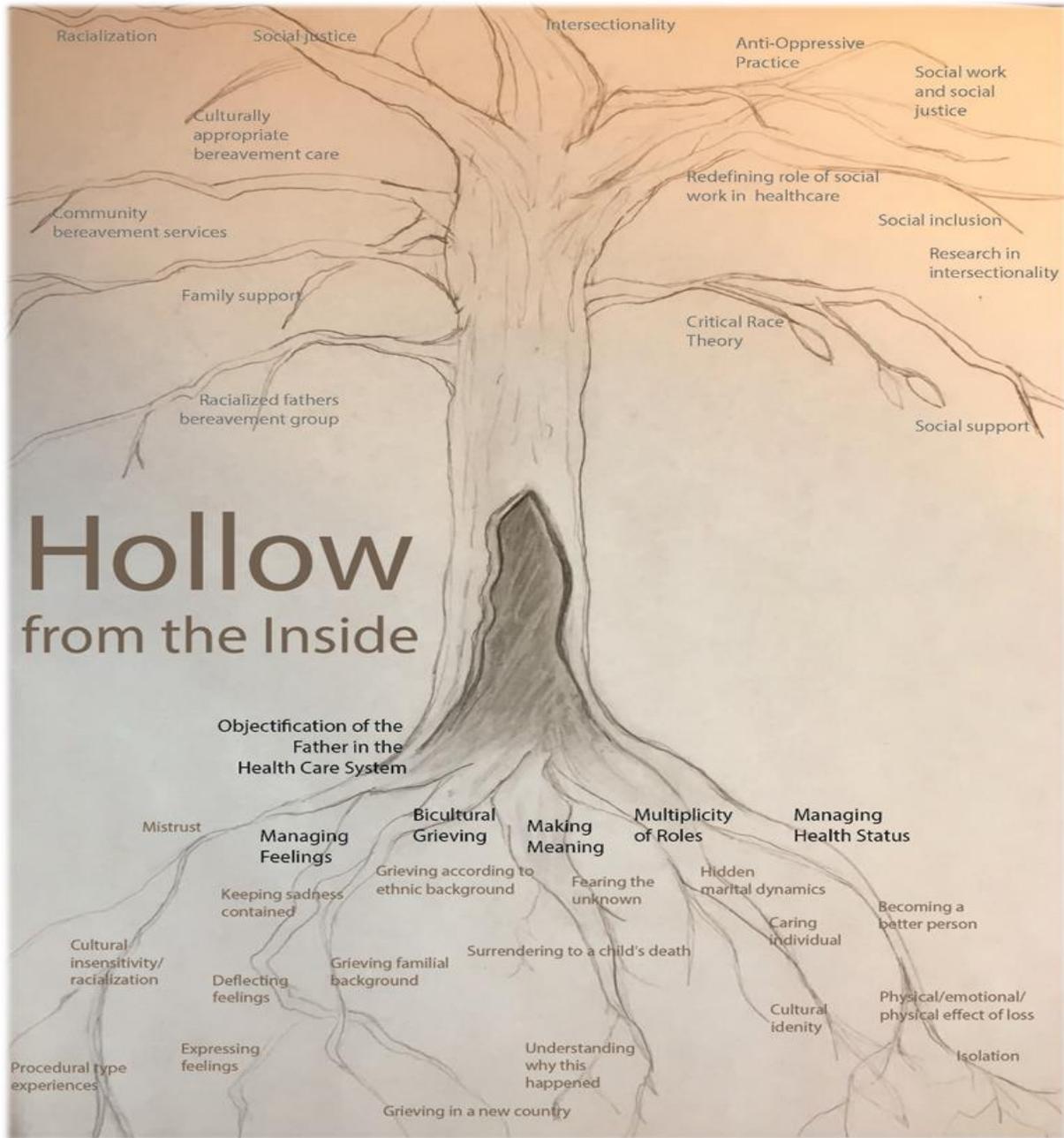
already have experienced multiple losses through immigration and despite coming to a new country for what is perceived to be a better life, the loss of a child undermines that experience and in fact contributes to ongoing losses for the father. I recommend that future research focus on how policies, structures and guidelines in healthcare may or may not impact racialized fathers in general but more specifically when a child has died. This type of research can be completed on local, provincial and national levels to support deeper understandings of the needs of racialized immigrant fathers and ways to effectively respond to their needs.

Recommendation 2: Research that focuses on the needs of healthcare provides supporting racialized immigrant fathers.

In my conversations with racialized immigrant fathers who participated in this research a clear need exists to initiate and institute changes in service delivery to fathers. Creating opportunities for research that can continue to enhance evidence-based practice can help bridge the gap in service delivery, create greater understandings of fathers' needs, and enhance opportunities for partnership with racialized immigrant fathers. Engagement in this type of research may contribute to empowering research participants to take actions in implementing research recommendations. Healthcare providers might find a variety of ways to become change agents by working in partnership with the research participants. Racialized immigrant fathers need allies and advocates to address inequality and oppressive policies that may impact their access to services and retaining great health outcomes. A research agenda in healthcare with this focus would be beneficial for families, the healthcare system and society at large. Examples include, the impact of healthcare organizational structures and the grief support provided to

immigrant fathers or healthcare providers' understanding of anti-oppressive practice in paediatric palliative care.

Figure 5: Hollow from the Inside: Codes and Categories rooted in immigrant fathers' experience of the death of a child, key theories and proposed branches for future practice



Caption: Figure 5 reflects codes, categories, key social work theories and recommendations that are important in practice with racialized immigrant fathers who have experienced the death of a child.

Strengths and Limitations of the Study

While this study has many strengths, there are also some limitations associated with this research. The strengths of this study included the opportunity to provide a platform for racialized immigrant fathers to discuss their experiences of parental bereavement from their own perspectives. This was a huge accomplishment as some research participants identified that this was the only time they had an opportunity to express what they were feeling and had felt went they lost their child. Participating in this research provided them an outlet to share their grief. It was also recognized, on the other hand, that for many fathers there was a significant gap between the date on which their child died and participation in the research interview, thus identifying concerns about limited or absent supports for these fathers within the healthcare system.

Another strength of this study is the privilege to add this body of work to limited resources and research focusing on the experiences of racialized immigrant fathers who have suffered the loss of a child. Additionally, the possibility exists that healthcare providers and policy makers can build on the results of this study to develop new programs and or develop research agendas to enhance service support for racialized fathers.

Next, some limitations are presented. First, the inclusion criteria limited the diversity of the study sample. Specifically, by limiting the exploration of lived experiences to those of racialized immigrant fathers and excluding racialized refugee fathers the potential to gather other voices was lost. Based on pre-migration, migration and post-migration experiences of immigrants and refugees these two groups have differing experiences and it would have been informative to explore if any of these impact the father's experiences when their child has died. Second, since the interviews were conducted in English, fathers who were not able to communicate in English were excluded. It is likely that my inability to include these fathers in

the study presented a missed opportunity to understand the grief experiences of fathers in their first language. I am also aware that by conducting the interviews in the participant's first language there might have been a natural way for fathers to express their lived and grief experiences.

I acknowledge the fact that I am an immigrant woman from racialized background and that my biases and assumptions may also have impacted the study results. However, I put processes in place with my supervisor to address these biases and assumptions. These processes include journaling and discussing my assumptions with my supervisor.

Methodological Limitations

I experienced several limitations in conducting the study associated with the research methodology, constructivist grounded theory. First, the University of Calgary Conjoint Faculties Research Ethics Board supported the mode of recruiting participants for this study. Their recommendation was that the Rotary Flames House at Alberta Children's Hospital should contact all participants by letter. This recruitment process required that I wait for an interested father to call me to get more information regarding the research purpose and scope. This affected the number of participants who were recruited and interviewed. While the recruitment process potentially could have had implications on theoretical sampling within constructivist grounded theory, I am confident that the eight fathers interviewed provided rich, detailed, and comprehensive information regarding their experience of losing a child and the effect this had on their health statuses.

Using the reflective journal after each interview was necessary for me to monitor my biases. I wondered how the discussion of the codes, and categories would have evolved if I had had a co-researcher who was White, or Canadian-born, or male, or who had not lost a child

through death, or who was not employed within the healthcare system. This individual's biases and worldviews may have been different from mine based on different aspects such as life experiences and family history. These factors could possibly impact the data analysis and would have been interesting to explore.

Lastly, the flexibility of constructivist grounded theory allows leeway for the researcher to employ the method in the ways that will work best in their situational context. No two grounded theory studies follow precisely the same methods because strategies for application of the methods are an outcome of each researcher's skills, discipline, cultural background, and pre-existing knowledge of the studied phenomenon. I believe that constructivist grounded theory methodology gave me specific tools and methods, but I had to make the study come alive with the participants' stories.

Conclusions

The loss of a child might be the most profound loss that an individual may ever experience. This study addressed the many aspects that the death of a child has impacted the lives and health status of eight racialized immigrant fathers. The participants provided a wealth of insightful information to inform this research. Six key categories emerged through the data analysis process including: objectification of fathers in the healthcare system, managing feelings, bicultural grieving, making meaning, multiplicity of immigrant fathers' role and managing health status. Although this study shows that the issues concerning racialized immigrant fathers who have lost a child are similar to other studies of bereaved fathers in terms of what they might be experiencing, comparative research involving racialized immigrant fathers across Canada and other countries is needed to ascertain similarities and differences. Additionally, this research also is unique in that it found that immigration-related losses influence how bereaved fathers are

impacted by the death of their child. This chapter included recommendations for social workers, frontline healthcare providers, researchers and policy makers.

My hope is that this study is the start of efforts to intentionally re-frame what racialized immigrant fathers are experiencing when they settle in Canada and increase awareness of how experiences of multiple losses can impact a father's health status. Fathers who lost a child in Canada experienced the magnitude of these multiple losses in specific ways, often characterized by hopelessness and emotional as well as sometimes spiritual, devastation. On top of that, bereaved fathers have to take care of their families' needs in Canada and are often expected to care for their extended family in their country of origin at the same time. It is my hope that healthcare providers and policymakers will consider the research provided through fathers' voices and recommendations of this study and strive to address racialization in healthcare and embed strategies to address these injustices. These strategies should include the historical, cultural and social world of the fathers. As a result, racialized immigrant fathers will have access to services that address social isolation, reflect their cultural and religious beliefs, support them in making meaning of their child's death and feel less objectified by healthcare providers. The voices of fathers who have informed this research have contributed to deepening my understanding of their lived experience of the death of their child and I am honoured to share this work in my doctoral dissertation.

The development of the theory has been a great learning experience for me as a novice constructivist grounded theorist interested in the lives of racialized immigrant fathers. The constructivist grounded theory: hollow from the inside - the death of a child serving as a reinforcing process for ongoing loss linked to racialized immigrant fathers' experience of

immigration, offers insight and understanding of the experiences of the fathers when their child has died.

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APPENDIX A: INFORMATION AND CONSENT FORMUNIVERSITY OF
CALGARY**Information and Consent Form**

TITLE: When a Child Dies: Experiences and Health Status of Racialized Immigrant Fathers in the Healthcare System in Calgary

SPONSOR: Self-Funded

INVESTIGATORS:

Linda Kongnetiman

PhD Student, Faculty of Social Work, University of Calgary

Dr. Daniel Lai

Faculty of Social Work, University of Calgary

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

My name is Linda Kongnetiman and I am a doctoral student at the University of Calgary. My university advisor Dr. Daniel Lai and I are doing a research to better understand the experiences of immigrant fathers and their health when a child dies. I am going to give you information and invite you to be part of this research. Before you decide, you can talk to anyone you feel comfortable with about the research. This consent form may contain words that you do not

understand. Please ask me to stop as we go through the information and I will take time to explain. If you have any questions later, you can ask them of me as well.

WHAT IS THE PURPOSE OF THE STUDY?

We are trying to learn more about the impact of a child's death on immigrant fathers, their health after the loss and their experiences with the healthcare system. We also want to know more about the type of services that immigrant fathers need when their child dies. This knowledge might help us to learn more about how to better take care of fathers.

WHAT WOULD I HAVE TO DO?

You are being invited to take part in this research because we feel that your experience as an immigrant father can contribute much to our understanding and knowledge of the health care system and experiences of fathers when a child dies.

If you accept to take part in this research you will be asked to participate in an interview with myself. The interview will last about 90 minutes. It will take place at a time convenient for you. We will ask you questions about the loss of your child and to talk about your experiences with healthcare services when your child was hospitalized and passed away. We would also like to talk to you about your health and how the death of your child has impacted your health. We will tape record the interview but no one else except for me (Linda Kongnetiman) and my advisor (Dr. Daniel Lai) will have access to the information. Your name will not be identified on the tape recorder. If something is unclear on the tape or we need more information from you I will contact you again to talk about this.

WHAT ARE THE RISKS?

If you take part in this research we do not expect that you will experience any harm but you may be uncomfortable and sad because of the topic. If you are upset by any of the questions and

would like support, you will receive support from the researcher or someone else that knows about losses.

WILL I BENEFIT IF I TAKE PART?

There will be no direct benefit to you, but your participation is likely to help us find out more about how to better understand the experiences of immigrant fathers. We will also be able to advise healthcare professionals how to improve services for immigrant fathers and their families.

If changes are made to services after the research you will benefit directly from using the services.

DO I HAVE TO PARTICIPATE?

It is your choice to take part in this study. To take part is completely voluntary. At any time during the interview you can choose to stop answering the questions or partake in the study. Opting out of the study does not affect the services and or support you receive in healthcare.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

You will not have any expenses as a result of taking part in this research and there is also no payment for taking part in this research.

WILL MY RECORDS BE KEPT PRIVATE?

No information of who you will be given to someone else other than me and my advisor. All your personal identifying information will be removed from the information. All interview files, information collected, will be stored in computer files and cabinet of locked in my office and kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is. After the research is finished the tape recorder

with your voice will be destroyed after 7 years and all written information will be kept by me for research and publication purposes only.

SIGNATURES

Your signature on this form indicates that you understand the information to take part in the research and you agree to take part. You may stop participating in the interview at any time without it effecting your health care. If you have more questions, please contact:

Linda Kongnetiman PhD(c)

Or

Dr. Daniel Lai

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary.

Participant's Name

Signature and Date

Investigator/Delegate's Name

Signature and Date

Witness' Name

Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

APPENDIX B: RECRUITMENT NOTICE

August 14, 2013

Recruitment Notice

Study Title: When a Child Dies: Experiences and Health Status of Racialized Immigrant Fathers in the Healthcare System in Calgary

Introduction

You are receiving this letter as you have had a connection to the Alberta Children's Hospital. We would like to invite you to participate in a study being conducted at the University of Calgary by Linda Kongnetiman PhD(c) and her PhD Advisor Dr. Daniel Lai. This research will help better understand the experiences and health of immigrant fathers who have suffered the loss of a child. We are trying to learn more about the fathers' experiences and listening to what they have to say about their experiences.

The interview will last about 90 minutes and will take place at a time and a location convenient for you. They will ask you questions about:

- Your experiences of losing your child;
- Your experiences in healthcare when your child was hospitalized and passed away.
- The impact of this loss on your health

We know that your privacy is important so all your personal information will not be part of the final report. Only the researchers involved in this study will see your answers. No personal information will be shared with anyone outside of the research team.

If you are interested in participating in this research or have specific questions related to the research please contact Linda Kongnetiman.

Kind Regards,

Megan Miller MSW RSW

Michelle Agopsowicz MSW RSW

Grief Support Coordinators, Alberta Children's Hospital, Grief Support Program

APPENDIX C: LETTER OF SUPPORT ROTARY FLAMES HOUSE

Dear : Ethics Review Board

RE: Study Title: When a Child Dies: Experiences and Health Status of Racialized Immigrant Fathers in the Healthcare System in Calgary

This letter is to notify you that we are in support of Linda Kongnetiman PhD student at the Faculty of Social Work, University of Calgary to recruit potential participants for her thesis project. We will be sending out the recruitment letter on her behalf and contacting the fathers over the phone to determine their willingness to participate. Those fathers who have expressed interest to be interviewed for this study will be contacted by Linda.

If you have any questions or concerns please let us know.

Sincerely,

Krista Sanden

Unit Manager Rotary Flames House

APPENDIX D: PROTOCOL**Protocol****Faculty of Social Work****Linda Kongnetiman**

Telephone:

Email: lkongnet@ucalgary.ca

Study Title: When a Child Dies: Experiences and Health Status of Racialized Immigrant Fathers in the Healthcare System in Calgary**Investigators:**

Linda Kongnetiman

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Project Summary**Introduction**

This study is about understanding the lived experiences and health of racialized immigrant fathers when a child dies. The experience of losing a child for any parent can cause stress, anger, resentment, physical and emotional distress (Li, Precht, Mortensen & Olsen, 2003). The loss of a child is perceived as much more stressful for a parent compared to all other deaths (Chamberts & Chan, 2004). While most existing research have focused on the impact of losing a child for mothers it is important to gain understanding on the experiences of fathers as well. Staudacher (1991) identified that it is crucial for the health of a father surviving the death of a child to reflect on the manner in which the child passed away and the strong emotions that accompany the loss. Additionally, many fathers experience the stress of balancing their tasks of making decisions for the burial and being the strong person for other family members (Staudacher, 1991). Although many fathers try not to express their grief due to the role they have as a caretaker, their expression of it may take many forms (Staudacher, 1991).

Previous research findings have indicated the impact of death of a child on the health of the fathers (Doka, 2009; Li, Precht, Mortensen & Olsen, 2003). For example, many fathers express the loss of their child through anger, guilt, suppressing and blocking of their experiences. These issues can impact the father's emotional well-being and in turn impact the overall health of the fathers. Health is represented by the self-rated perception of an individual and includes assessing absence of disease and disease severity, injury, mental health and psychological reserves, and social functioning (Shields & Shoostari, 2001; Statistics Canada, 2009 & Zhao, Xue & Gilkinson, 2010).

The role of culture, the manner in which the "news" was shared with the fathers, their experiences from the males' perspectives in the health care system, their roles in their communities, and their health status are areas to illuminate through research. Regardless of these fathers' cultures, the type of death a child suffered, or the age of a child at time of death, each father's experience is considered to be unique. Understanding these fathers' experiences will aid in specific knowledge creation regarding their experiences and health status. The research findings will also help to fill the gap in limited research existing on the topic of grief and bereavement of fathers, specifically fathers from racialized backgrounds (Davies, Gudmundsdottir, Worden, Orloff, Sumner & Brenner, 2004). The results could provide foundational knowledge for social work practice and education, and for further research. The desire is that the results will create greater awareness and understanding of issues affecting racialized fathers when accessing grief and bereavement services. This has been reported as an ongoing challenge for grief and bereavement counselors in child health, Alberta Health Services. Also, the results will help to inform providers of other related health and human services through a better understanding of the perspectives of fathers.

Although fathers are involved with taking care of their child on a daily basis (Macfayden, Swallow, Santacroce & Lambert, 2011), their voices have not been included in research. Regardless of the circumstances surrounding the death of a child, a father's grief and ways of coping deserve as much attention in research as a mother's grief. Obtaining data apropos the experiences and health status of racialized immigrant fathers when their child has died can have important implications for social work practice and policy. Gaining understanding about the

lived experience and unique needs of these fathers could create knowledge for program development in the area of grief and bereavement care leading to improved services for racialized men and their families.

Research Goal, Objectives and Questions

The goal of this study is to understand the lived experiences of racialized immigrant fathers in the health care system in Calgary after the death of a child. This research project intends to also explore the impact of the loss on the health status of these fathers.

The overarching question for my research study is:

- What are the lived experiences of racialized immigrant fathers when their child dies?

The two sub questions are posed as follows:

- What are the lived experiences of racialized immigrant fathers in their interactions with the health care system when their child dies?
- How do racialized immigrant fathers understand the impact of the death of their child and the impact of their experiences in the health care system on their health?

Research Methods/Design

The proposed study will adopt Charmaz' constructivist grounded theory (2009, 2010, 2011); a qualitative research methodology; to inquire about the experiences of these fathers.

Constructivist grounded theory is a research method that evolved out of grounded theory (Glaser & Strauss, 1967). To understand the development of constructivist grounded theory by Charmaz a brief discussion of the grounded theory method will be provided followed by a discussion of constructivist grounded theory.

Study Participants and Recruitment of Sample

The target participants of this study are ten racialized immigrant fathers who suffered the loss of a child. All interviews will be conducted in English and therefore only English interview guidelines will be used. To be included in this study the fathers have to meet all of the following criteria:

- A current/former client served by Palliative Care and Grief Support Services at Alberta Children's Hospital

- A father of a child who passed away no less than 12 months and no more than 5 years prior to the time of the study
- A “racialized immigrant” (for the purpose of this research racialized immigrant refers to a visible minority person who immigrated to Canada as an adult)
- A father born outside of Canada who has come to Canada as an immigrant (self-reported) with attention to variation in participants in terms of stage of settlement and time in Canada
- A father able to communicate with the interviewer and able to conduct the interview in English - an interpreter will not be provided because of financial constraints

Participants will be recruited through the help of the Palliative Care and Grief Support Services Coordinator staff at the Alberta Children’s Hospital. The Palliative Care and Grief Support Services Coordinator will send out a letter to the fathers and follow up with a phone call after one week. The fathers who have expressed interest will be put in contact with the researcher. An interview date and time will then be set up.

Data Collection

The proposed study will generate data through individual face-to-face interviews with racialized immigrant fathers. The method for data collection more commonly used in constructivist grounded theory is semi-structured interviews (Denzin & Lincoln, 2005). Each interview will last approximately 90 minutes and will be conducted at a mutual agreed location between the participant and the researcher. Written informed consent for face-to-face or verbal consent for over the phone interviews will be obtained from all research participants. The consent form will describe the research objectives, procedures, methodology, possible upsetting issues, and duration and confidentiality issues.

To support the researcher in having a clear focus on the interview process, an interview guide has been created. This guide (Appendix G) includes questions focusing on the fathers’ experiences, values, beliefs, perceptions on losing a child, experiences in the health care system, and impact on their individual health status. However, the interview will be directed by the participants as the researcher and participants proceed with the conversation. As the study

progresses the interview guide will be adapted to reflect the issues arising in earlier interviews that might not have been included.

Data Analysis

This study will use a constant comparative approach to analyze the collected data (Charmaz, 2011). This means that the transcripts will be coded line-by-line and the codes identified will be analyzed from father to father (on a case-by-case basis) and; across fathers for comparison, and be placed into categories reflective of themes. After reviewing the first interviews initial coding framework will be developed. The researcher will share the codes with her academic advisor for verification and to ensure that the reliability is maintained. The researcher will also use memo-writing to have access to additional data. Additional data collection and focused coding will be used to continue the data analysis process until theoretical saturation is attained (Charmaz, 2011). Sorting, mapping, integrating, and diagramming the data will be completed as part of theory construction (Charmaz, 2006/2011). ATLAS/ti will be used to analyze the data in a systematic manner. As this is a qualitative research the principles of credibility, transferability, dependability, and confirmability will be used to achieve scientific rigor, internal validity, external validity, reliability and objectivity (Creswell, 2007).

Informed Consent

Written informed consent will be obtained from the fathers at the interview. The participant will get a signed copy of the consent form for their file.

Safety Consideration

The safety of the participants is very important. A study exploring the experiences of fathers after a child has died has the potential to cause emotional distress. While the study poses no physical harm for participants, the discussion content has the potential to elicit upsetting memories of the death of the child. Therefore, measures will be implemented to decrease any potential difficulties or harm, as follows:

- Participants will be ensured that they can withdraw at any time during the study if they are experiencing any difficulties.
- Participants will have a list of resources during the day and after hours to contact in case they experience emotional difficulties after the interview ended.
- Participants will also have the phone number of the researcher.

A list of community resources is included in the ethics application to ensure that participants have access to resources when needed.

To ensure participants' privacy and confidentiality the collected interview files and transcriptions will be locked in a filing cabinet at the researcher's office. Only the researcher and her supervisor will have access to the raw data collected. Although specific personal information such as country-of-origin, immigration history, age, religious affiliation and language spoken will be collected, only aggregated data stripped of identifying respondents' information will be published in the final report. For the purpose of data analysis, the data will be saved on the hard drive of the researchers' office computer. Access to the computer is only available through a personal password. After completion of the research project collected data will remain in a locked drawer for seven years and then shredded.

Expected Outcomes of the Study

From a policy perspective, the results of this study will provide policy-makers with unique perspectives of the experiences of racialized immigrant fathers after suffering the loss of a child. This will aid in decision-makers in program and service planning's dedication to enhance end-of-life community services and culturally appropriate bereavement services.

This study is expected to contribute to the limited research that exists on fatherhood studies in Canada that deal with the experiences of fathers when their child has died and has the potential to provide valuable information unique to the experiences of racialized immigrant fathers after the death of their child. Also, the results will inform health care organizations and service providers on how to develop, expand and or enhance programs and services to better meet the needs of these fathers. Through dissemination of the research results in the community,

awareness of these issues will create a better understanding of what some fathers from racialized immigrant backgrounds experience and their health when their child dies. On a macro level, social workers can use the data of this research for ongoing research in the organizations they are employed. The study results also have potential to support social workers in their efforts to continue advocating for cultural competent grief and bereavement services for racialized immigrant fathers when their child has died.

Follow Up

After data collection has been completed the participants will receive a copy of the final report and will be notified if anything arises in term of policy changes or program development based on the research results. The researcher is committed to do this for Five years after the research.

Implementation and Timeline

The research will be completed in two years. Ethics approval from both the University of Calgary and the Alberta Health Services will be sought in 2013. Planning, networking with health care professionals in the area of paediatric palliative care and grief support, networking with community contacts, and identifying and recruiting of participants will be implemented in the same year. Data analysis and the report writing process will commence in 2013 and continue through 2014.

All documents supporting the research are attached. For the convenience of the ethics board a copy with a complete reference list is also attached.

APPENDIX E: MEMOS**Memo**

Surrendering to a Child's Death is a concept that I see emerging in the interviews. What I have witnessed is that the fathers never completely surrender to the fact that they have lost their child. The word surrender signifies to me that the fathers' are addressing their grief, consulted with others and find ways to live day by day. Now when I look at what the dictionary identifies as the meaning of surrender it is: submit, lay down arms, give in give up or admit defeat. At first, I was against using this as a possible code for what was emerging but what I see based on what the fathers have been sharing is that with some there is some form of admitting defeat, with some there is a feeling of laying down their arms of attack to the healthcare system, with some they had to give in to protect their wife or other children. Surrendering was a difficult concept to see with the fathers.

It was challenging to put meaning to all the codes initially that were emerging. I had to go back and review the codes and categories and reorganize and describe them. This was completed in consultation with my supervisor. To make meaning of what the fathers were saying the two first interviews were transcribed and coded then three more interviews were completed which then were also transcribed and coded followed by three more interviews. In reviewing the initial codes, I was exploring if some of the codes are related and could be collapsed. I was also trying to see which codes were similar and could be combined. This also resulted in theme building.

There were some specific things that came to the surface. Some of the fathers seem to anchor the experiences of the death of their child/children from a hidden cultural root.

Interpreting the behaviours of the fathers during the interview was very interesting as there were obvious differences in how the fathers expressed their feelings. That truly showed diversity in grieving the loss of a child. It was also evident that some fathers internalized the grief experience

as some were very overt, expressive of what they were feeling. When some fathers discussed their experiences in the healthcare system it was also clear that they had ill feelings about what they experienced in accessing health services for their child. In general, many of the fathers felt let down by the healthcare system. The treatment of their spouse and child during hospitalization was one aspect that came loud and clear in terms feeling lied to, angry, mad, tired, and effected by human error.

In some ways some of the fathers felt as if the human element was missing and that they were not being treated as human beings. One father responded that it seems as if the “doctor’s office was more like a processing factory”, in his opinion it seems as if the doctor saw patients quickly and they had to get through as many patients as possible.

In some ways I am not sure if the fathers completely understand the role of the healthcare system, their roles when their child is hospitalized and ways of advocating on their own and families’ behalf.

APPENDIX F: INFORMATION AND CONSENT FORM



Information and Consent Form

TITLE: When a Child Dies: Experiences and Health Status of

Racialized Immigrant Fathers in the Healthcare System in Calgary

SPONSOR: Self-Funded

INVESTIGATORS:

Linda Kongnetiman

PhD Student, Faculty of Social Work, University of Calgary

Dr. Daniel Lai

Faculty of Social Work, University of Calgary

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

My name is Linda Kongnetiman and I am a doctoral student at the University of Calgary. My university advisor Dr. Daniel Lai and I are doing a research to better understand the experiences of immigrant fathers and their health when a child dies. I am going to give you information and invite you to be part of this research. Before you decide, you can talk to anyone you feel comfortable with about the research. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have any questions later, you can ask them of me as well.

WHAT IS THE PURPOSE OF THE STUDY?

We are trying to learn more about the impact of a child's death on immigrant fathers, their health after the loss and their experiences with the healthcare system. We also want to know more about the type of services that immigrant fathers need when their child dies. This knowledge might help us to learn more about how to better take care of fathers.

WHAT WOULD I HAVE TO DO?

You are being invited to take part in this research because we feel that your experience as an immigrant father can contribute much to our understanding and knowledge of the health care system and experiences of fathers when a child dies.

If you accept to take part in this research you will be asked to participate in an interview with myself. The interview will last about 90 minutes. It will take place at a time convenient for you.

We will ask you questions about the loss of your child and to talk about your experiences with healthcare services when your child was hospitalized and passed away. We would also like to talk to you about your health and how the death of your child has impacted your health. We will tape record the interview but no one else except for me (Linda Kongnetiman) and my supervisor

will have access to the information. Your name will not be identified on the tape recorder. If something is unclear on the tape or we need more information from you I will contact you again to talk about this.

WHAT ARE THE RISKS?

If you take part in this research we do not expect that you will experience any harm but you may be uncomfortable and sad because of the topic. If you are upset by any of the questions and would like support, you will be receiving support from the researcher or someone else that knows about losses.

WILL I BENEFIT IF I TAKE PART?

There will be no direct benefit to you, but your participation is likely to help us find out more about how to better understand the experiences of immigrant fathers. We will also be able to advise healthcare professionals how to improve services for immigrant fathers and their families. If changes are made to services after the research you will benefit directly from using the services.

DO I HAVE TO PARTICIPATE?

It is your choice to take part in this study. To take part is completely voluntary. At any time during the interview you can choose to stop answering the questions or partake in the study. Opting out of the study does not affect the services and or support you receive in healthcare.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

You will not have any expenses as a result of taking part in this research and there is also no payment for taking part in this research.

WILL MY RECORDS BE KEPT PRIVATE?

No information of who you will be given to someone else other than me and my advisor. All your personal identifying information will be removed from the information. All interview files, information collected, will be stored in computer files and cabinet of locked in my office and kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is. After the research is finished the tape recorder with your voice will be destroyed after 7 years and all written information will be kept by me for research and publication purposes only.

SIGNATURES

Your signature on this form indicates that you understand the information to take part in the research and you agree to take part. You may stop participating in the interview at any time without it effecting your health care. If you have more questions, please contact:

Linda Kongnetiman PhD(c)

Dr. Daniel Lai

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary.

Participant's Name

Signature and Date

Investigator/Delegate's Name

Signature and Date

Witness' Name

Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

APPENDIX G: INTERVIEW GUIDE**Faculty of Social Work****Linda Kongnetiman**

Email: lkongnet@ucalgary.ca

Interview Guide

These are only guidelines. Questions will not be asked sequentially but this instrument is merely for conversation. Not all questions will be used. This is the content that the researcher is attempting to cover in the semi-structured interview.

Study Title: When a Child Dies: Experiences and Health Status of Racialized Immigrant Fathers

Investigator:

Linda Kongnetiman

PhD Student, Faculty of Social Work, University of Calgary

Supervisor:

Dr. Daniel Lai

Faculty of Social Work, University of Calgary

Demographic Information:

Name:	Age:
Ethno-cultural group:	Religion:
Number of children:	Names and age of children:
Arrival in Canada:	Country of origin:
Arrival in Calgary:	Language spoken:
Extended family residing with you:	Marital status:
Date of child's death:	Child's date of birth:

Fathers' Grief and Bereavement Experiences

Can you share your experiences surrounding the death of your son/daughter (name) with me?

Customs and Traditions

- What are your beliefs and customs regarding bereavement?
- what are the differences in the beliefs and rituals when dealing with the passing away of girls and boys?

How do fathers grieve in your cultural home country?

Is this different from how mothers' grief and how so?

- What is the role of family in supporting the bereaved father?
- What is the role of community or friends in supporting bereaved father?
- What are the roles of religious leaders when supporting bereaved father?
- With regards to a child's passing away and fathers' bereavement do you feel that the beliefs and customs are honored in your current community?
- What are the supports that your current community provides for fathers who have lost their child?
- Who has been supportive to you in your grief journey?
- What are your beliefs about accessing and receiving counseling/support with the death of your child, i.e. talking about your child and emotions with professionals?

Who do you talk to about the death of your child

Meaning of Your Child's Death

- Why do you think your child died?
- Can you tell me about your afterlife beliefs?
- What is the meaning that you and your spouse (partner, child's other parent) give to your child's passing away?
- Have there been any changes to your beliefs, faith or spirituality as a result of this experience?
- What would you like to tell other fathers about your experiences of losing a child?

The Hospital Experience

- Tell me about your experiences at the hospital?
- Can you provide me examples of how your beliefs and customs were honored in the hospital?
- Were you involved in counseling support at the hospital?
- How was counseling for you and your family?
- What rituals took place in the hospital?
- What would you like to have happened in the hospital?
- What type of barriers if any did you experience in the health care system?
- What words, phrases or expressions would you have liked to hear?
- What meaning do these have to you?
- What are some of the questions you would like to have been asked?
- Tell me about some of your experiences where you did not feel supported if there were any?
- What would you like to see change?
- What would you like to say to the health care professionals you encountered?
- What would you like them to know about your experiences and why?

Your health Status

Tell me about your health?

What are some of the reasons you consider yourself a healthy person?

Do you have a family doctor?

How many years consecutive have you been completing your annual checkups?

Can you share with me how the death of your child has impacted your health and well-being?