

(RE)VISIONING WHOLE-PERSON CARE:
AN INTERPRETATION OF THE HEALTH CARE EXPERIENCES OF
CULTURALLY DIVERSE PERSONS LIVING WITH A LIFE-LIMITING ILLNESS

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Abstract

Trends in Canadian demographics reflect a growing multicultural population with diverse perspectives on health and illness. This phenomenon brings unique challenges and opportunities to health care professionals to provide excellence in Hospice Palliative Care (HPC). Cross-cultural care can be complex and cultural differences may result in poor health outcomes for minority persons at end-of-life. The purpose of this study was to explore the lived experience of health care for culturally diverse persons who had been diagnosed with a life-limiting illness. Guided by the principles of hermeneutic phenomenology, it aimed to identify what culturally diverse persons considered important to their health care and to understand how mainstream and minority cultural approaches to care were enacted in their experiences. Data were generated through in-depth interviews with ten participants with various palliative diagnoses. Data analysis included the contextual development of four paradigm cases to uncover primary themes related to the participants' experience of health care. These cases were categorically compared and contrasted with the other cases to further develop the themes. A conceptual picture of whole-person care that included the key dimensions of holistic care, integration of multiple care knowledges, and prioritization of collaborative care emerged through this process. The findings revealed that the participants addressed gaps in whole-person care by drawing on both mainstream and minority cultural beliefs and practices to meet their physical, mental, emotional and spiritual needs. This study points to the need for social workers and other health care professionals to re-conceptualize biomedicine as one cultural approach to health and illness alongside others of HPC and culturally diverse persons.

Preface

Ethics approval for this research was received from the University of British Columbia Behavioural Research Ethics Board (BREB): BREB number: H08-02078.

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Chapter 1. Introduction

I have always felt that the action most worth watching is not at the center of things but where edges meet. I like shorelines, weather fronts, international borders. There are interesting frictions and incongruities in these places, and often, if you stand at the point of tangency, you can see both sides better than if you were in the middle of either one. This is especially true, I think, when the apposition is cultural.

— Anne Fadiman, *The Spirit Catches You and You Fall Down: A Hmong Child, her American Doctors, and the Collision of Two Cultures*

Canada has a large and growing multicultural population with diverse perspectives on health and illness (Statistics Canada, 2006). Health care professionals are increasingly called upon to provide care to individuals and families whom they perceive as culturally different from themselves. These occasions bring unique challenges and opportunities to mainstream Hospice Palliative Care (HPC).

Cross-cultural care can be complex and research has shown that cultural differences may result in poor interactions and inappropriate outcomes at critical junctures in end-of-life care for minority persons (Boston, 1999; Bruera, Russell, Sweeney, Fisch, & Palmeret, 2002; Kagawa-Singer & Blackhall, 2001; Kakauer, Crenner, & Fox, 2002; Ngo-Metzger et al., 2003; Siriwardena & Clark, 2004). Therefore, there has been a growing demand to enhance the cultural competency of health care providers who work in various medical settings with palliative patients (Bosma et al., 2010b; Ferris et al., 2002; Perloff, Bonder, Ray, Ray, & Siminoff, 2006).

The Starting Point

My interest in cross-cultural care stems from my clinical practice as a social worker in an acute care hospital. During the past eighteen years, I have worked in a large and busy inner city hospital with over 450 beds. It serves a diverse population that includes

seniors, new and established immigrants, middle class families, gay men, IV drug users and homeless people. It is a faith-based organization that has been historically committed to meeting the health care needs of diverse and marginalized people.

Over the years, I have worked in the areas of critical and palliative care with many terminally ill patients and their families. I have observed a range of reactions among culturally diverse persons to serious diagnoses such as cancer, AIDS, and end-stage heart and kidney diseases. In many cases, I was surprised by the ways in which patients and families responded to a life-limiting illness in terms of how they communicated about it with one another and health care providers, what they identified as care priorities, how they made medical decisions, and the types of treatment choices and care plans they pursued. My surprise occurred because some of their reactions and goals were noticeably divergent from what I thought I knew about different ethno-cultural groups.

In health care, knowledge about culturally diverse patients is primarily conveyed through condensed summaries or 'factfiles' that describe common beliefs, values and practices of a range of ethnic and religious groups (Gunaratnam, 1997). Although these descriptions can be helpful in understanding some behaviours, I realized that they often are not uniformly applicable to all members of a group in similar situations. Furthermore, there are often significant differences in cultural beliefs and practices within family units themselves. As my clinical experience accumulated, I learned that cultural beliefs and behaviours are not static phenomena that can be easily catalogued in this format.

I observed how difficulties occurred in medical interactions when the cultural expectations of patients and families were different from those of health care professionals and hospital systems. I saw how unacknowledged and unresolved cultural differences can exact a significant toll on patients, families and care providers alike in terms of their time, attention and energy. There were clinical instances when I felt that care professionals had misunderstood or minimized what patients were trying to convey about what was important to their care according to their cultural background.

To illustrate this experience, I have included a story about Mr. Kim, a patient with whom I worked a few years ago. I have removed or altered any identifying information to protect his confidentiality.

Mr. Kim's story

Mr. Kim was a 74-year-old Korean man. He was married with two adult children — a son, who was the eldest, and a daughter a few years younger. Mr. Kim and his wife immigrated to Canada ten years before I met them; both their children were already living in Canada and were well established here. I first met Mr. Kim when he was transferred from a surgery unit to the palliative care unit for pain and symptom management and discharge planning. He had recently undergone surgery (colostomy) after a diagnosis of colon cancer.

Both Mr. and Mrs. Kim spoke limited English, so much of our communication occurred with the assistance of their children or a hospital interpreter. During his first admission, Mr. Kim spoke very openly about his cancer diagnosis and requested detailed medical information from the unit physicians. He was very involved in making treatment decisions and care plans for himself. Although he discussed his illness and treatment plans with his family, he assumed the lead in making decisions. He appeared very optimistic and hopeful that his health would improve. Once Mr. Kim's symptoms were controlled, he was discharged home and shortly after began a series of radiation treatments as an outpatient.

I was surprised by much of Mr. Kim's behaviour because it seemed incongruent with what I had read in descriptions of Asian culture and my experiences with other senior Asian patients. For example, I was surprised how openly Mr. Kim spoke about his cancer diagnosis — often, Asian patients did not use the word cancer or speak about it so directly. I was also surprised by how involved he was in making care plans — again, it was not unusual to see Asian elders delegate decision-making and treatment-planning to their children, particularly their sons.

I did not see Mr. Kim again for ten months, at which time he was re-admitted to the unit because of new symptoms of pain, nausea and vomiting, and anorexia. He had lost 20 pounds, and he appeared thin and frail. Mr. Kim provided general information about his symptoms and the progression of his illness, but directed the unit staff to his son and daughter for details. He also requested that test results and care options be discussed with his son and daughter, which they would then review with him and his wife. With his

permission, several investigations were then initiated to determine the reasons for his new symptoms. Unfortunately, the tests revealed that the colon cancer had metastasized significantly and now involved Mr. Kim's abdomen and liver. The prognosis associated with this spread was poor.

Mr. Kim's son was hesitant to disclose this prognostic information to his father. However, the care team encouraged him to tell Mr. Kim about his prognosis, primarily because Mr. Kim had been so interested in his medical status before. Moreover, the team advocated that it was especially important for Mr. Kim to know the full extent of his disease so that he could make plans for the short time that was likely remaining to him. The team emphasized that it was important for Mr. Kim to receive this information so that he could make informed decisions about treatment and care goals.

Mr. Kim's daughter was very opposed to sharing this information with her father because she felt that doing so would "rob him of any hope" for the future and that he would "just give up." She explained that in Korea it was important for the family to protect seriously ill members from "bad news." However, in the end, Mr. Kim's son decided to follow the medical team's recommendation to tell his father about the test results and related prognosis during a family meeting. Mr. Kim said very little when he received the news. He had no questions and declined to hear any detailed information. He instructed the physician to communicate with his son regarding plans for ongoing care. Mr. Kim's daughter was very upset that her brother had disclosed the full report of the medical findings and implications to their father. From that time on, Mr. Kim appeared to withdraw from the unit staff and his family. He continued to decline and died several weeks later.

Reflections on cross-cultural interactions in end-of-life care

I have often reflected on Mr. Kim and his family's experience of end-of-life care, and the ensuing process of grief and bereavement for each of them. Mr. Kim's expectations of care from his family and health care providers appeared to change as his illness progressed, and his interactions with each of them altered accordingly. I observed how the health care team's priorities, which were primarily focused on truth-telling, informed consent and individual decision-making, were different from those of Mr. Kim and his

family. The team's emphasis on disclosing Mr. Kim's prognosis was less important to his family, who were more focused on preserving his sense of hope and related well-being. Furthermore, the team's desire for Mr. Kim to be actively involved in decision-making was contrary to his expressed wish for his son and daughter to receive medical information on his behalf, and to subsequently take the lead in care planning according to what was best for him and his family. I believe that these expectations for care reflected his cultural values and beliefs, although they were not acknowledged at the time. Mr. Kim and his family were confronted with the challenge of honoring these in the face of different values and practices of mainstream Western health care.

This experience and others like it motivated me to learn more about the nature and dynamics of cross-cultural interactions that occur in end-of-life care. To begin this research process, I conducted a review of relevant literature, which I outline in this chapter. I also discuss some limitations in conventional approaches to culturally competent care that stem from the way in which culture is conceptualized within them. Through this process, I identified various gaps in knowledge and practice that shaped the questions for my research project.

What the Literature Tells Us

Culture makes a difference

As my clinical example demonstrates, the role of culture is significant in health care, and how it is conceptualized and applied has enormous consequences for patients, families and health care providers. In the context of HPC, culture influences communication patterns, decision-making styles, responses to symptoms, treatment choices, and emotional expression at end of life (Valente, 2004; Werth, Blevins, Toussaint, & Durham, 2002). Cultural meanings of illness, suffering and dying shapes the explanatory models that patients and care providers draw upon in their interactions with one another (Kleinman, 1988). Accordingly, each cross-cultural encounter is more or less a "negotiation of difference" depending on the degree of cultural congruency between patients and health care providers (Dorazio-Migliore, Migliore, & Anderson 2005).

Studies show that when cultural differences are inadequately addressed, inferior care occurs. This is demonstrated by inequalities in utilization of, and access to, HPC services, pain and symptom management, and location of death (Bosma, Aplan, & Kazanjian, 2010a; Bruera et al., 2002; Karim, Bailey, & Tunna, 2000; Krakauer, Crenner, & Fox, 2002). Various factors have been identified that can complicate cross-cultural exchanges and contribute to these negative outcomes, which I discuss below.

I don't speak your language

Language differences between patients and health care professionals have been identified in the literature as a significant challenge to successful HPC to minority patients. Several studies in Western settings have identified how patients and families of various ethnic backgrounds are unable to clearly express their needs to care providers when they speak little or no English (Nyatanga, 2002; Randhawa, Owens, Fitches, & Khan, 2003; Siriwardena & Clark, 2004). In Born, Greiner, Sylvia, Butler, and Ahluwalia's (2004) study, Latino participants emphasized how "the ability to communicate with a patient is key to providing comfort, medical care, spiritual, and family support" (p. 252). Chinese, Filipino, Indian and Italian participants in an Australian study shared a similar perspective and suggested that some end-of-life issues are best expressed in one's ethnic language (McGrath, Vun, & McLeod, 2001).

Health care providers have also emphasized the problems posed by language barriers that impede "attempts at providing a negotiated package of care" that addresses the range of needs of ethnically diverse patients (Owens & Randhawa, 2004, p. 419). Lack of bilingual health care professionals and/or appropriate interpreters frequently frustrates this process even further (Chan & Kayser-Jones, 2005; Gelfand, Balcazar, Parzuchowski, & Lenox, 2004; Kramer & Auer, 2005).

Specific consequences that result from unmet needs have been attributed to language and communication barriers. In two separate cases studies that explored the care experiences of an African American couple and a Chinese woman, Kagawa-Singer and Blackhall (2001) discovered how bidirectional misunderstandings between patients and care providers led to "unnecessary physical, emotional and spiritual suffering" (p. 2995). In Chan and Kayser-Jones' (2005) study, which explored the experience of dying for

Chinese nursing home residents, they found that the inability of residents to speak English resulted in “suboptimal management of symptoms such as pain and dyspnea” (p. 28). Furthermore, when patients and families do not speak the main language in a society, they often do not learn about HPC resources that may be available to them in their community. In de Graaf and Francke’s (2003) study of terminally ill Turks and Moroccans in the Netherlands, participants indicated that one of the reasons that they were unaware of home health care services was because they did not read or understand the Dutch language. Similarly, Gelfand et al. (2004) found that limited understanding of English by Mexican Americans was one of the barriers to their awareness and subsequent utilization of hospices.

Different perspectives, misplaced assumptions

The whole truth

Communication challenges in cross-cultural care are not only related to language limitations, however. They also arise from a broader lack of understanding of culturally diverse beliefs and practices in the context of end-of-life care (Owens & Randhawa, 2004). For example, Western medicine’s emphasis on ‘truth-telling’ and full disclosure of medical diagnoses and prognoses to patients runs counter to the perspectives of various cultural groups. In McGrath et al.’s study (2001), participants stated that they were not comfortable talking about death and dying, and found the Western way of informing people directly about the terminal nature of their disease as “too abrupt” and “blunt” (p. 307). Participants in an Arab-American focus group also indicated that they were “against telling their family members bad news” about their health status (Duffy, Jackson, Schim, Ronis & Fowler, 2006) and Mexican American participants similarly asserted that “hospice staff should not tell a patient that there is no hope and they are dying” (Gelfand et al., 2004, p. 11). This was also reflected in the clinical example I presented earlier.

Chinese seniors in a Canadian study indicated that discussions about death and dying that are expected in advance care planning can disturb the “emotional balance” of individuals by highlighting negative scenarios, which subsequently curtails their engagement in this process (Bowman & Singer, 2001, p. 460). Likewise, Chan and

Kayser-Jones (2005) found that the anticipated bad luck associated with talking about death often limits discussions about hospice care and its philosophy with Chinese nursing home residents and their families. Various Aboriginal cultural traditions also assert that speaking explicitly to patients about terminal illness and death may subsequently hasten it (Ellerby, McKenzie, McKay, Garipey, & Kaufert, 2000).

Health care providers have described how such cultural perspectives constrain interactions with patients and hamper care planning. As one professional care provider explained regarding her work with minority patients, “One of the biggest challenges...was trying to discuss health care...and end of life wishes...[their] culture does not allow them to discuss these issues for fear they would become true” (Kramer & Auer, 2005, p. 658). Paradoxically, the Western medical expectation that patients provide informed consent to access HPC services, which involves acknowledgement of a terminal diagnosis and prognosis, can contribute to conflict between the values of minority patients and mainstream care providers and preempt their use of such resources.

Families take care of their own

The expectations that families have of themselves to provide care to their members can also impede utilization of HPC services. Various studies have shown how a sense of obligation may prevent ethnically diverse families from accessing community supports. In Gelfand, Balcazar, Parzuchowski, and Lenox’s (2001) study, Mexican respondents stated that families may be too “embarrassed to use hospice” because to do so would indicate the inability of family members to carry out their caregiving roles (p. 394). Similarly, mixed feelings of “honor and shame may inhibit the use of professional home care” by Turkish and Moroccan families (de Graaf & Francke, 2003, p. 804) just as Chinese family members may feel that they are not meeting the responsibilities of filial piety if they agree to hospice care for a parent (Kagawa-Singer & Blackhall, 2001; Ngo-Metzger et al., 2003). African Americans stated that they were reluctant to utilize hospice services because they feared that “hospice would displace family members from their traditional role of caring for their dying” (Jenkins, Lapelle, Zapka, & Kurent, 2005, p. 590).

Health care providers may hold a similar assumption that particular ethnic groups will automatically take on this caregiving role. Consequently, referrals to hospice services may not occur for some ethnic families because physicians assume that they will care for their own (de Graaf & Francke, 2003; Enguidanos, Yip, & Wilber, 2005; Ngo-Metzger et al., 2003). Enguidanos et al. (2005) discovered in their research that African Americans and Latinos were more likely to die at home than their white counterparts do, but they were less likely to receive hospice care. Unfortunately, family members who are not referred to palliative care services often feel that “they had no choice in how they wished to care for their loved one” (McGrath et al., 2001, p. 307).

We need one person to decide

Finally, cross-cultural differences regarding the locus of decision-making can influence end-of-life care outcomes. In mainstream Western health care there is an emphasis on individual patient autonomy. However, within many ethnic groups, a family-centered approach represents the norm for care planning. Studies have shown that many ethnically diverse patients and families such as Asian Americans, Korean Americans, and Mexican Americans prefer a family-centered model of decision-making in the context of health care (Blackhall & Frank, 1999; Ngo-Metzger et al., 2003). In a study that explored minority and non-minority perspectives on what constitutes a good death, minority participants identified the importance of integrating extended family in end-of-life decision-making and care provision (Tong et al., 2003). This opinion was echoed by bereaved family members in Hanson, Danis, and Garrett’s (1997) study. The authors suggested that, “because current practices emphasize individual autonomy rights, physicians may overlook family or purposely exclude them from key clinical discussions” (p. 7).

Health care providers often find it difficult to facilitate such cultural traditions in the context of Western medical and legal parameters. In a focus group of palliative care providers, a social worker spoke about the incongruence of the consumer-directed approach focused on the individual versus the collective approach preferred by different ethnic groups: “Our society is so individualized...that it’s like ‘this should be the spokesperson’ [but] what do you do when it’s an entire family...they want to be

interchangeable [but] to have that...meld with our culture and...our legal system demands can be challenging” (Kramer & Auer, 2005, p. 658). Similar concerns were also expressed by health care providers who worked with First Nations communities in northern rural Canada (MacLean & Kelley, 2001).

Gaps in culturally competent care

With the awareness that cross-cultural interactions can be complex and result in poor or inappropriate care outcomes because of the reasons above, end-of-life conceptual frameworks have expanded their focus to include the phenomenon of culture and its influence on patient and family experiences of health care (Ahmad & Bradby, 2007; Ferris et al., 2002; Nolan & Mock, 2004; Stewart, Teno, Patrick, & Lynn, 1999). There have been corresponding expectations to provide health care services that are responsive to the cultural diversity of North American society. Cultural competency, cultural sensitivity and ethno-sensitive practice are common terms that have become prominent in contemporary health care policy and practice. These approaches to care are endowed with almost religious significance as the panacea for the multiple and various problems that can occur in cross-cultural interactions in medical settings (Perloff et al., 2006). However, limitations associated with these approaches in end-of-life care have been identified in the literature.

(Not) understanding the shifting nature of culture at end-of-life

In conventional models of culturally competent care, patient and family culture is conceptualized as a set of characteristics that are fixed and freestanding, and organized in condensed factfiles as noted earlier. However, research has shown that cultural values and behaviours are not so static and that they may shift in importance and prominence at end-of-life. For example, Willis (1999) observed in his study of palliative care among Australian Aboriginals that in the “face of serious illness or death, cultural conventions about gender and race proved to have a degree of flexibility that was not apparent when there was no crisis” (p. 424). Similarly, Morris, Suissa, Sherwood, Wright, & Greer (1986) noted in their early study of terminally ill cancer patients that cultural values can alter for people as an illness progresses: “what was once important may seem insignificant, while things once ignored have greater weight” (p. 48). Patrick, Engelberg,

& Curtis (2001) pointed out in their study about the quality of dying, that patient preferences about the dying process may change prior to death, and they recommended further investigation into the stability of these preferences over time. Duffy et al. (2006) posed a similar query in their study — they too wondered about changes in end-of-life preferences that can occur longitudinally for ethnic patients.

Interestingly, Diver, Molassiotis, and Weeks (2003) found that minority patients in a hospice day program did not present culture-specific needs. The authors did not think that patients were compromising their cultural wants in this instance, but suggested instead that acculturation and a desire “to fit into” mainstream culture partially explained this observation. However, they also questioned whether this inclination to fit in would be as strong throughout the “terminal stages of care” (p. 395).

These studies indicate that cultural beliefs and practices relevant to care appear to change over time for individuals living with a terminal illness. However, the ways and extent to which this occurs as an illness progresses has not been specifically explored.

(Not) understanding the interplay of people, places, and cultures

Patrick, Engelberg, and Curtis (2001) also underlined how the “dying experience is likely to differ across health care systems and types of health care providers as well as across cultures and social groups” (p. 724). For example, Nolan and Mock (2004) point out that few studies have explored the impact of organizational and professional culture on end-of-life care for patients as they move through different care settings such as hospital, hospice and home. Specifically, they criticized conceptual frameworks of end-of-life care for failing to include the interaction between patients and different health care systems in their analysis of outcomes of care.

It is important to look at these encounters closely because it is within them that different cultural practices are presented and negotiated by patients, families and health care providers. Some recent studies have described how care professionals “foreground” or “background” their different cultural identities in order to make connections with patients (Kirkham, 2003; Owens & Randhawa, 2004). However, the ways in which patients draw on minority and mainstream cultural discourses when engaging with care providers have not been closely examined.

(Not) understanding the experience of successful cross-cultural care

Although many studies have identified various negative outcomes of unresolved cross-cultural exchanges and reasons for them, there has been no investigation into clinical encounters where cultural differences are either minimally evident or otherwise effectively negotiated. In my clinical experience, I have observed examples of cross-cultural interactions where mutually accepted care strategies and goals were successfully established between health care providers and patients. What accounts for these positive cross-cultural exchanges in HPC has not been described or explained in the literature. An investigation of these experiences can provide valuable insight into when and how culture presents as either a positive or challenging feature in medical exchanges.

Applying another perspective

These studies and experiences show that patients and health care providers appear to draw on various cultural beliefs and practices at different times and in different contexts. This depiction of cultural representation as fluid and versatile offers a new and relevant lens to interpret the experience of cross-cultural care. Different ideas about this notion of culture have been presented by several scholars, which can be used to understand this phenomenon further.

Geertz (1973) described culture as a dynamic “web of significance” through which people make meaning of both the ordinary experiences, and the extraordinary events, that happen in their everyday lives. Cultural meanings emerge out of active negotiations that occur within and between members of particular social groups. It can be viewed as an “evolving collective product” comprised of “values, rules, prohibitions, preferences, symbols, meanings, language and practices” that change and transform as they are imagined and reimagined (Estroff & Henderson, 2005, p. 5). Dhamoon (2006) preferred to use the term “cultural” as a verb to express this continuous activity.

From this perspective, the culture of an individual is not perceived as a single unchanging identity with one corresponding blueprint for behaviour attached to it (Hunt, 2005). Within a pluralist society, people may be able to choose from a repertoire of ideas and actions offered by various cultural discourses. As Yan and Lam (2000) pointed out,

there can be “more than one possibility for people in a multicultural society to be what and where they want to be culturally” (p. 485).

Different scholars have offered various descriptions of how people exercise agency in the formulation and representation of their cultural identities. Foucault (1979), for example, described how individuals draw on personal and unique “technologies of the self” to make critical choices about the discourses and practices that they incorporate into their activities. Other authors have looked to Bourdieu and drawn on his concept of *habitus* to explain the repertoire of behavioural choices available to people in their daily interactions (Dorazio-Migliore et al., 2005; May, 1999; Samuelsen & Steffen, 2004). Various other analogies have also been used to conceptualize the building blocks of cultural construction. These include Swidler’s (1986) “toolkit”, Nagel’s (1994) “shopping cart”, and Waldron’s (1995; see also May, 1999) “cosmopolitan alternative.”

Each of these theories outlines in various ways how we build cultural identities by selecting items from various discourses, which we then strategically deploy in different daily contexts. This process may be particularly deliberate for individuals who are positioned at the margins of society because of cultural categorizations related to their race, ethnicity, class, gender or sexuality. Those on the margins often consciously maintain a “dual perspective” with “one informed eye on the dominant culture and another on their own” (Laird, 1998, p. 25). In this way, they appraise what the dominant culture expects and “react differently in different settings, for different purposes, with different people, in ‘so-called’ culturally appropriate manners” (Yan & Lam, 2000, p. 486).

These ideas about the ways in which cultural identities shift, and associated behaviours change, have not been used to interpret the experience of cross-cultural HPC. They can provide a useful framework to understand how cultural discourses and practices may be more or less important at end-of-life.

Purpose of the Research Study

In summary, it is evident that culture influences the experiences of end-of-life care for individuals and their families. It affects communication, information sharing, individual

and family behaviours, and decision-making. Because of its influence, culture has been identified and incorporated as an important component in conceptual frameworks regarding HPC, and culturally competent services have been developed accordingly.

However, within mainstream health care, culture has been typically presented as a phenomenon comprised of static essentials that are uniformly important rather than as a dynamic collection of beliefs and practices that are variously enacted over time and circumstance. Although research has shown that the latter presentation of culture occurs, it is not clear when and in what ways this happens. This is an important topic to explore because an enhanced understanding of what culturally diverse persons consider important to their care, and specifically when and how their cultural beliefs and practices are significant to it, will contribute to the design and delivery of health care services that are relevant and meaningful to them as their illnesses progress.

Therefore, the purpose of this research project is to gain a better understanding of the lived experience of mainstream health care for culturally diverse persons who have been diagnosed with a life-limiting illness. Emerging from my own clinical experiences and gaps in the literature, I identified the following three research questions to meet this objective. Although they are presented as individual questions, they overlap with one another.

- 1. What do culturally diverse persons consider important to their health care?**
- 2. What are the experiences of mainstream health care for culturally diverse persons living with a life-limiting illness?**
- 3. In what ways are mainstream and minority cultural discourses enacted in the context of their health care, and how do they affect the experience of care?**

Chapter 2. Methodology

How do we experience the lifeworld? On the one hand it is already there; on the other hand we take part in shaping and creating it. In other words, the world is given to us and actively constituted by us: reflecting on it phenomenologically, we may be presented with possibilities of individual and collective self-understanding and thoughtful praxis.

— Max van Manen, *Researching Lived Experience*

Hermeneutic phenomenology informed my approach for exploring the experience of mainstream health care for culturally diverse persons. In this chapter, I will outline the rationale for using a qualitative research framework, and I will describe some key principles of hermeneutic phenomenology that I drew on for this study. I will then describe the steps that I took to conduct the research and analyze the data.

Reasons for Using a Qualitative Research Approach

As discussed above, much research to date has described how individual cultural beliefs and practices of minority persons affected their experience of health care. The research has frequently focused on the challenges that mainstream care providers and systems face when these practices do not match their own. The assumption that is prevalent through much of the literature is that minority cultural meanings of health and illness are substantially different from those of mainstream health care, and that expectations of minority patients are subsequently singular. From this perspective, the culture of minority patients is problematized as a source of divergence and tension in health care. Furthermore, these cultural beliefs and practices are perceived as reified entities that are fixed and unchanging.

Based on my clinical experience, I was not convinced that this picture fully reflected the experience of health care for culturally diverse persons who were living with a terminal illness. I wanted to learn more about their lived experience of health care from their perspective, and explore what they viewed as important in health care and the place of culture in that perception. Therefore, I turned to qualitative inquiry methods to explore

these questions because they are well suited for developing in-depth insight into subjective experiences (Creswell, 2007). They include flexible strategies that have the capacity to respond to new data as it emerges, and thereby generate relevant and rich detail regarding multiple facets of an experience or event. Qualitative research is very appropriate for inquiry into social phenomena of which there is limited understanding (Patton, 2002).

My commitment was also to forefront the voices of individuals who were experiencing palliative and end of life care. Drawing on interviews, observations and documents, the qualitative researcher attempts to “make sense of, or interpret, phenomena in terms of the meanings people bring to them” (Denzin & Lincoln, 2005, p. 3). Qualitative inquiry aims to speak and let speak the things of our everyday world as we experience and encounter them (van Manen, 1997). Therefore, participants are acknowledged as experts of their own experience and their perspectives are valued accordingly in qualitative research. This was a fundamental tenet of my project.

Hermeneutic phenomenology

I specifically chose hermeneutic phenomenology as a qualitative research approach for my study because it aims to discover the everyday meaning of lived experiences. Benner (1994) stated that “the goal of interpretive phenomenology is to uncover commonalities and differences” in these experiences (p. 104). It asks the question: “What is this or that kind of experience like?” in all its aspects (van Manen, 1997; p. 9).

Hermeneutics is a branch of phenomenology that is historically associated with Heidegger (1927/1962) and more recently with Ricoeur (1981), Benner (1985), Gadamer (1994), and van Manen (1997). It rests on an ontological thesis, which is conceptualized in Heidegger’s concept of *Dasein* — a hyphenated notion of *being-in-the-world* that encompasses the interdependency of self and world. The meanings of phenomena are constructed within the context in which they are situated, and interpretations of them occur accordingly. It takes into account the socio-cultural and historical traditions that give structure and meaning to our everyday ways of being in the world (Brykczynski & Benner, 2010; van Manen, 1997). Because hermeneutics offers a contextual approach for

exploring people's experiences, it is particularly useful for studying the phenomenal realms of health and illness (Benner, 1985).

The hermeneutic circle is a fundamental concept within interpretive phenomenology (Heidegger, 1927/1962; Gadamer, 1994). It depicts the spiraling process of description and interpretation that is integral to hermeneutics. It is within this circle that the multiple contextual features of a phenomenon are acknowledged and taken into account. Understanding of human experience is gradually developed through a back and forth movement among these individual parts while keeping a direct gaze "on the things themselves" (Heidegger, 1927/1962). Thus, comprehension of the whole occurs in terms of its parts and simultaneously the parts are understood in terms of the whole.

It is within the hermeneutic circle that the preconceptions or 'fore-structure' that a researcher brings to an inquiry are also integrated into the interpretive process. Heidegger's conceptualization of being-in-the-world precludes the practice of phenomenological bracketing or reduction historically associated with phenomenology. He argued that it was not possible for individuals to set aside their presuppositions and become detached observers of the lifeworld surrounding them. Instead, he emphasized that the process of generating knowledge requires the conscious and "constant task...of working out these fore-structures in terms of the things themselves" (Heidegger, 1927/1962, p. 153).

From this perspective, existing understandings of social phenomena are viewed as flexible interpretations that are open to revision. As Gadamer (1994) pointed out, "the important thing is to be aware of one's own bias, so that the text can present itself in all its otherness and thus assert its own truth against one's own fore-meanings" (p. 269). In this way, understanding of a phenomenon emerges out of a mutual dialogic relationship that Gadamer described as a 'fusion of horizons'. This occurs on many levels through the "co-constitution of foreground and background, parts and whole, interpreter and interpreted, researcher and research participants, data and theory in a circular or spiral form" (Addison, 1999, p. 148).

This understanding of knowledge construction offered a practical way for me to reflect on my history and experience as a palliative care social worker, and to reconsider and

modify the ideas I already had about cross-cultural care in juxtaposition to the information provided by the research participants. Within this process, I also considered how my perspective on culture and health care was shaped by my social location as a middle class, Caucasian man.

Of course, much of what occurs in daily life is so pervasive and taken for granted, it goes unnoticed (Leonard, 1994). Thus, a central task of hermeneutical analysis is to reveal an encompassing and meaningful understanding of a phenomenon that was hidden or unintelligible before — to make something visible “that otherwise happens ‘behind my back’” (Gadamer, 1994, p. xviii). The outcome of this process is the comprehension of a new horizon of meaning that was not apparent before.

The focus of hermeneutic phenomenology on the lived experiences of persons in their everyday lives has direct implications for health care practice. Van Manen (1997) describes hermeneutic phenomenology as a phenomenology of praxis, which encompasses an iterative integration of knowledge and action. He outlines the vocative function of phenomenological text — the idea that it actively addresses the writer and the reader and evokes responsiveness in them. As he (2001) pointed out, “the more vocative a text...the more likely that it communicates complex qualitative understandings that contribute to the practical and ethical ‘knowledge’ of the professional practitioner”, which subsequently shapes his or her actions (p. 469).

The relevance of hermeneutic phenomenology to the enrichment of professional practice is one of the reasons it is so widely used in health research (Benner, 1994; Brykczynski & Benner, 2010; Morse & Field, 1995). As Thome, Esbensen, Dykes, and Hallberg (2004) underlined in their study of the meaning of living with cancer, the main objective of phenomenological research is to “transform personal meanings and experiences...into disciplinary understanding” that enhances professional competency and sensitivity (p. 401). As a social work practitioner and researcher in hospice palliative care, this was another important reason for using a hermeneutic phenomenological approach for this study.

The Research Process

Ethics approval

I received ethics approval from the Behavioural Research Ethics Board at the University of British Columbia. Based on this ethics approval, I also received institutional ethics approval from the Vancouver Coastal Health Research Institute and the Providence Health Care Research Institute to conduct this research in several of their community and hospital sites. Similarly, the British Columbia Cancer Agency allowed me to inform patients at the agency's Vancouver site about this study for recruitment purposes.

Participant selection

The goal of this research project was to develop a rich and contextualized understanding of cross-cultural health care at end of life from the perspective of persons who were living with a life-limiting illness. I aimed to explore the particularity of this experience to understand it well. Therefore, I used a combination of criterion and maximum variation sampling strategies to facilitate recruitment of palliative participants from diverse cultural backgrounds (Patton, 2002). The rationale for using these purposeful strategies was to seek information-rich cases so as to maximize what could be learned about cross-cultural care. Phenomenology researchers may purposefully select multiple cases to identify different aspects of the same phenomenon (Benner, 1994; Creswell, 2007).

The primary criterion for participation was a palliative diagnosis. This meant that participants had been diagnosed with a progressive, life-limiting illness. Secondly, I sought culturally diverse individuals. Culture is conceptualized in various ways, but for recruitment for this project I started with the criterion of ethnicity, which is how it is generally described in health care. However, I was prepared to expand this designation to include participants who identified themselves according to other cultural descriptors or locations. Although I was open to including individuals of all cultural backgrounds, I actively sought participants who were Chinese, East Indian, First Nations, or Western European because they represent the primary ethno cultural groups in Canada generally,

and British Columbia specifically (Statistics Canada, 2006). Individuals who spoke English, Cantonese, Mandarin and Punjabi were eligible for the project. For the three latter groups, I was prepared to hire an interpreter to assist me to conduct interviews and to translate transcriptions. The final criterion for the project required that participants were older than 19 years, and were willing and able to share their thoughts and feelings about their care experiences.

Locating participants

I started the recruitment process by asking third party health care professionals to invite potential participants to join the study. I am well connected through my social work position to a large number of hospice palliative care professionals that include physicians, nurses and social workers in Vancouver. I contacted many of these health care providers in person and/or by telephone and email to inform them about the study and to request assistance in recruitment for it (Appendix 1). I provided information flyers to them to pass on to potential participants; these flyers were written in English and Chinese (Appendix 2). My telephone and email information was included in these flyers and individuals were asked to contact me directly if they were interested in the study or wanted more information about it. Alternatively, potential participants had the option to give permission to the referring professional to pass on their names and contact information to me to contact them. The third party recruiters also posted flyers about the study in strategic locations at their sites. Potential participants were welcome to self-refer to the study after viewing the flyer. The third party recruiters were not informed about who contacted me about the study or became involved in it.

Through the course of the research, 21 individuals expressed interest in becoming involved in it. I followed up with each person by telephone. During this first conversation, I reviewed the research purpose and process, confidentiality procedures and eligibility criteria. When an individual met the criteria for the study and was still interested in participating in it, I arranged to provide them with a consent form (Appendix 3) to review before our first interview. In some cases, I dropped the consent form off at their home or sent it to them by email or ground mail. Arrangements were also made at that time to meet for the first interview. A location, date and time was determined

together according to what was most convenient for the participant. I met the majority of participants in their homes because it was the easiest and most comfortable venue for them. I also interviewed one person in hospital and two people in a research office.

After the initial review of the criteria and purpose of the project, two individuals were found to be not eligible for it, and one person decided not to participate in it. Of the remaining 18 people, the health of eight declined rapidly after they had agreed to participate in the study. For many of these people, interview arrangements had been confirmed, but they became too unwell too quickly to follow through with them. I anticipated this possibility because it is well documented that sample attrition is an inherent problem in palliative care research (Randall & Downie, 1996). It is not unusual for participants to withdraw from a study because of new limitations associated with illness progression. In some cases, participants may die during the course of a research project. These outcomes speak to the difficulty in predicting the trajectories of progressive illnesses and an individual's proximity to death (Christakis & Lamont, 2000; Vigano, Dorgan, Buckingham, Bruera, & Suarez-Almazor, 2000). For this reason, I accepted new participants into the study throughout the project's duration.

In the end, ten individuals participated in the study. This sample size is consistent with recommendations for phenomenological research (Creswell, 2007; Kvale, 1996). Sample size is guided by the purpose of the inquiry, and the quality and amount of data generated by it. Too large a sample can compromise depth of understanding for breadth of information (Patton, 2002), which would have run counter to my goal of developing a rich and in-depth understanding of cross-cultural care. Furthermore, when considering sample size, it is important to take into account the volume of data derived from multiple interviews and repeated observations with the same participants (Benner, 1994).

The participants in the study included six women and four men. Their ages ranged from 33 to 90 years old. Eight participants had cancer diagnoses, one participant was diagnosed with cancer and advanced chronic obstructive pulmonary disease, and one participant had been diagnosed with AIDS and kidney failure. I provide a brief description of each participant at the end of this chapter (Tables 1 – 10).

Data Generation

Interviews

The primary data source for this study was interviews. Kvale (1996) stated that the goal of the research interview is to “obtain descriptions of the lifeworld of the interviewee with respect to interpreting the meaning of the described phenomena” (p. 6). It is an excellent means by which to generate relevant data about lived experiences because it is a purposeful conversation that allows the researcher to become immersed in the participant’s world. Moreover, it is an interactive dialogue about a topic of mutual interest. The exchange is based on a curious and open attitude that focuses on incomplete understandings and misunderstandings, and it aims to achieve comprehensive insights about changes that occur across time and context (Addison, 1999). Because the aim of this research project was to understand the lived experience of health care from the perspective of palliative patients themselves, the use of interviews was a suitable strategy to generate relevant data about it.

I felt well qualified to conduct interviews with the participants about this topic because of my practice experience in the areas of critical and palliative care for the past seventeen years. During that time I worked with many people who were dying, and provided support to them and their families and friends during that process. This clinical background provided me with the skills to conduct in-depth interviews about sensitive issues with care and compassion. I also had had occasions to work closely with interpreters in medical exchanges where individuals and families spoke little or no English. These experiences provided a relevant background for conducting interviews for this research project.

The interviews were semi-structured. I loosely followed an interview guide (Appendix 4) to ask the participants open-ended questions about their illnesses, their experiences of care, their interactions and relationships with health care providers, and their ideas about what was important to good care. I also explored their thoughts about culture and its relevance to health care. I used open-ended questions because they allowed the participants to construct answers that were meaningful and significant to them (Mishler, 1986). A semi-structured format also permitted flexible changes to the order and focus of

the interview questions. This allowed me to respond easily to new ideas as they emerged during the interview, which promoted greater involvement from the participants (Kvale, 1996).

Openness and flexibility in the interviews were also important because of the cultural diversity of the participants. I recognized from the outset that cross-cultural interviewing potentially added a layer of complexity to the project. In short-term studies particularly, interactions with culturally diverse participants are vulnerable to misinterpretations and miscommunications (Patton, 2002). I thought it would be especially important to know what type of questions could be asked without being disrespectful or intrusive.

To that end, I piloted my interview guide with several social work colleagues whose cultural backgrounds reflected those of potential participants. Their feedback was very helpful to identify appropriate questions and strategies for exploring sensitive topics. For example, they offered useful suggestions on how to ask questions about experiences related to serious illness and palliative care because direct inquiries about such topics can be considered inauspicious. Seymour, Payne, Chapman, and Holloway (2007) noted this same concern in their study with Chinese elders regarding end of life care. They found that participants were quite enthusiastic to share their stories when the interviewer stayed close to the topics of significance identified by them. I found that the participants in my study responded similarly. Active listening that conveys a genuine interest in understanding the experiences of participants often concomitantly encourages their willingness and ability to communicate about them (Benner, 1994).

It did take some time to find an effective way to explore notions of culture in the interviews. With the first two participants, I started with some direct inquiries about culture, but this approach yielded a limited response that lacked depth and richness. The questions were too abstract and vague for the participants. As I wrote in a research memo after one of the first interviews: *One of the challenges [for participants] is to talk about 'ways of being' in the world that people don't necessarily think about — that is, 'we've always done things this way'... I can see M struggling to explain the 'taken-for-granted' beliefs and practices in her life because that's exactly what they are — taken-for-granted.* (Research Memo)

In a later entry, I wrote: *I find it difficult to get at people's personal culture — it seems hard to speak about it explicitly.* (Research Memo)

I brought my concerns forward to my doctoral advisors and student colleagues. Through discussions with them and further readings about narrative analysis (Reissmann, 2008), I realized that cultural discourses would become evident during the analysis of the participants' narratives, even if they did not describe them explicitly during their interviews. With this in mind, I changed the interview format and started with inquiries that would elicit stories about their illness and experiences of care. Often references to cultural beliefs and practices emerged spontaneously in these narratives. I then asked questions about culture later in the interview in relation to the stories the participants had already told. For example, I would ask, "How much of what you've described about your health care experiences is cultural?" or, "What would you want your health care provider to know about your culture?"

This approach worked very well, and was reflected in my memos after using this format for the first time: *This was the first interview where I started with questions about the 'story of illness and care'. This flowed very well and at different points S made some connections/linkages to culture on her own. It wasn't until later in the interview that I asked specifically about culture and whether some of what she had described/talked about was 'cultural'. S was able to respond to this question meaningfully because now there was a context for it.* (Research Memo)

Because the goal of interpretive phenomenology is to develop an in-depth understanding of an experience, more than one interview is usually conducted with participants (Benner, 1994). To adequately explore the various care experiences of participants in one conversation is unlikely. Therefore, I interviewed eight participants twice, and in some instances I also spoke to them on the telephone later to clarify certain points of information. I conducted most of the second interviews within a few weeks of the first. I was not able to carry out a second interview with two participants because they became too unwell to do so.

Second interviews provided an opportunity to delve further into the experiences of the participants and to ensure that understanding had occurred. This approach was congruent

with the process of the hermeneutic circle. In preparation, I listened carefully to the recordings of the first interviews and read the related transcripts. I noted key points and questions for further clarification or elaboration. These included contradictions or surprises in meanings that became apparent. I also looked for any avoidance or lack of follow-through on my part regarding particular issues or meanings. I asked questions and offered tentative interpretations during the second interview to facilitate in-depth comprehension and thick description of the lived experiences of the participants.

All interviews were conducted in English, although one participant (Fiona Lee) did have an interpreter present. She moved back and forth between English and Mandarin when she had difficulty understanding me or expressing herself clearly in English. Before I started the interview, I reviewed its focus with the interpreter so she had a good understanding of what I intended to explore in the interview (Patton, 2002). Furthermore, I requested that the interpreter provide full translation of responses as verbatim as possible rather than reporting summaries of information. This was a way of staying as close to the participant's experience as possible. I also relied on the interpreter to help me understand non-verbal communication such as silences or breaks that occurred in the conversation.

All interviews took place between January and November, 2009. They were digitally recorded with the participants' permission. The length of time for each interview ranged from 45 minutes to two and a half hours. The average total time that I spent with each participant was between four and five hours. I transcribed the first two interviews myself and then arranged for a professional transcriber to complete the remainder. She signed a confidentiality agreement before starting this project. The recordings were transcribed verbatim with pauses, repetitions and grammatical errors included. I then reviewed each transcript completely while listening to the recording. Through this process, I checked for accuracy and inserted additional information about non-verbal communication such as changes in tone, volume, or speech rate. The transcripts formed the majority of data for this study.

As a final note, I was sensitive to the various symptoms that the participants were experiencing, particularly fatigue, so I did not ask them to read the transcripts for

accuracy. As described above, I used second interviews and follow-up telephone calls to clarify transcript information and my understanding of it.

Field notes and memos

Other data sources for this study included field notes and researcher memos. I wrote field notes immediately after each interview was completed. The purpose of the field notes was to capture what occurred in the interview beyond the words exchanged. The meaning of a participant's lived experience is not only conveyed by words, but also by their voice tone, facial expressions, posture and gestures during the interview (Kvale, 1996). I described these non-verbal communications in my field notes and included initial reflections on their intent and meaning. I also documented information about the setting of the interview, the participant's physical symptoms, the nature of the rapport established, and how well questions were asked. These observations were important to include in the field notes because they provided further contextual information for interpretation (Patton, 2002). They also added to the thickness of description that enriched later analysis.

In qualitative research, the interviewer is considered a research instrument, who can draw on his or her intellectual, bodily and emotional modes of knowing. Self-reflective and analytic memos are recommended ways for researchers to track their various ideas and reactions as they occur during data collection (Creswell, 2007; Addison, 1999). Therefore, I started to write memos at the beginning of the research process. I included questions, speculations, and musings regarding the data as they emerged along the way, as well as pictures and diagrams that visually depicted possible overlaps and connections among them. I also used the memos to consider my previous knowledge, beliefs, and assumptions. As discussed earlier, the explication of presuppositions is essential to the research process in hermeneutic phenomenology. As van Manen (1997) described, writing about them became an opportunity "to turn this knowledge against itself" in light of other perspectives brought forward by the participants (p. 47).

Both research memos and field notes became part of the data corpus for analysis in this study. A distinct advantage of triangulating multiple data sources is that the data from each can be used to illuminate the others (Maxwell, 2005). Furthermore, unexpected

insights can emerge through their intersection. With this data in hand, I started the in-depth analysis.

Data Analysis and Interpretation

Methods of analysis

There is no single standardized set of analytic methods in hermeneutic phenomenology (Patton, 2002). In fact, it has been said that the method of hermeneutic phenomenology is “that there is no method” (Gadamer, cited in van Manen, 1997, p. 30). Nonetheless, even though scholars may describe their analytic steps differently and use a variety of them, they ultimately base the interpretive process on the hermeneutic circle (Addison, 1999; Benner, 1985; 1994; van Manen, 1997). As Benner (1985) explained, the hermeneutic process of “interpretation entails the systematic analysis of the whole text, a systematic analysis of parts of the text, and a comparison of the two interpretations for conflicts and for understanding the whole in relation to the parts, and vice versa” (p. 9). This process of interpretation reflects a dialogic structure of questioning and answering the data at all points in the research continuum (Gadamer, 1994; van Manen, 1997).

For this research project, I drew predominantly on the methods of thematic analysis described by van Manen (1997) and Benner (1985; 1994). They both described the activity of analysis as a process of ongoing hermeneutic reflection. Van Manen (1997) poetically described themes as “knots in the webs of our experiences” around which our everyday activities are spun and lived through as meaningful wholes (p. 90). Analysis is the circular, reflective process by which the themes that are embodied in the ‘knots’ of the data are gradually unraveled to reveal their meanings.

Van Manen described three approaches to discover these themes (1984; 1997):

- First, he suggests that the researcher start the analysis process with a holistic or sententious approach that includes reading a text as a whole to capture its main significance. This fundamental meaning is then expressed in a sententious phrase.
- In the selective approach, the researcher returns to the text and listens to or reads it several times for sentences or phrases that seem particularly revealing about the

phenomenon or some aspect of it. These parts of the text are then selected or highlighted to illustrate a thematic aspect of the studied phenomenon.

- A more detailed approach can also be used to examine the text in-depth. This includes reading each sentence or sentence cluster in the text and asking what it reveals about the phenomenon. This activity contributes to a rich and nuanced understanding of the meaning of an experience.

Benner (1985; 1994) also described several strategies to reveal themes, some of which overlap with and reflect aspects of van Manen's methods:

- Like van Manen, Benner recommends that the researcher start the interpretive process by reading the whole interview text for a global understanding of the narrative.
- The researcher then identifies a *paradigm case*, which may be a case that they think they understand well or one that is puzzling or unsettling to them. Benner explained that, "paradigm cases are strong instances of concerns or ways of being in the world, doing a practice, or taking up a project" (1994, p. 133). They are used in interpretive phenomenology as *recognition* strategies to advance thematic analysis — that is, once one paradigm case is developed, another case is reviewed on its own and in light of the first case and so on. For example, when a case is identified as distinct because of its thematic clarity or vividness, other more subtle cases with similar or different themes can be more easily recognized. The similarities and differences among cases can be revealed by asking questions about what makes a case noticeable in relation to others. Thus, paradigm cases allow researchers to understand an individual case in its own terms as well as in relation to others.
- Paradigm cases are also an effective *presentation* strategy. When they are used in research projects, they offer readers the "opportunity to engage in the practical world of the participant and come closer to the lived experience" (Benner, 1994, p. 114). Many scholars have used paradigm cases as recognition and presentation strategies in their research (Chesla, 1994; Doolittle, 1994; Mak & Elwyn, 2003; Spichiger, 2010; Weiss, 2010; Wros, 1994). Narrative

reconstructions of particular cases serve a similar purpose (Christ & Christ, 2006; Mount, Boston, & Cohen, 2007; O'Connor, 1997; O'Connor, Phinney, & Hulko, 2010; O'Neill, 2002; Rosenthal, G. 1997).

- Benner outlines that the researcher should also read the text to identify exemplars that will augment paradigm cases and theme interpretation. The exemplars are operational in the sense that they are chosen to illustrate an important aspect of a phenomenon. Their collection and (re)arrangement offer researchers a way to refine their practical understanding of qualitative distinctions regarding the meaning of an experience.

Developing paradigm cases

With these strategies in hand, I engaged in the analysis process. To this point, my dialogue had been primarily with the participants directly. It now shifted to a back and forth exchange with the written text. I immersed myself into the data by reading and rereading individual interview transcripts and field notes in their entirety in order to capture the main significance of the text as a whole. I then wrote a summary of my ideas about the text, which I concluded with a sententious statement that captured its fundamental meaning as much as possible.

As I moved through the different texts, individual cases began to stand out for me. In some instances, specific cases appeared especially noteworthy because of the rich and substantial themes I was uncovering in them. Others caught my attention because they *seemed* to reflect important meanings, even though the meanings appeared ambiguous and vague to me. Benner (1985) pointed out that cases that are perplexing can also be chosen for more detailed analysis even if the researcher is not “able at first to articulate *why* the case stands out or *what it depicts*” (italics in original; p. 10).

Following Benner's strategy of paradigm cases, I chose a case for more in-depth interpretation according to a particular theme that seemed pronounced in the participant's story. I utilized van Manen's selective and detailed approaches to examine the interview text. I coded sections and sentences to capture thematic aspects of the participant's experience, and highlighted exemplars of them. To facilitate this part of the analysis process, I used ATLAS.ti, which is a qualitative software program. It has a range of

functions that enables coding and memo-writing, as well as rapid search and retrieval of data sections. This allowed for easy back and forth movement between segments of data within this case, and eventually across all of them.

I developed four in-depth paradigm cases following these steps. As I did with the first paradigm case, I chose three other participant cases because diverse aspects of the experience of mainstream health care appeared distinct and richly described in their narratives. I used the paradigm cases to make these salient themes visible. The paradigm cases also offered a way to analyze the experiences of participants in their broader socio-cultural context rather than examination of them in isolation from it. As Benner (1985) pointed out, “if attempts are made to decontextualize the meaning [of a phenomenon], then the phenomenon is changed or rendered meaningless” (p. 10). This was important to the analysis because I was especially interested in the personal and cultural discourses that informed the meanings of the participants’ experiences.

I considered each paradigm case individually and then in relation to each other and the other remaining six cases. I did this to flesh out the themes further while also looking to see whether there was anything I was missing. As described above, “the practical world of one paradigm case creates a basis for comparison of similarities and differences” with other cases (Benner, 1994, p. 114). Through this process, I determined that the four paradigm cases highlighted several distinct features of the experience of cross-cultural care that were more or less reflected in the narratives of all the participants. No other primary themes appeared evident and so I stopped the development of additional paradigm cases at this point.

Moving around the hermeneutic circle

Hermeneutic analysis is an iterative and organic process that moves around the hermeneutic circle. However, because of limitations associated with writing about an experience, I realize how linear and predictable the process sounds as I describe it here. As Addison (1999) reflected, it is difficult to communicate “the circular feel of [this] research procedure” (p. 147). In actuality, I moved constantly back and forth among these levels and activities of analysis. To maintain my focus, I kept my research questions at the forefront. I tracked and reflected on emerging themes and continually

cross-referenced them with transcripts and field notes to ensure they were grounded in the data. As I moved through the texts of each participant, I read them for thematic comparisons within themselves and across others. Throughout this process, I wrote ongoing detailed analytic memos to sort through and clarify the meanings of the participants' experiences. Often new interpretive questions or ideas would arise which would take me back to the data and themes. Sometimes these inquiries reflected false starts that I would later drop as more plausible interpretations took shape. I recognized that the rejected false starts still served to advance my understanding (Benner, 1994).

I finally developed my thematic ideas and interpretations further into "phenomenologically sensitive paragraphs" that eventually became chapters (van Manen, 1997, p. 95). This expansion included an ample description of each paradigm case that incorporated exemplars to illustrate the primary themes. I varied the exemplars to bring different dimensions of the phenomenon into view (van Manen, 1997). I then developed an expanded conceptual picture of the experience of mainstream health that brought the various themes together. I incorporated insights and exemplars from the lived experiences of all the participants into this reconstructed depiction. I have presented the four paradigm cases in chapters three to six and the combined conceptual depiction in chapter seven.

Enhancing credibility

As Guba and Lincoln (2005) reminded us, the degree to which research findings are deemed valid allows one to answer the question: "[may I] trust myself in acting on their implications?" (p. 205). Validity speaks to the authenticity of research and the trustworthiness of its outcomes. With this in mind, I took several steps to enhance the credibility of this study.

Scholars offer different descriptions of validity and criteria for achieving it in qualitative research. Polkinghorne (1989) stated that research findings are valid when they are clearly well-grounded, well-supported, and convincing to the reader. To meet these criteria, I included diverse participants in the project so as to elicit a wide range of care experiences. The goal in choosing a variety of cases was to maximize what could be

learned about this experience. I gathered the data consistently and carefully, and followed systematic procedures for analysis.

My aim was to achieve a plausible interpretation of the meaning of the participants' experiences, which Taylor described as the "ultimate criterion for any hermeneutic explanation" (Taylor cited in Leonard, 1994, p. 58). Utilization of the hermeneutic circle to analyze the data facilitated the construction of a reasonable interpretation of the meaning of the participants' experiences of care (Packer & Addison, 1989). Within that process, I solicited feedback from the study participants regarding my interpretations of the meaning of their experiences. Follow-up "hermeneutic interviews" were opportunities to further interpret the significance of those meanings with the participants and to explore any contradictions or ambiguities in the developing account (van Manen, 1997). I incorporated their responses to clarify and expand my understanding. Lincoln and Guba (1985) considered active collaboration with research participants in the development of interpretations to be "the most critical technique for establishing credibility" in a study (p. 314).

Similarly, I had critical "hermeneutic conversations" with my research advisors and other doctoral students regarding emergent themes and interpretations (Addison, 1999; van Manen, 1997). These thoughtful and challenging discussions helped generate deeper insights about hospice palliative care for culturally diverse persons. They offered a forum to move further out into the hermeneutic circle by uncovering interpretations that I had not considered before by virtue of the everyday familiarity that can obscure data when you are deeply immersed in it (Plager, 1994).

Along similar lines, Wolcott (1990) judged the validity of a research project in terms of the degree of enhanced understanding it achieves for the researcher and others. This perspective reflects Gadamer's (1994) suggestion that the validity of an interpretive inquiry is related to the extent that it fulfills its ethical role to move us beyond our given understanding of a topic to a new, more generative one. As I reflect on my experience of conducting this research, I realize I have acquired new knowledge that goes beyond my initial presuppositions.

I also expect that the research findings will resonate with readers regarding their experiences of health care or perceptions of it. Moustakas (1994) identified this type of reverberation as an indicator of intersubjective validity. It is within this interaction that there is an “interchange of perceptions, feelings, ideas, and judgments regarding the nature of reality” (p. 57). This type of affirmation reflects Buytendijk’s (1962) concept of the “phenomenological nod” and Lather’s (1991) face validity that results in a “click of recognition” and a “yes, of course” response. Any of these reactions will strengthen the credibility of these research findings.

Finally, increased validity is also established when the philosophical perspective and specific worldview of the researcher is made explicit (Polkingthorne, 1989). Creswell (2007) referred to Guba and Lincoln’s standard of *positionality* as reflective of this expectation because it requires that “the ‘text’ should display honesty or authenticity about its own stance and about the position of the author” (p. 212). My epistemological position is that knowledge of ‘reality’ is socially constructed through intersubjective experiences within the lived world. I have made this perspective explicit in my description of the research project. Therefore, as I offer my interpretations of the experience of care for culturally diverse persons, I keep in mind what van Manen (1984) said: “a phenomenological description is always one interpretation, and no single interpretation of human experience will ever exhaust the possibility of yet another complementary, or even potentially, richer, description” (p. 40).

Introduction to the Participants

Before I present the four paradigm cases fully in the next chapters, I provide below a brief synopsis of each of the ten participants (Tables 1 – 10). In these descriptions, I include criteria information regarding diagnosis and cultural background. I also include a vignette with an overview of contextual information with the intention of bringing the reader closer to the participants’ lived experiences (Benner, 1994). In some instances, I include my subjective impressions of the participants that emerged during my interactions with them. They offer additional nuances to the uniqueness of the participants’ presentations and experiences. As I wrote these descriptions, I was sensitive to concerns regarding confidentiality and privacy, and have changed or omitted

identifying information accordingly. The first four vignettes I present are of the participants that I chose for the paradigm cases. They include Brenda Harper, Prakash Gupta, Fiona Lee and David Nolan¹. I briefly identify what stood out thematically as especially distinctive in their lived experiences in relation to the other participants. As I mentioned above, I chose the paradigm cases because they highlighted rich and in-depth descriptions of different aspects of the phenomenon of cross-cultural care. In the synopses of the remaining six participants, I highlight additional features of the primary themes identified in the paradigm cases that were also apparent in their experiences. These participants include Martins Firmanis, Mary Kovacs, Nathan Cohen, Frida Bahena, Theresa Wong and Sarah Mah¹.

Although I highlight primary themes and related features in participant synopses, many of them are apparent across the participants' stories and experiences. In the chapter following the four paradigm cases, I combine the primary themes categorically in a conceptual depiction that incorporates exemplars and insights from all the participants' stories.

¹ *All participant names are pseudonyms.*

Table 1. Participant Synopsis: Brenda Harper

Diagnosis	Non-Hodgkin's lymphoma
Cultural background	First Nations
Language	English
Vignette	<p>Brenda is a First Nations woman in her mid-sixties. She communicates in a direct and straightforward manner, and the expression, 'what you see is what you get' comes to mind when describing her. She appeared very reflective and thoughtful during our interviews.</p> <p>Brenda was diagnosed over ten years ago with non-Hodgkin's lymphoma. She draws extensively on her Native beliefs and practices to deal with her illness. She uses the Medicine Wheel particularly as a model to holistically identify and address all aspects of her care. She also uses conventional Western medicine. Since her diagnosis, she has undergone several surgeries as well as radiation and chemotherapy. She relies on these treatments to slow the progression of the cancer and to manage her symptoms — she recognizes that they will not cure the lymphoma.</p> <p>Brenda is not married. She has one adult daughter, who lives locally, and several siblings, who live throughout the province. She lives alone in a rented apartment in a large urban setting. Brenda worked as a counsellor before her diagnosis. She stopped working shortly thereafter and received disability benefits until she recently "retired." At the time of our last interview, Brenda said that several new tumours had recently been discovered by her doctor, which indicated that the cancer was progressing again.</p>
Distinct Theme	Brenda's stories underline the importance of a holistic approach to health care that draws on mainstream and local cultural knowledges ² and perspectives.

² *I use the plural of knowledge to reflect the social constructionist notion that there are multiple ways of understanding the world, or versions of 'truth' about the world, that circulate as discursive products of cultures and history (see Burr, 1995).*

Table 2. Participant Synopsis: Prakash Gupta

Diagnosis	Lung cancer and chronic obstructive pulmonary disease (COPD)
Cultural background	Fijian; Hindu
Language	English; Hindi
Vignette	<p>Prakash was a small man with a quick smile. He was in his mid-fifties when he joined this study. He immigrated to Canada from Fiji about 35 years ago. He was the first member of his family to move to Canada — he eventually sponsored the immigration of several siblings as well as his parents. Prakash was married for a brief time, but this relationship ended in divorce. He never remarried and he had no children.</p> <p>Prakash dealt with lung cancer and COPD for many years. Although he was cancer-free for over a decade after an initial surgery, it recurred in the later 1990s. It slowly spread to other parts of his body while his COPD also advanced. Prakash drew on Hindi beliefs to philosophically make sense of his experience of illness and anticipated death. He regularly combined conventional Western medical treatments with cultural practices to manage his illnesses and symptoms. Like Brenda, Prakash valued a holistic approach to health care. He died several months after my last interview with him.</p>
Distinct Theme	The importance of sharing medical information with patients was central to Prakash's experiences. When this occurs, patients are empowered to collaborate in decision-making regarding care strategies and goals. Furthermore, when the limits of mainstream medicine are reached, patients may feel freer to draw deliberately on minority cultural beliefs and practices to make meaning of their illness and to respond to its progression.

Table 3. Participant Synopsis: Fiona Lee

Diagnosis	Nasal pharyngeal cancer
Cultural background	Chinese
Language	English, Mandarin
Vignette	<p>Fiona was a woman in her late fifties who emigrated from mainland China about 20 years ago. She spoke Mandarin and English, although she was not as confident speaking the latter. During our interview, she moved back and forth between the two languages with the help of an interpreter. She had been married, but her husband died about two years ago; they had no children.</p> <p>Fiona was a woman who had many interests and abilities. She studied physics and math in university and she eventually became a teacher of these subjects. Closely linked to this interest was her passion for creating and solving Sudokus. She was also an avid reader and at the time that I met her, she was completing the edits of a book of a friend's essays.</p> <p>Fiona was diagnosed with nasal pharyngeal cancer in 2004. After the cancer was initially treated, Fiona was in remission for about one year. Unfortunately, the cancer recurred and spread to her lungs shortly after. She experienced numerous and ongoing chemotherapy treatments over several years to slow the progression of the disease. Fiona combined both Western and Chinese medicines to treat her disease. Although she knew that her cancer was very serious, she remained hopeful that it could be controlled. I interviewed Fiona only once. Shortly after our meeting, she returned to China where she died three months later.</p>
Distinct Theme	<p>Fiona's experiences show how important it is for health care providers to offer hope and encouragement to patients who are dealing with a serious illness—even in the face of very unlikely odds. Her stories revealed the need to be reminded that miracles are possible.</p>

Table 4. Participant Synopsis: David Nolan

Diagnosis	AIDS; end-stage kidney disease
Cultural background	Gay man of English background
Language	English
Vignette	<p>David is a thin, 45-year-old Caucasian man of average height. He presented as a talkative person with a good sense of humour. He was very keen to share his experiences in this research study so others could learn from them to improve care for people living with chronic, life-limiting illnesses.</p> <p>David was born in central Canada and describes his cultural background as English and lower middle class. He is a gay man, who lives in a condominium in the Lower Mainland with his partner, Barry. David worked in the computer industry previously, but he has not been employed for many years because of health limitations; he receives a disability income.</p> <p>David was diagnosed with AIDS almost 20 years ago. He has experienced many serious AIDS-related opportunistic infections since then, often multiple times. On several occasions he nearly died. Because of AIDS and treatments for it, he is now also blind. He depends on his partner to escort him wherever he needs to go. He also has chronic renal failure and he undergoes dialysis three times a week at the local hospital. David's illnesses are progressive and he holds no expectations for a cure. He describes his health status as stable, but fragile and vulnerable.</p>
Distinct Theme	<p>David's stories show that culture is fluid and shifting, and that people can strategically present different cultural identities in various health care contexts to achieve their care goals. The circumstances under which goals for quantity and quality of life may alter are also revealed in David's experiences.</p>

Table 5. Participant Synopsis: Martins Firmanis

Diagnosis	Liver cancer
Cultural background	Estonian; Christian
Language	English; Estonian
Vignette	<p>Martins presented as a warm and friendly 90-year-old. I met with him twice in his home. He lived alone in a large two-storey house in an affluent neighborhood in Vancouver. He had been married twice — his first wife died before he immigrated to Canada and his second wife died a few years before I met him. He had one daughter, who was actively involved in his daily life and care.</p> <p>Martins was originally from a small Northern European country. Although he had immigrated to Canada over 60 years ago, he spoke English with the heavy accent of his original homeland. He was raised on a farm in a Christian Protestant household. He spoke proudly of his background and his desire to visit his childhood home one more time.</p> <p>Martins had been diagnosed with liver cancer. At the time of his diagnosis, he was told that he had less than a year to live. When I met him, he had lived several years beyond that prediction — he appeared to enjoy the fact that he was a prognostic puzzle to his doctors. He underwent various treatments, including surgery, since his diagnosis.</p> <p>Martins expressed a lot of ambivalence about the health care he had received. Although he valued Western medicine highly, he also thought that health care systems were often inefficient and ineffectual. Martins drew on his cultural knowledge to make meaning of his illness — his Christian beliefs along with his rural upbringing informed his understanding and acceptance that life is a natural cycle, which includes death and dying. From that perspective, he ultimately accepted the limitations of medicine. Martins died in a local hospice a month after our second interview.</p>
Thematic feature	Martins' experiences demonstrate how people turn to their cultural beliefs and practices to make meaning of their experiences when medicine has reached its limits. Culture offers a philosophical framework to understand dying and death as a natural outcome of life.

Table 6. Participant Synopsis: Mary Kovacs

Diagnosis	Ovarian cancer
Cultural background	Hungarian; Roman Catholic
Language	English; Hungarian
Vignette	<p>Mary was a 67-year-old woman who emigrated from Eastern Europe over 40 years ago. Hard work, independence, and self-reliance were central themes to her story. She emphasized the importance of perseverance and determination in the face of adversity and challenge, which is how she approached all parts of her life, including living with cancer. These values and practices derived from her strong Roman Catholic faith and were reinforced by similar beliefs reflected in her national identity.</p> <p>Mary married at a young age and had two daughters. She ran a retail business with her husband in their home country, which they reestablished when they arrived in Canada. Mary and her husband eventually divorced, although they stayed closely connected over the years when she became his care provider after he was diagnosed with dementia. She believed that family must come together in times of need.</p> <p>Mary had been diagnosed with ovarian cancer several years ago. Since her diagnosis she underwent surgery as well as chemotherapy and radiation treatments. By the time I met Mary, she was in a palliative care unit in a local hospital where I interviewed her twice. She was very enthusiastic to participate in this research study (she had done so before in another study) if it might make a difference to others with cancer. She was an engaging woman, who spoke openly and directly about her experience of living and dying. She was never discharged from the palliative care unit — she died there about one month after our last interview.</p>
Thematic feature	Mary's experience reveals how patients may eventually resist the primary goals of mainstream health care for quantity of life when they determine that their quality of life is too compromised. Her story shows that this may occur even when patients were previously apt to follow the recommendations of their health care providers without question.

Table 7. Participant Synopsis: Nathan Cohen

Diagnosis	Colon cancer
Cultural background	English; Jewish
Language	English
Vignette	<p>Nathan was a 38-year-old Jewish man. He was born in England and immigrated to Canada as a child with his family. He had worked for several years in telecommunications, but stopped working after he was diagnosed with colon cancer. Soon after, he moved back to his parents' home because of financial constraints.</p> <p>I spoke with Nathan several times on the telephone and met with him twice—first when he was a patient in a local hospital and then again in his parents' condominium where he was living. Nathan had a long history with health care systems. As a teenager he was diagnosed with colitis, which required close and ongoing medical monitoring. In his mid-thirties, he was diagnosed with colon cancer. Unfortunately, Nathan's story was a litany of medical mistakes, which he described with frustration and disappointment. He reflected on these mistakes to help him make sense of the otherwise inexplicable “nightmare” in which he felt stuck. He valued expertise, competence, efficiency, and fairness—qualities that were emphasized in his Jewish background. Unfortunately, Nathan did not experience these regularly in his health care. Moreover, he described the health care system as “doctor-centred” rather than “patient-centred”. The last time I saw Nathan, he was dependent on tube feeding for his nutrition and his overall condition was declining. He died four months later.</p>
Thematic feature	The challenges that Nathan experienced in his health care underline how important it is for care providers to communicate directly with patients, actively listen to them, and consider their ideas regarding etiology and their suggestions for treatment to ensure patient-centred care.

Table 8. Participant Synopsis: Frida Bahena

Diagnosis	Breast cancer
Cultural background	Lesbian woman of Chilean background
Language	English; Spanish
Vignette	<p>Frida was a woman in her early sixties, who was born in South America. She fled her homeland after a military coup there and came to Canada as a refugee with her husband. Frida had been an active labour and human rights activist since that time. Because of this background, she especially emphasized the importance of fairness and equity in health care.</p> <p>Frida had a daughter and several grandchildren. She divorced her husband over ten years ago and lived with her female partner in a working class neighborhood in a city in the Lower Mainland. Frida studied nursing and worked in this profession for many years until she became ill. She stopped nursing then and received long-term disability benefits.</p> <p>Frida was diagnosed with stage-four breast cancer four years ago. At that time, she thought that she had only a month to live—a year at the outset. She expressed her gratitude for the time she had since then because she always knew that her diagnosis was palliative. She was focused on pain and symptom management so that she could maintain her quality of life as much as possible as the cancer continued to progress.</p> <p>Frida drew on the knowledges of Western medicine and the folk remedies of her rural upbringing, as well as those learned from other people from various backgrounds, to manage her health. Culturally, she described herself as an “unfinished quilt” with diverse values and practices that contributed to her care. During our last interview, Frida told me that the cancer may have metastasized to her brain—she was waiting for test results. She said she wasn’t quite ready to die, but felt that death might be approaching sooner than she thought. Frida died several months later in her home surrounded by family and friends.</p>
Thematic feature	Central to Frida’s stories is the assertion that mutual respect between patients and health care providers is essential to health care. Both are equal team partners with relevant knowledges and insights that should be similarly considered when determining treatment and care goals.

Table 9. Participant Synopsis: Theresa Wong

Diagnosis	Breast cancer
Cultural background	Chinese; Christian
Language	English; Cantonese
Vignette	<p>Theresa is a small, energetic Chinese woman in her early fifties. During the interviews I had with her, she often spoke very rapidly as the stories she told tumbled out.</p> <p>Theresa emigrated from Hong Kong over 20 years ago. She is married to a Chinese man, and they have two daughters who were born in Canada. Theresa trained as a nurse in Hong Kong and over the years she has worked in various health care settings. Ironically, she was working as a chemotherapy nurse in a large acute care hospital when she was diagnosed with breast cancer two years ago. Since then she has had a partial lumpectomy, radiation treatments and received chemotherapy herself. Unfortunately, a lesion was recently discovered on her liver, which indicates further progression.</p> <p>Theresa is a strong believer in Western medicine. She tends not to use Chinese medicine or other complementary remedies for fear that they might interfere with the effects of Western treatments. However, in some cases she has turned to complementary medicines when their efficacy has been demonstrated through scientific research. This is the same approach that she has recommended to her patients. During my last interview with her, Theresa expressed worry about the lesion in her liver and her ability to continue to take the chemotherapy currently prescribed to her because of its severe side effects.</p>
Thematic feature	<p>Theresa's stories show how health care providers are focused primarily on physical problems and treatments without considering the "bigger picture" of the mental and emotional impact of living with a serious illness and coping with the major treatments for it.</p> <p>Theresa's experiences also demonstrate how cultural identities evolve and change over time as people incorporate and apply different cultural influences.</p>

Table 10. Participant Synopsis: Sarah Mah

Diagnosis	Breast cancer
Cultural background	Chinese; Christian
Language	English; Cantonese
Vignette	<p>Sarah is the youngest participant in the study at 33 years old. She presents as a warm and welcoming person with a quick laugh. She engaged easily during our two interviews and was very reflective as she shared her experiences. Sarah is originally from Hong Kong and immigrated to Canada with her family when she was a young teenager. She currently lives with her parents and siblings in their family home.</p> <p>Sarah was diagnosed with breast cancer when she was 31. Initially, the lump in her breast was identified as a cyst and six months went by before a cancer diagnosis was confirmed. Since then Sarah has undergone surgery, six rounds of chemotherapy and 24 radiation treatments. She now takes oral chemotherapy daily, which will continue for the foreseeable future.</p> <p>Sarah's approach to her health care is holistic and she uses a combination of Western, Chinese and complementary medicines to treat the cancer and enhance her well-being. Sarah's parents have been a significant support to her during this time, particularly her father who has helped her navigate the cancer care system based on his own knowledge as a cancer patient. Although Sarah's health status is currently stable, like David, she described the anxiety that is always more or less present while living with such a serious diagnosis. This uncertainty was evident during our last interview when she said that she would be very interested in reading the findings of the research project if "she was still alive" when it was completed.</p>
Thematic feature	<p>Sarah's stories show how active collaboration with health care providers regarding care planning is important to patients. This includes sharing information with patients and consistently soliciting their ideas and suggestions for treatment. As was the case with other participants, Sarah's experiences reveal how important it is to combine mainstream and local cultural knowledges to provide holistic care.</p>

Chapter 3. Drawing from Two Knowledges: The Story of Brenda Harper

An Introduction to Brenda

On a sunny Tuesday morning, I arrived at Brenda Harper's brown stucco apartment building. It is a large low-rise complex with over 80 suites in a busy urban centre in the Lower Mainland. I scanned the building directory and rang her suite number; she answered quickly by buzzing me through the front door. I walked into the building and travelled down a long hall to the last apartment, where I met Brenda in her doorway. She introduced herself and invited me inside.

Brenda is a Cree woman in her early sixties. She is average sized with short black hair and dark green eyes. She was dressed in navy pants and a burgundy sweater. She showed me into her one-bedroom apartment where she lives alone. It is laid out in an open design with the kitchen, dining area and living room all flowing into one another. There is a set of French doors off the living room that leads onto an outside patio. The doors were partially open and through them I could see a park across the street.

There was a love seat in the living room with a single recliner in front of the television. The TV was turned on, muted and set to the channel station. The colors of the walls and furniture were mostly neutral pastels. Any bright colors came from several prints hanging on the walls. Although the pictures had a Native sensibility about them, Brenda pointed out that the artist was not First Nations. I noticed a dream catcher, but otherwise there was nothing specific that reflected Brenda's Native heritage. Generally, there were not many knick-knacks or personal items in the rooms that revealed very much about Brenda's personal life.

Brenda was diagnosed with metastatic non-Hodgkin's lymphoma in 1998. During the past 12 years she has undergone multiple surgeries, radiation treatments and chemotherapies in an effort to slow down the progression of the lymphoma and to manage the symptoms associated with it. She explained that the cancer cannot be cured and that it is progressive, although apparently slow-moving. Brenda's oncologist predicted an initial prognosis of seven years that she has outlived for some time now.

Recently, she developed some new tumours on her back, which indicates further progression of the disease. She hopes that the radiation treatments she just underwent will slow its development once more.

Brenda had been invited to participate in my study by a counsellor at a community agency that provides support services to persons living with cancer. I had talked with Brenda once before on the telephone. During that conversation, I reviewed the purpose of the study with her and her interest in participating in it. Brenda told me that she had been involved in a previous research project and so she was somewhat familiar with the process. She said that it was important for her to participate in research studies if her experiences might contribute to better care for people living with cancer. She did wonder whether she had “anything to offer” to this study, but as we talked about it in more detail she recognized the relevance of her experiences to the topic.

Once Brenda agreed to become involved, she was keen to set up a time to meet. Subsequently, we arranged for this interview within two weeks of our telephone conversation. After quickly showing me around the apartment, Brenda seemed eager to get started with the interview. We sat at the dining room table, where I set up my recorder. I reviewed the consent form with her and highlighted several key points. Brenda quickly read it over and signed it.

It took some time to establish a comfortable rhythm in the interview. At times, Brenda appeared almost impatient with the questions. Initially, her responses were quite succinct with little elaboration. This was especially apparent as I asked some background questions regarding her diagnosis. She emphasized that she did not remember information about timelines and details associated with tests and treatments: “I don’t remember those kinds of things.” As the interview progressed, Brenda gradually engaged more fully and the scope of her responses expanded.

Brenda explained along the way that she was feeling tired after doing some volunteer work that morning, which may have accounted for her initial brevity. Although Brenda stopped working as a counsellor soon after her diagnosis, she still volunteers weekly at a downtown shelter where she facilitates a support group for women who are homeless, and who are coping with addiction and/or mental illness as well. She said that the group

that morning had been especially intense and had taken a lot of energy to facilitate. I offered to meet another time, but Brenda said she was fine to continue and as we talked more she regained some energy.

Our first meeting lasted for over an hour. I met with Brenda six weeks later for another interview to clarify and explore different aspects of her experiences. Brenda engaged easily and quickly during the second meeting. She looked more rested and relaxed, which reinforced my impression that she had been quite tired during our first interview. Since then, Brenda had located two magazine articles that featured previous interviews with her. She shared them because they included information about her personal journey of rediscovering her Native heritage, which was relevant to what we had talked about during our first interview. I thought the fact that she took the time to look for these articles also indicated her ongoing interest in the study. In the end, I met with Brenda twice and had several telephone conversations with her for a total of about four to five hours.

Diagnosis and Treatment:

If I Was Your Mother, What Would You Recommend?

Brenda began the story about her illness with the discovery of a lump on her neck one Friday evening. She was practicing a stress reduction exercise she had learned at work that day when she discovered the swelling. She said that she was not initially “paranoid” about it, but she did go see a doctor the next day because she did not want to worry about it over the weekend.

[The] counsellors were getting trained in the tapping [method] at work to help relieve stress. It's a method of de-stressing for clients. So I went home after work — [it] was a Friday night and I started [tapping]. I was just reviewing [the exercise] and I tapped and one of them was above my shoulder bone here and I tapped and I felt a little something. I thought that's peculiar. [It was] Friday night — I didn't get paranoid about it but I thought, uh, I just want that off my chest, I don't want to worry about it for the weekend [or] whatever.

So the next day Brenda went to a local clinic. The doctor there referred her to a surgeon, whom she saw the following week. He assessed the lump as inconsequential. Brenda said he was perplexed that she had been referred to him in the first place.

So I went to the surgeon Monday and the surgeon examined it and he said, "Oh, I don't know why they sent you here...it seems to be a lymph node that's, ah, [swollen]. I can't imagine why they sent you here."

With the delivery of this assessment, the appointment was over and Brenda's response was "to forget about it." She appeared to be comfortable with the surgeon's appraisal despite the ongoing presence of the lump. This response was interesting because it reflected how patients may rely on the opinion of medical experts to determine whether something is right or wrong with their bodies, whatever their personal physical experience might be otherwise.

The assurance that all was well did not last long, however. Within three months a new symptom emerged. Brenda began to feel increasingly fatigued, which worried her. Furthermore, the lump did not disappear and was still on her neck. Whereas she had seen a locum physician before, she now returned to her regular family practitioner, who shared her concern about the fatigue and the lump.

After three months, I was quite tired. Very tired. I was still working. So I went to my MD...[and] I told her about it. She said, "I'm going to send you to the surgeon [again]."

At Brenda's request, her family doctor referred her to a different surgeon from the first one she saw. The second surgeon also initially minimized her symptoms in a similar way to the first one — suggesting that further investigation was unnecessary.

And I said, "Don't send me to the same one." So she sent me to another one [surgeon] and he said the same thing — "Oh, I don't know why they sent you here. I agree with Dr. R."

However, Brenda was not prepared to accept this assessment this time. She challenged the surgeon's recommendation to ignore the symptoms, particularly the ongoing presence of the lump, by making her situation personal.

And I said, “Doctor, if this was on your neck, what would you do?” And he stopped and he said, “I’d probably have it removed.” I said, “You’d better remove it then.” And they found out [then that] it was non-Hodgkin’s lymphoma.

Later in the interview, Brenda refers back to this instance as an example of a strategy she now uses when her concerns are not taken seriously by a physician. She has also asked the question, “If I was your mother, what would you recommend?” This approach pushes the physician to consider her symptoms from both a clinical and personal perspective. It appears to refocus the doctor’s gaze to see her as an individual rather than just another patient with a symptom that elicits a rote response. As Brenda points out:

If the doctor just says tadatadatada [each time], he sure doesn’t have to stretch himself, does he? [His response] becomes like an automation and he doesn’t have to improve [his assessment] or whatever.

She learned that this strategy shifts the attention of physicians to consider her person and situation more specifically because she connects it to their own lives.

Unfortunately, the initial investigation also revealed that the lymphoma had metastasized to other parts of Brenda’s body, which left her wondering when the cancer had spread: “[When I received the diagnosis], it had already spread so who knows when it spread? Prior to the discovery [of the lump] or after in the three months interim?” Regardless, when Brenda first heard that she had metastatic cancer, she thought she was going to die imminently. “I thought when I was diagnosed that I would probably die [soon] so I didn’t want to go back to work.” This conclusion was not based on specific prognostic information provided by her physician, but rather appeared to reflect a broader social discourse that equates cancer to death. “I didn’t know that much about cancer and I think many people have that same response. It’s like a death sentence.” Interestingly, Brenda’s physicians did not appear to try to counter this assumption. In fact, Brenda received very little information about prognosis from her doctors. Some general pamphlets were given to her, but she pointed out that unless you ask specific questions, the doctors are too busy to discuss your situation in detail with you: “I’m sure my doctor, my personal MD would have explained it more to me but they’re all so busy all the time.”

Therefore, Brenda attended some information sessions to learn more about lymphoma generally.

I went to a seminar by the Cancer Agency and a professor from UBC explained very, very well how the whole [lymphoma works] — the bad cells and how they hide and tadatadatada... That was [sponsored] by the Lymphoma Society. It was very informative.

Brenda is not motivated to seek prognostic information, however. She explained that she does not find speculation about the future beneficial. She described how staying focused on the present is a more effective coping strategy for her.

I don't know that I want to know about the future: a) because I don't know the future and b) because if I started thinking too much about the future, what am I going to think about? Laying in a hospital where I can't breathe or whatever, full of, whatever. I mean it doesn't, that seems so — that would seem like a real downer to me so I really try to stay in the present.

When Brenda has inquired about the future, she has done so because her daughter wanted to learn more about the progression of her illness.

Dr. L told me [my prognosis] — my daughter actually wanted to go in and ask him how long I had to live — she came in with me one time [and asked], “How long does mom have?”

Thus, Brenda connects her motivation to seek prognostic information to her desire to support her daughter and her information needs rather than her own.

Brenda has received a range of treatments since her initial diagnosis. Almost immediately, she had several lymph nodes surgically removed from her groin, one breast and under one arm. She received about 20 radiation treatments early on and recently several more for new tumours on her back. Our conversation revealed that she has undergone many rounds of different chemotherapies almost continuously since her original diagnosis, although she is currently on a five-month break.

B: *[At first] I had radiation front and back [but] they couldn't contain it. It had already spread...[and then] I had two lymph nodes around my groin area removed on either side with an operation and [then] under my arm on one side and on my breast...and then he put me on, on chemo. Pretty aggressive chemo and I couldn't deal with it. Yeah, I was quite sick and my blood count went really low...*

H: *So you've been having chemo treatments off and on really since the beginning then.*

B: *Mmhmmm. And I had some more radiation too recently [for the tumours on my back].*

The side effects related to the different treatments, particularly the chemotherapy, have been severe. Brenda now requires regular intravenous treatments to boost her immune system because of the combined residual impact of the different chemotherapy treatments.

I have to have what's called ITG. It is to build up your immune system because I got terrible colds over the past few years since I started taking the chemo. So we offset it with the ITG...I go in once a month for three, four months to get that every fall to help me to build up my immune system to fight the infections or whatever.

Brenda did not voice any complaints about the therapies she has received except to say that she had been “quite sick” because of them. She has continued to take them and she has completed the multiple rounds prescribed to her. Perseverance through side effects is a challenge that Brenda appears to accept as a cancer patient. Brenda attributes some ongoing physical symptoms to aging, which may be another way for her to explain and cope with the treatment effects. “I don't feel a 100 percent [compared to before the treatments], I'm aware of that, but then I'm getting older too.”

The Experience of Care: What is Important

You have to be assertive

Brenda relies primarily on the knowledge and interventions of mainstream healthcare providers to combat the physical progression of her disease. She describes how she has “faith” in the expertise and experience of her oncologist and depends on him to make appropriate treatment recommendations and decisions for her: “If it’s Dr. L [oncologist], I have a lot of faith in him [and] his decision making...I go along with it, with what he would suggest.” Brenda underlines how important it is to feel confident in the competency of doctors and their commitment to do all they can to keep patients well.

*I think it is very important to believe and to trust your doctor’s [abilities].
I think that’s really important in the healing. I think [it’s important] —
and it feels like confidence for me — to know that he will try to keep me
alive as long as possible.*

At the same time, Brenda does not naively accept the discourse that depicts physicians as all knowing. She referred again to the time when she challenged her surgeon’s assessment that the original lump on her neck was benign and insisted on a more thorough analysis of it. She gave an additional example of a family member who was recently diagnosed with cancer to illustrate how important it is to be assertive in interactions with health care professionals to achieve particular results and not to assume that they have complete knowledge about individual situations and needs.

***You have to be really proactive** (emphasis is Brenda’s) *in the system. [My cousin’s] been in pain for three weeks and hasn’t asked for any medication. So I said to her yesterday, “You have to ask, they will not.” And to assume that kind of authoritative, doctor authority and he’ll know everything just because he’s a doctor is very naïve. I said, “You have to tell him.” That’s probably where our people are really lacking — [that] is being proactive.**

Brenda pointed out that many First Nations people, especially older people, hold this perspective, which is “an old fashioned perception that [doctors] are above [others] or

something.” She also underlined that there are some doctors who like to be the “boss” and “in control” and so do not counter this perception.

I think sometimes older people think that doctors can mind read. We put them too much up here (gestures high up). Like they know everything. They don't. They are very limited unless you give them some input too, right...[although] I suppose some doctors like [this attitude] for their ego [laughs].

Brenda opposes this “pedastalizing” regardless of who perpetuates it because it makes people passive, and in some cases, like a “victim — I don't think it's beneficial for anybody.”

Brenda's story shows that she has deliberately learned to be more verbal and assertive in her interactions with health care professionals. She sees herself as different from her cohort because of these proactive skills — she describes herself as “a bit unusual within our First Nations people, especially at my age.” She attributes the development of these skills to two processes that were intertwined. First, when she became sober and joined Alcoholics Anonymous (AA) over 30 years ago, she started a process of self-examination by following the AA program and going to “every seminar I could” for self-improvement. Secondly, Brenda deliberately reconnected with her Native heritage, which took her on a journey back to her band. She describes a profound process of letting go of her internal sense of shame of being Native and developing a new confidence as she reclaimed her culture.

I really think first of all one of the important things...is that there was so much shame in being First Nations...I guess somehow as a child I began to believe that there was something innately wrong with me...So it took experiencing — like living, going, and fasting, and learning the things of what we really are, who we really are to be able to let go of that shame. And to know who I am. I guess that's the biggest thing...yeah, just the shame of who I am and then all of a sudden, oh, pride in who I am — my God, this rich, rich awareness and culture.

Brenda spoke about how “society” determines who we are and how we should act. Based on her experience, she views this construction as contrived and inaccurate — it creates differences unnecessarily and can be reshaped. As Brenda reframed her cultural identity, she recognized that First Nations and White people are more similar than either realize.

I think it's letting go of our perceptions of who we're supposed to be, who society says we're supposed to be [that will change things]. Don't you think we're all the same, basically? Like this glass of water. We're all the same...but because we've been given this information in our brain, tadatada, [we think we're different]. So the more that we take away the misinformation, we become similar. Which is what the Caucasian need to do too [laughs]. Oh yeah, get rid of some of that misinformation that they've got.

This insight has been significant for Brenda. The realization that she did not need to buy into the prevailing negative discourses regarding Native identity was liberating for her. At one point she speaks about how “the truth will set you free.” With this realization, she confidently draws on Aboriginal beliefs and practices and combines them with mainstream knowledge to manage her health.

Be prepared: Make a list

With this confidence, Brenda has learned to be assertive in her interactions with health care providers. She asks questions to get the medical information she requires and provides information to practitioners so that they can make adequate assessments and treatment plans — “they can't mind read” otherwise. To facilitate this process, she arrives at appointments with a list in hand that includes questions to ask and information to report. She has developed this strategy because doctors are very busy with limited time. She is conscious of not wasting their time and she has learned how to get the most out of her appointments.

I'll go in there and I'll have a list of whatever I have to get done, okay. I don't take up their time...this is what I'm here for and not here for — these are the things that I need to have looked at.

Brenda has taken on the responsibility of not imposing on the doctor's time. She has accepted the discourse of physician busyness and the subsequent expectation that patients keep appointments focused and short. For example, she pointed out how pleased her new family doctor was when she arrived at her first appointment with a list. "She said that she really appreciated that I have a list. It seemed like she appreciated the fact that I acknowledged her [busyness] a little bit." The doctor's reaction served to reinforce Brenda's continued use of lists for subsequent appointments.

Stay focused on physical concerns

Another way that Brenda has adapted to the expectations of her doctors is by consciously keeping her concerns bounded. Specifically, Brenda includes only physical problems on her list — she does not expect her physician to address psychosocial concerns. In fact, she speaks about this as if it is common knowledge in health care.

Well, it just stands to reason again...if I haven't dealt with my emotional stuff and I go in there to try to get that met at some level, if I'm [looking for] pity or whatever, I think it irritates doctors.

Brenda suggests that doctors may be cautious in their initial interactions with patients if they are expecting more than physical care. Therefore, they may be quick to reinforce the appropriate use of appointment time.

So maybe they have a prejudice against all patients that they're, you know, they're going to take up time [by] feeling sorry for themselves or whatever, I don't know. And then when they find out you aren't like that and just want to deal with what's real and not try to get more, then they seem to really respect that and give you more.

She understands that what is "real" for doctors are the physical aspects of illness. When patients adjust their care expectations accordingly, doctors engage more fully with them. Implicit to this discourse is the message that psychosocial concerns are secondary and not a legitimate aspect of the medical purview.

Attend to psychosocial and spiritual needs in other ways

To compensate for this narrow perspective of health, Brenda turns to her Native knowledge for a broader vista. She believes that well-being encompasses more than physical status.

Oh, [health] is more [than just physical], I mean, because we are more than that. We are. We are four parts, right? We have mental, emotional, spiritual and physical [parts]. That's the way it is.

This conceptualization is based on the Native Medicine Wheel that highlights each of these components. Brenda explained that it is important to attend to all these parts equally for the wheel to be in balance. As she talked about this image, Brenda reached for some paper to illustrate it for me. She showed how some recent changes in her volunteer work have affected all these aspects in her life, particularly the emotional and mental realms. In addition to working at the women's shelter downtown, Brenda also volunteered at a halfway house. She recently stopped going there because of philosophical differences she had with changes to the program's direction.

I'm [feeling] a little bit empty...because I was going out to volunteer at this house and because of something that happened [there]...it didn't agree with my value system so I'm, I'm not going out there [anymore]. But that took up two days, an hour a day twice a week. So that [area in my life] is a little bit empty now...I've not been feeling good since that happened, right...I know that [volunteering] also serves a purpose, hmmm, it fulfilled [a gap]...so as I'm drawing this I'm just realizing how effective [this exercise is in pointing that out] — this is just like the Medicine Wheel...[it shows me that] I need to fill this part with something because it met a real big need for me.

Similarly, Brenda reflected on the experience of a friend who had recently died, and the significance of a spiritual gap in her life.

B: *Like my friend the doctor that I met at the retreat, she just died a couple months ago or whatever, right. And she had all this knowledge.*

H: *About the disease, you mean?*

B: *About the disease, yeah. But do you know what she was seeking at the end? She was seeking, like, spiritual guidance. So to miss that, I guess, would be to miss a big part.*

H: *[It] sounds like part of the [healing] work then is trying to put [all four] pieces into balance if they're out of balance.*

B: *I would think so, yeah. [But] a lot of people just discover it at the end. For instance, their spiritual [needs], right. Or they're only willing to go there at the end — that's what I've seen anyway...*

She spoke about the experience of her friend with sadness. It illustrated how illness affects people multi-dimensionally and not only physically. Unfortunately, these aspects of care are not always adequately acknowledged or fulfilled by patients themselves or their care providers.

Generally, Brenda does not turn to mainstream health care to address her mental, emotional or spiritual needs. Instead, she follows the guidance of the Medicine Wheel and draws on Native beliefs and practices to promote healing in all parts of her life. She talked about how she participates in Native “ceremonies” as often as possible, which she compares to going to church or temple for others. She goes to sweat lodges at different times as well. She seeks out medicine people and receives healings from them in the form of prayers and special medicines.

I go to medicine people. I've certainly had healings from medicine people [for the cancer]...[There's] a protocol you go through to approach them to ask them to do special prayers for you and they will be guided if they're going to brush you off or whatever they are going to do. Or give you medicine even. I've taken different medicines too [given by the medicine people].

Brenda described how these cultural practices, particularly going to ceremonies for healing, have become more important since her lymphoma diagnosis. “I go every time I

can.” Brenda did not tend to share this cultural information with her doctors for several reasons. First, she stated that there was often no time to do so during her appointments.

[For example], Dr. L is so fast. I did tell him that I went to [a retreat], right. [I’m not sure] he could retain it because he’s very, very fast. I mean, you’re in there, boom, and then out.

Brenda explained that she has talked about her participation in Native ceremonies with two of her previous family doctors, although also because of limited time, not often or in detail: “We would have a little bit of conversation.”

Secondly, Brenda’s decision to share this information is also related to whether she thinks her physicians will be judgmental or supportive of her cultural activities, which is something she determines as she establishes a relationship with them and gets to know them better.

B: *I had a very good doctor in [the Valley]. I just got a new one here not very long ago so I don’t know her very well. But certainly the MD I had in [the Valley] and the other one in [the Interior] were very supportive of my ceremonies and stuff. But we would have [only] a little bit of conversation [about it].*

H: *Would they ask you about [these things]?*

B: *No, we just developed a relationship so I would tell them [sometimes].*

Brenda said that she would talk more about these activities if asked about them. However, Brenda’s story suggested that it did not really matter to her whether her doctors were aware of, or endorsed, her Native healing practices.

In some instances, Brenda did attempt to meet her mental, emotional and spiritual needs through mainstream health care agencies and services. For example, she attended different support groups, workshops and retreats over the years. She found that those with a holistic focus were most helpful to her.

B: *I heard about this [community support group] through a friend, whose friend had died and who had gone to [this group]. And I really respect*

this man. And when he told me about it, I thought, that sounds good. And then I went on a retreat.

H: *So you've done one of their retreats.*

B: *Yeah, and I'm going to do another one in September [because] they certainly look at all parts [of your life].*

However, this comprehensive focus was not the norm for other mainstream groups that Brenda attended. Often discussions centred on an exchange of information about cancer progression, symptoms and treatments, and nothing else. Brenda was more interested in learning from others with cancer how they improved their health — for example, how diet and exercise was helpful to them. Brenda was interested in learning how she could become an active participant in her own healing.

Like [learning] basic knowledge about food and what I shouldn't eat and exercise — all that stuff. [It's] very informative and it's good, but what type [of cancer] I have and what phase I have and what does that mean — I don't know that that would do me much good...I went to a couple of groups at the Cancer Agency and I didn't find it too, um, helpful. There were a lot of people at all different stages and they seemed to be [focused on medical information] — I came out of there feeling less well than when I went in. I mean if they are going to do a group, I think there should be something [said] about attitudes...maybe some [participants] don't understand how to be positive and how to deal with their emotions or stuff.

Brenda also wondered how equipped health care professionals are to address emotional or spiritual concerns of their patients. For example, she did not find the social worker at one of the clinics she attends as “very effective” in addressing these areas. Again, Brenda cites the busyness of health care professionals as a possible reason (or excuse) for the limited holistic services offered by them. “I don't know if they don't have the time or...they don't have the training.” Later, Brenda spoke about how physicians may not consider other components of well-being because they are not aware of them within themselves.

I wonder that they just don't know [about other needs] either. They just don't have an awareness of it because...I mean, it's constantly up here, isn't it (pointing to her head).

Brenda suggested that this intellectual preoccupation is not unusual for most people: “that’s our society though, isn’t it?” Brenda points to a dominant social discourse that values intellectual knowledge over emotional or spiritual experience.

Recognize the value of diverse knowledges and practices

Brenda provided an example of how she brought the knowledges and practices of Western medicine and Native culture together. She described how she would take sweet grass to her radiation treatments to support herself emotionally and spiritually.

I would imagine smudging the whole place and smudging the instrument that they use to give the radiation...I wanted to obviously look after my emotional and my spiritual [needs]...and my mental [needs] when I was there.

Brenda also intended to augment the “power” of the radiation to physically benefit her as much as possible by attending to these other dimensions simultaneously.

Brenda did not feel that the clinic technicians respected her cultural practices. They were focused on completing the steps of the treatment and were unaware or indifferent to Brenda’s efforts to create a healing environment for herself. “They’re so focused on [their technical stuff]...I don’t think they even cared or noticed hardly [what I was doing].” Brenda confronted them about their behaviour.

And I didn't like their attitude. So I remember saying to them, “Excuse me, but this is my life and I don't want this kind of environment.” Because I would be praying and stuff when I was lying there. And I would take my sweet grass, right. So I wanted the environment really nice...soft music would have been nice...meditative music.

Brenda wished for a respectful and calming space where she could practice her cultural activities safely. At a later point, she talked about the risk involved in sharing information about cultural beliefs and practices with health care providers. She said she

is very careful about doing so because “it’s too precious for me to have it negated, misunderstood, or whatever.” In one instance, she required some medical attention because of a cultural ritual she participated in previously. She expressed how she did not want her doctor “to inquire about it or say how come [she partook]...I wanted somebody to understand.” When Brenda told this story, I recognized the importance of trust in cross-cultural care — to know that you will not be judged or questioned about cultural activities. The fact that Brenda had a positive relationship with her family doctor allowed her to safely share cultural beliefs and practices that contributed to her overall well-being.

Although Brenda initially did not identify a holistic approach to care as something she would expect from her physicians, she began to re-think this opinion as we talked more. She recognized that part of the reason that she did not turn to mainstream health care services for holistic support is because she had other options to meet these needs. She drew another picture to illustrate the various resources that contributed to her healing.

So if that’s my healing (drawing a large circle) so to speak, right. Then having confidence in Dr. L is an aspect of that healing, but there are many other parts to it, eh. That’s one. I don’t know how big it is. I haven’t thought about it before now. But it’s one part. There is also where I go to ceremonies for healing, the healing ceremonies, okay, for spiritual [needs]. [And] the sweats. There’s so many.

As Brenda identified the various resources available to her, she realized that not everyone has the same access to them. It was like a light went on for her when she realized this inequity.

But what about my [cousin] who may not [have these options]? How wonderful it would be if her doctor would say, you know, “Are you looking after your emotional? Maybe this is where you can go to get some help about it.” Because she has no awareness [of this need] and she doesn’t let me tell her. She’s older than me. Or your spiritual [needs], right. “Are you looking after that?” What a wonderful opportunity.

She suggested that the Medicine Wheel can offer a functional template for this discussion.

I think of what we use most, First Nations, [we] use the Medicine Wheel, right? Which is just a circle divided into four [for] looking at the four aspects: physical, mental, emotional, and spiritual. And then looking at maybe what the needs are within that circle. It would be so simple to start a dialogue [from there].

In this way, Brenda recognizes that her culture has something tangible to offer to mainstream health care. That this approach is not recognized or valued seemed to surface at various times in her story. For example, as she talked about it further, Brenda expressed her frustration that physicians did not inquire about these different parts of a person's life, particularly because their recommendations carry weight with them. "It makes me kind of angry because they've so much power, so much influence." Although Brenda suggested that other health care providers such as social workers could also explore these areas with patients, she believes that it is especially important that doctors do so as well. My interpretation of this suggestion is that the doctor's position of authority in health care imbues these other components of well-being with significance that patients will take more seriously. She concluded that for physicians to be more "responsive to the four areas [would enhance the] quality of life" for a person who is ill.

Be compassionate. Be present. Be personal.

Brenda identified several other attributes that she believes are essential to good care. She spoke about the importance of compassion, especially in the face of ongoing decline. For example, she described how her oncologist does not say 'no' to people regardless of how busy he is or sick they are.

There was a woman in the next bed to me [in the hospital]—she was treated at the cancer clinic and they told her to go home and die, kind of thing. And she went to see him and he took her on.... Now people can say that's just because he wants to make money or whatever. I don't know. [I think] maybe he has a lot of compassion.

As noted above, Brenda was reassured by this event because it signified to her that her doctor will do all he can to keep her alive. What is also implicit in this story is the

importance of maintaining hope even at the end of life. At the same time, Brenda expects her doctor to be “upfront” and honest when further treatments are no longer possible.

Furthermore, Brenda emphasized several times how important it is for health care professionals to be “present” in their interactions with patients. She spoke about her experiences with practitioners who seem to work on the setting of automatic pilot — who are not engaged with the individuals to whom they are providing a service. She contrasts this to her experience with her oncologist.

*He looks at me...[he] shakes my hand and holds it. And he says, “Hi, Brenda, how are you?” And it’s just a feeling I get that he is **completely involved** (my emphasis) in my case and sometimes I’ve seen him look up—like this other doctor wasn’t going to give me a treatment...and he looked up and it was like he went to an intuitive place and he said, “I’ll do that myself.” So it’s so small those things, but they’re enough for me.*

Brenda describes an experience of real connection with her doctor that is established through eye contact, physical touch, and carefully listening to her. She also values his intuition, which she interprets as spiritual knowledge: “I think he uses a lot of help if you will, from Spirit or whatever you want to call it.” This approach overlaps with, and connects to, her Native beliefs. Furthermore, she points out that the ability to be present in interactions does not correspond to the length of time spent with a patient.

I mean Dr. L is very fast, okay. But when he is with me he is present for that very short time. That’s my sense. Whereas another doctor could spend half an hour with me and not be present.

Finally, Brenda also talked about how relationships with health care providers became stronger when she challenged the rigidity of professional and patient roles by expanding the boundaries around them. She spoke about how she would inquire about her doctor’s children, or send a card or bring flowers to an appointment to express her appreciation for their care. This was a way of connecting with her doctor as a person — not just as a professional. It is not only important for Brenda to be viewed as a whole person, but she also needs to see the people who provide care to her as complete human beings too.

I watch the doctors and they said the same thing — that they like people sending them a card or something, acknowledging them...I guess their humanness is always there.

Similarly, this is what Brenda also feels is acknowledged in her when practitioners pay full attention.

Main Points

Brenda has lived many years with a palliative diagnosis and her lived experience reveals several important aspects of health care relevant to people living with a life-limiting illness. First, Brenda demonstrates how new skills and behaviours can be deliberately chosen and developed to meet care needs within mainstream health systems. For example, she adopted a proactive approach with health care professionals that included becoming more assertive in her interactions with them. She also accepts and relies on her doctors' expertise to treat her disease, but rejects the medical discourse that defines health only in physical terms.

Brenda draws on the Native Medicine Wheel to conceptualize a broader framework of well-being that also includes mental, emotional and spiritual dimensions. She has developed a holistic approach to her care that combines mainstream interventions that focus on countering the physical progression of her disease with Native beliefs and practices that address her psychosocial and spiritual concerns. By doing this, she challenges the prevailing perspective of an all-knowing physician and forefronts her own experience and expertise regarding her needs and care. However, the authority of physicians does place them in a unique position from which they can promote holistic care and advance a discourse that supports it. She recommends the Native Medicine Wheel as a template for health care providers to use to integrate the perspectives of Western medicine and Native health together.

Finally, Brenda describes a number of features that are essential to good hospice palliative care. She identifies compassion, engagement, open-mindedness and competency as important professional attributes. These qualities are universal and cut across cultural differences. Brenda's experience also points to the importance of

respectful attitudes and supportive environments to create a sense of safety for patients to explicitly introduce their cultural beliefs and practices into mainstream health care settings.

Brenda's story shows how she successfully combines the knowledges of mainstream health care and Native culture. By doing so, she has been able to identify and address her diverse care needs in different ways to achieve ongoing quality of life in the context of progressive and terminal illness.

Chapter 4. Learn the Right Way, Get the Right Results: The Story of Prakash Gupta

An Introduction to Prakash

Prakash Gupta was a small man with a big smile and a twinkle in his eye. He was 57 years old and originally from Fiji. He had just turned 19 when he immigrated to Canada in the fall of 1971 with “\$50 in my pocket” and no “winter jacket.” He arrived by boat to Vancouver when “the downtown harbour was just wooden planks.” He had no family here and knew no one. He had come to Canada with the belief that he could make a better life for himself here.

He rented a small room at the YMCA downtown. Once he was established there, he started to search for a job, which he found at a McDonald’s restaurant within a few days of his arrival.

McDonald’s had just come into Canada. One shop was downtown, one in Richmond, and the other shop then just opened up near Surrey Place, near Whalley. So I used to take [the] bus and go and work there for three months.

This marked the start of Prakash’s life in Canada. He used the job at McDonald’s to ensure that his basic needs were covered as he looked for other opportunities.

As it turned out, Prakash’s time at McDonald’s was short-lived. He soon found a new job that launched his career as a mineral analyst for mining companies. He described how he would go to the “Manpower office” during his breaks at work to look for a new job — something that would pay more and be more interesting than standing behind a grill cooking burgers and fries each day. He was ambitious in his desire to get ahead and was prepared to work hard to do so.

And I used to have four-hour shifts — two hours, an hour break — then another two hours. So I walked over there [Manpower office]. And there was this opening for a lab technician in Port B so I went for it, and I got

it...so I ended up in Port B for eight years in the camp...that's where I got my training, you know.

Since then, Prakash worked at various mining sites in different parts of western Canada. Many of these locations were in remote areas where he lived in both small camps with just a few workers and in very large mining compounds with hundreds of people.

Part of Prakash's motivation to pursue this career was to establish his financial security quickly so that he could sponsor the immigration of other family members. Over the years, he helped several siblings to join him in Canada. Eventually he managed to bring his father and mother as well. They arrived in the early 1980s and lived with him until their deaths — first his father in 1985 and then more recently his mother in 2007. Prakash was his parents' primary provider and caregiver during the time they lived with him and especially as they declined in health.

I was looking after my mom. She just passed away last — two years ago. Right in my arms. So my time was more dedicated to her...[to] take care of her. Same thing with my Dad when he was around, right.

Prakash assumed this role without question because he was the eldest child in his family. He explained that filial responsibility was expected in his culture. The expectation that family members look after one another during times of need was one that also emerged later in Prakash's story about his own illness.

Prakash lived alone in a house in a Lower Mainland community. He had several brothers and sisters who lived locally and who were in regular contact with him. He described his family as very close, with daily telephone conversations or visits.

Phone calls start coming 10:00 in the morning every day — 10:00, 11:00, everybody checking on me, right. And then 8:30, 9:00 [in the evening] they all check on me [again]. So it's been going since my mom was around, they're still doing the same thing.

Prakash did not have children. He was married for a brief time in the 1980s, but this relationship was short-lived. It eventually ended in divorce.

Prakash was invited to participate in my study by a member of a community hospice team. He received care at home from a palliative care physician, home care nurse, hospice volunteer and home support worker. Prakash received these services because he had lung cancer and chronic obstructive pulmonary disease (COPD). Although the lower lobe of his right lung was surgically removed when first diagnosed with cancer in the 1980s, he was not a candidate for further surgery, radiation treatment or chemotherapy since its recurrence in the mid 1990s. Consequently, the focus of care since then was on symptom management that included efforts to mitigate Prakash's experience of chronic coughing, pain and shortness of breath. Prakash lived for many years with lung cancer, which was an unusual length of time with this diagnosis.

I met with Prakash twice and spoke with him on the telephone several times for a total interaction of about five hours. My first contact with him was on the telephone. I was immediately aware of his symptoms while we talked — our conversation was broken up with frequent episodes of coughing followed by several moments of Prakash catching his breath. During this first phone call, I reviewed the purpose and process of the study with him and he quickly agreed to participate in it. Later he talked about the importance of research and particularly the value of exploring the experiences of individuals that did not reflect medical predictions.

[Suppose] someone is supposed to be palliative in six months, but he managed to go for, let's say, eight [years], six years or four years or five years or whatever...let's find out what this person is doing or whatever. While he should be going down the drain fast but he's not. There must be something [to explain that], you know.

Prakash saw himself as part of this group of exceptions — “mine is a unique case so it doesn't flow with the general flow,” which was his motivation to become involved in this study. He believed that there was something to learn from his unusual experience of living so long with a palliative diagnosis. We arranged to meet for our first interview at his home shortly after this initial discussion.

When I walked down the street to Prakash's home for our first meeting, I noticed a house that stood apart from the other bungalows on the block — it was a striking two

storey home that looked recently renovated. I was curious about it and as I made my way along the road I wondered whether it was Prakash's house, which, in fact, it turned out to be.

Prakash greeted me at the front door. He was dressed neatly in a tracksuit. When I went inside, I shared my positive impression of the house with him, which appeared to please him a lot. He explained that he had indeed completely renovated it in 2003. The house was unique because it was an early prototype for energy efficiency. Prakash quickly pulled out several magazine and newspaper articles that described the progressive features of his home. He then invited me on a tour of it and pointed out its special characteristics. Each room we entered was very neat and clean. I learned later that this was especially necessary because Prakash could not tolerate any dust because it exacerbated his cough and shortness of breath. As Prakash talked about his house it was obvious how proud he was of his home and the innovations he had introduced into it. Prakash's initiative to do what he could to improve his health and manage his symptoms, which was reflected in the creative design of his house, was a theme that ran through his story of living with lung cancer and COPD.

We eventually returned to the living room for the interview. This room was dominated by a huge, built-in entertainment unit that included a 50" flat screen TV. There was also a fireplace and a big wood coffee table surrounded by two leather couches. On the walls, there were family pictures of Prakash's parents and brothers and sisters. Prakash explained that he watched a lot of TV because of the limitations related to his illness that kept him home much of the time. Hence, making the living room comfortable for himself was a priority.

We continued for a few moments with small talk and then turned to the purpose of the visit. Once more, I reviewed the research project with Prakash and completed the consent form with him. When I turned on the recorder, I noticed his demeanor change somewhat. He seemed more self-conscious and initially less expansive in his responses to my questions. Whereas previously he spoke quite openly and easily, he now seemed more reticent. He appeared to find the recorder distracting — his eyes kept going back to it. After a few minutes into the interview, his focus on it diminished and he seemed to

forget about it and resumed his earlier flow of story telling. Our interview went for almost an hour and a half. None of this hesitation was apparent during our second meeting — Prakash seemed as comfortable with the recorder turned on as he had been previously with it turned off. I felt that we had established a positive rapport that enhanced the depth and scope of our dialogue.

Diagnosis and Treatment: Nothing More Will Work

Prakash began his story by describing how healthy he was when he first arrived in Canada. He pointed out that his medical examination prior to immigration showed that “there was nothing” and that his health was good. This was confirmed by a regulatory chest x-ray he underwent before he started his first mining job several months later. He explained that shortly after starting to work in a laboratory he developed a cough, which gradually became chronic for him. For several years thereafter, annual check-ups and x-rays continued to be clear despite the persistence of his cough. Prakash carried on with his regular work with the understanding that there were no serious medical concerns in the face of this ongoing symptom.

When I came to Canada in 1971, I had my medical; there was nothing so I had clearance to come to Canada. So I was okay. Then I started working in the mine. Within, within a month's time I started coughing and things like that. And then every year I had a medical x-ray for mining reasons. I also had an x-ray [cough] before I started, which was a regulation [of the] Mining Act [cough]. So there was nothing. And after a while I started having these coughs and all that.

Prakash emphasized his healthy status prior to the start of his employment because he attributed the diagnoses of cancer and COPD to his work environment and experiences. “Basically, I think I had it through exposure to work in the mining. But up to today the WCBS [Workers’ Compensation Agency] have not accepted it as a work-related case.” Later Prakash explained that the Workers’ Compensation Agency did eventually agree that the etiology of his COPD was work related, but it continued to deny his claim that his diagnosis of lung cancer stemmed from similar reasons. In this case, the

interpretation of the agency overrode Prakash's explanation about his illness. Therefore, he received only a partial workers' disability pension.

As was the case with Brenda Harper initially, Prakash's worries were generally allayed by the physician's positive assessment even though he was coughing on a daily basis. For many years, Prakash accepted the medical opinion that 'all was well' as an accurate appraisal of his physical status even though his symptoms continued. All this changed abruptly in 1980.

One day I started really having a lot of coughing and pain. So I went to the doctor and he did a, send me for [an] x-ray. So on Thursday I went for an x-ray, on Sunday I ended up in the [hospital] with [an] operation ...I had a bad case of bronchitis and they found that I had [a] huge, uh, tumour, size of a goose egg — with tentacles. When they opened it up they found it to be quite massive. So they removed my lower lobe.

Prakash described this event in a matter-of-fact way — as a singular experience that was quickly and efficiently resolved. As it turned out, the surgery was successful and Prakash was cancer-free for many years. He returned to work a few weeks after his operation: "I have to go back to the work again and I got more exposed to chemicals and fumes and all that." He carried on in the same field for many years even though his COPD continued to worsen.

In 1996, a biopsy revealed that the lung cancer had recurred, which was reflected in new symptoms of fatigue, anorexia and pain. Prakash's oncologist determined that neither radiation nor surgery would be beneficial to him because of the type of cancer he had and the way in which it had spread. He also would not be able to tolerate chemotherapy because of his compromised physical status related to years of living with COPD. Prakash explained how the physicians said that "they can't do anything for me," so the focus shifted to symptom management: "I just went for more medication for pain and all that."

According to Prakash, curing his disease was perceived by his doctors as the only way of "doing something" for him. To not have the capability to resolve a medical problem appeared to translate into not being able to "do anything" for a patient, which was the

message conveyed to Prakash: “nothing would work on me because they said, you know, these are the alternatives but, you know, nothing will work for you, unfortunately.” Pain and symptom management, which is central to palliative care, appeared conciliatory in this scenario compared to the elevated purpose and activity of acute curative medicine. What Prakash subsequently deciphered from this attitude is when you are deemed palliative, you are just “buying time.”

Semi-annual scans revealed that the lung cancer continued to slowly advance. Recently, changes were observed in Prakash’s liver and kidneys, which suggested that the cancer was now spreading to these organs. Prakash described how his doctors have been stymied by his overall stability in the face of ongoing disease progression: “They looking at the CT scan and they’re looking at me and they can’t figure out. They say, you know, you should have been cremated long time ago [chuckles].” Although the physicians have been perplexed by Prakash’s longevity, they seem minimally interested in uncovering explanations for it. Prakash recalled two previous conversations with doctors about his stable status:

[They] just said, you know, it’s good you’re going, working, looking good, whatever. Wish we had more patients [like you], you know. They ask me how come, you know. I says, “I don’t look at it that way. I just ignore it, the fact that it is cancer.”

Beyond these cursory comments and inquiries, further information or investigation was not sought. In fact, Prakash stopped seeing an oncologist because he was not receiving any curative treatment for his cancer. He was followed primarily by his family doctor, who monitored his status and attended to his various symptoms: “We don’t even talk about cancer...I just talk to him about my bronchitis or medication, that’s all.”

The Experience of Care: What is Important

I’ll make the final decision

Prakash emphasized how he wanted the “facts” all along the way regarding his disease and the treatment options available to him. He expected his doctors to make recommendations for treatments according to their knowledge, but he would then “do the

dissecting and postmortem” himself, i.e., make his own decisions for ongoing interventions based on his experience of them. For example, Prakash made the final decisions about the medications he took for symptom management according to the side effects they generated.

I was on five or six different medications. Painkiller, depression, and all that. I cut them all off slowly.... One of them was giving me, uh, metallic taste so I deleted that. Another one gave me constipation, the other one dizziness. So they all had side effects. Some of them, three of them had, you know, extra [side effects] — like vomiting, nausea.

He pointed out that doctors will often prescribe a number of different medications for various purposes without careful consideration of their interactions and the cumulative side effects that may become very difficult for patients to tolerate. In some cases, all the medications may not be necessary.

Doctors will say, ‘well, try this, try that, try that’, right...when you consider [the] whole bunch of these side effects from this medications, and [then I figure out] I can manage with two of these...[and] I’m doing much better. [The] accumulative side effects would be too — was too much for me.

As Prakash summed up, sometimes “the side effects are worse than the cure,” resulting in a diminishment of his overall quality of life.

Prakash experienced different reactions from his doctors regarding his desire to make final decisions about treatment choices. He explained that his family doctor did not support this approach while his palliative care doctor encouraged his active involvement in decision-making. Prakash felt that his GP was of “the old system” where the patient was expected to simply follow what the doctor tells him or her to do. He linked this perspective to his family doctor’s role as a “professor and lecturer” at the university. He suggested that “they [university professors] tend to be more on the, you know, the gold standard old system” there — and by implication, not keeping up with the changing reality at the front line. On the other hand, he described the palliative care doctor as more open-minded — “he’s very flexible...he thinks more in a wider scope than just a very

narrow window.” He emphasized that it is this approach “that fits fine with me.” The support of Prakash’s palliative care physician helped him maintain his active role in decision-making despite his family doctor’s resistance to it. He communicated his wishes clearly and directly to both physicians.

[At] the end of the day both my doctors [know], if I want, you know, I’ll have the final say. That I’ve told them, you know, already in very straight and simple terms — at the end of the day I’ll make the final decision.

Prakash used the support of one doctor to counter the opinion of another physician to reinforce his actions in other instances as well. For example, he talked about how his mother’s geriatrician questioned his decision to send his mother to the local emergency on several occasions to treat her symptoms. He spoke to the emergency physician about this reprimand, who reassured him that he had done “the right thing” to call 911 at those times.

He says, “You made the right move. This is what we’re here for and this is what emergency [department] is for. Especially [an] emergency with high blood pressure and all that.” So that was a difference of opinion, you know. One doctor, the one who was visiting my mom at home, he’s not too happy because I’m taking her to another place [emergency department]. While the people over there, they said you made the right decision...it was their opinion [too].

Prakash was assured that his actions were medically justified, which appeared to be the most important criterion to him for evaluating the decisions he had made. Therefore, he viewed the emergency doctor’s opinion as more valid than the objections of his mother’s doctor, which seemed to reinforce his confidence to counter his opposition.

Nonetheless, there were exceptional circumstances when it was not possible to participate in treatment decisions. At those times, Prakash relinquished decision-making to the physician and accepted the consequences. This was the case when he urgently required surgery in 1980. The surgeon did not outline other possible options to Prakash before the surgery, and Prakash did not expect such a discussion. Instead, he relied on

the doctor to make the best decision in the moment, which in this instance was the removal of his right lower lung.

H: *It sounds like the, the surgery [removal of lower lung] was a decision that was made by the doctor at the time.*

P: *Mhmm, of course, yes.*

H: *And were you a part of making that decision?*

P: *No, at that time I wasn't, no. He just said, you know, you got a problem you might have to fix and that's all. And so we might have to operate [and take a part of the lung away]...so be it.*

Prakash expected the surgeon to take charge given the uncertainty of the situation and the fact that something had to be done quickly because he was so seriously ill. Even though Prakash lived with significant residual side effects from that surgery many years later, he accepted them as an unavoidable outcome of a necessary procedure that was aimed at keeping him alive.

H: *And the pain is in the chest?*

P: *In this side. And back whole, my body, you see it — when I had my first operation [it] is opened up from here [he traces a line from his chest to the back].*

H: *Oh, I see — so from the front right to the back.*

P: *Right. So my shoulder sort of dropped, you see.*

H: *I see.*

P: *Where they cut you up and patch you it's misaligned so this whole thing is misaligned some time. A lot of pain in that way too, muscles are all pulled [unevenly]...and when I'm coughing too, two metal pins there, they are rubbing in the ribs, so that's another [source of pain].*

Prakash's experiences indicated that participation in decision-making varied depending on the circumstances. In critically acute situations where decisions were potentially a matter of life or death, Prakash unquestionably deferred to the expertise of the doctor —

this position was taken for granted by him — “of course” the doctor decides. However, decisions about less urgent matters were not so unilateral and were also shaped by the knowledge and experience of Prakash. Furthermore, Prakash had potentially more opportunity in the latter situation to participate — even when medication was prescribed by a doctor, he could decide in the end whether to take it or not for his own reasons. Conversely, he could not direct an operation on himself while it was occurring.

Give me the facts

Prakash’s ability to make relevant decisions about medical care and future plans was only as good as the information he received about his illness. He strongly emphasized how important it was for doctors to be direct and forthcoming about a diagnosis, and especially about what they could offer to a person in terms of treatment. He did not want to be given the impression that more could be done medically than was actually possible. He talked about how he was a “straight shooter” in his interactions with others and he expected the same frankness in return from his health care providers.

Like, I’m not going to give you a promise [that] I will do this for you when I know damn well I’ll only be able to [do this much] — so don’t give false hope [cough]. [It’s] better to tell the person... ‘look, I’ve looked at it, I don’t think I can help you’ instead of giving false hope — it’s the worst thing you can do to a person.... Don’t keep me in the dark, it’s my life. Give me the facts. Don’t matter how good or how bad, but give me the facts.

Prakash believed that sharing this difficult information in an open and sensitive way was an essential part of providing good care.

[Open] communication is very important so that, you know, [it lets] the other party, lets them know that, you know, that we care about you and this is what it is. No point hiding that disease from [patients], you know, it’s their disease, might as well tell them.... So try to, you know, give them [the information in] the best way they can, that’d be nice for both parties.

At the same time, he did not feel that individuals needed to be repeatedly reminded of their terminal status: “You don’t have to focus it on me, [that is] ‘now you’re going to die, now you’re going to [die]’, just tell them once.” According to Prakash, knowing this information was important so that people could reconfigure their priorities according to a new, shorter time frame.

Well, if you, if you are upfront, the doctor says, “Okay, you’ve got this, this, you got short time.” You can start looking and say, “Look, I had such a good time, now I’ve got this little time, I’ll make [the] most of it, right.” I’m going to start enjoying whatever it is, the way I was doing and maybe I’ll start spending more time and see people more because my clock is running a little bit faster. Couple of seconds ahead everyday so you know, I have to make that journey in shorter time.... So by now I should start preparing things and all that. Ahead of time so, you know, at least, you know, by that time I should be prepared so you don’t leave things lying around which you want to do as a priority.

Based on this knowledge, Prakash also made decisions about appropriate care strategies and goals in the time remaining to him. On some level, this information was empowering to him because, “then I take it from there.” This outcome may also explain why Prakash felt that it was so important that physicians not offer false hope to him. He did not want to spend time and energy on mainstream strategies that would not make a difference when he could move forward with other personal and cultural approaches that would be helpful to him. So when no other curative medical interventions seemed possible, he took the initiative to deliberately draw more extensively on various cultural beliefs and practices to deal with his illness and to make meaning of it.

Stay positive: It’s not half empty, it’s half full

Prakash drew on his Hindu faith to make sense of his palliative status. In this case, the spiritual belief that death is a natural part of living was fundamental to how he coped with his terminal diagnosis.

For us...most of the Asian people or Indian people, people of Indian origin, they look at life as, you know, it’s, it’s a perpetual cycle [that]

comes and goes. Summer, fall, winter, spring...life is a journey and, you know, no matter what you do, you're going — at the end of the cycle, it's going to end.

Consequently, Prakash believed that he did not assign a moral value to his illness in the same way that was commonly reflected in mainstream attitudes.

[Our] society has sort of created illness as a bad word, you know. [A] horrific thing, like for cancer. [But] we [are] all going to die. What's the difference from dying from cancer or from something else?... It's six of this or half a dozen of that.

Prakash accepted that something would lead to his death, which according to his Hindu faith was a natural transition he need not fear: “You’re just changing into another clothing... [you’re] dying physically, your body is physically gone, [but] you’re just crossing to something different. Whatever it is, we don’t know. But whatever it is, don’t be afraid of it.” To Prakash, this belief meant that even though life can seem confusing and the prospect of death frightening when one is seriously ill, there was still an overall benevolent pattern, “a controlled chaotic state.”

This religious viewpoint appeared to encourage an attitude of acceptance that was neither despairing nor passive. Prakash believed that not knowing what would happen tomorrow left room for hope and optimistic expectations today. Based on this perspective, Prakash described how he deliberately cultivated a positive attitude that countered the medical assumption that cancer would be the inevitable cause of his death because there were no mainstream medical treatments for it.

Our mind is quite funny, right. Whatever we plugged in, it locks in, right. Just like a cassette player. Whatever cassette you put in, that's the one that's going to be going in, right. So if you put the tape in your brain that... 'I've got cured' or 'my disease is gone', and that's playing around, there's no other thing [that can] be playing [like] 'you have a disease, you have a disease'. Your tape is saying, 'I have no disease, I have no disease' ...instead of putting on 'I'm going to die, I've got cancer'. One is

a depressing one, one is a, you know, calming one...I make a choice of what tape I put in there. It's not half empty, it's half full.

He augmented this optimistic attitude through daily prayers and visualization. The prayers he recited were those he had learned from his religion. The visualization exercises he used came from mainstream self-help books that he had previously read. Each morning he prayed that, “God bless, everything’s going to be okay.” He followed this prayer with a healing visualization. Prakash’s goal was to use these cultural practices to slow down or stop the progression of his cancer and COPD, and to combine them with conventional medicine to mitigate the pain and symptoms associated with these illnesses.

Prakash drew on these mainstream and local cultural strategies to achieve and maintain an acceptable quality of life in the face of a terminal illness. However, Prakash had no intention of carrying on with any interventions if they no longer seemed to make a difference to his well-being. He presented an analogy of a sports car to make this point.

[Don't] sustain me for too long because, you know, [there's] no point sustaining [me] when the, when the Corvette's motor is blown — the, the ten-inch radial tires don't look any good there anyway. They are useless. So that's why when my whole system is collapsing, [there] is no point putting me, charging me up again because [that's] just wasting time.... Let me go, make it very fast and easy.

As Prakash summed up, if there was no likelihood for improvement, “then, you know, what’s the point” of prolonging the dying process. “The cycle is just getting complete so, you know, that’s all it is. Nothing less, nothing more, nothing less. That’s it.” This statement once more reflected Prakash’s acceptance that death is natural and inevitable.

There's a right way and wrong way of doing things

Prakash spoke of the importance of learning about the intricate workings of mainstream health care in order to manage effectively within it. This appeared to involve adopting new behaviours and letting go of previous cultural ways of doing things. For example, Prakash shared a story about how he modified his religious practices when he was living in a large mining camp.

P: *[A] sin is in the eye of the beholder, a judgment call. What, what is a sin to one person might not be committing a sin to the other. That's the way I look at it. Suppose you're told, 'Lying is a sin, don't lie'. But if you lie to save somebody's life, is that a sin?*

H: *Right, so it depends on the situation.*

P: *Exactly, exactly, exactly. See for us, most of the Hindus may not eat meat or may not eat certain kinds of meat or might not eat beef or something. For me, I've eaten everything because I was working in mining camps — so on the same grill they are cooking for 800 people, [they're] cooking chicken and then there is a steak. [Should] I tell them to clean the hot plate and make my chicken separate? It's not going to function. I'm there because the good Lord took me there to give me a job. And what he's offering me, I'll accept it.*

H: *So you have to adapt.*

P: *Yes, I just eat and, you know, be part of it. It's not a sin to sustain myself. In that particular thing.*

Prakash made a conscious decision to alter his behaviour to meet the expectations of camp protocol. Ultimately, this choice ensured certain benefits (regular meals) without upsetting the camp cooks or system through additional demands.

Prakash was similarly strategic in his interactions with health care professionals so that he would receive the services he required. His stories showed how important it was to start with a respectful attitude for health care providers and their protocols.

I treat them with respect to start off with, right. When they're busy, you have to wait your time, don't rush.... If they're busy and you're rushing them and all that, then, you know, it's not the right way of doing things, right. There's a right way and wrong way of doing things. So if you approach the right way then you will get the right results.

Part of the “right results” included being treated with respect in turn. “If you respect somebody then you can get respect. You don't get respect if you don't show respect.”

When asked how health care professionals have treated him, Prakash replied that “they all have been excellent everywhere...they treat you very well, you know...with dignity and respect.”

However, in a later interview, Prakash shared a troubling story about his experience in an emergency department when his mother was ill — an experience that was certainly devoid of respect and dignity. Prakash had called an ambulance for his mother because she became suddenly weak at home and could no longer walk without assistance. He described an interaction with the attending physician about the reason for his mother’s symptoms and the physician’s decision to discharge her home.

P: *My mom couldn’t walk around because her body went just like a rag doll and, you see, she would fall this way or that way. And the doctor...in emergency, he says, you know, “I don’t know, you know, what’s wrong with your mom — just take her home.” I said, “You did the test, you could have come [up] with something.” I said, “You are the specialist, right? You cannot tell me there’s nothing wrong with her because, look, she cannot [walk].” [The physician said] “Are you judging me or something?” I said, “I’m asking you a simple question. I brought her here, she’s not [better], she’s the same, but what is wrong with her? Any idea?” [The physician said again] “Are you questioning my judgment?...I am a doctor.” I said, “I know, but listen what I’m asking you. I’m just asking a polite question. What is the diagnosis? Is there any diagnosis, right? That’s all I’m asking. You know, I’m not questioning your judgment. I’m just asking has she got, you know, [high] blood pressure, okay, that’s a diagnosis, right. What is the diagnosis for this thing?” He blows his bloody whole fuse.*

H: *He blows his fuse.*

P: *He’s a Chinese guy. And [they’re] dragging my mom like, you know, just holding her by the belt and just [pulling her]—my mom is very fragile, she could hardly [walk], and the way they were holding her you could see the marks on her, right. I said, “You don’t have to do that, she’s so*

fragile” [and they said] “why don’t you...just sit down there.” What can you do? You just have to sit down.

H: *So you have to sit down?*

P: *Yeah. To see the abuse — basically [inaudible] as far as I’m concerned it is just like abuse. Nothing — just shoving [her] around like, you know.*

H: *But you feel that you can’t respond to it.*

P: *You cannot. They will kick you out and they’ll call security. Forget it. Don’t argue with the hospital. No, don’t even try to. Just, you know, shut your trap up. That’s about it. ‘Cause, you know, they just call the security and end up creating a problem because you cannot discuss with them if they made a decision. You cannot, you know, ask any questions too many times. Some of them would just lose their cool.*

Prakash’s feelings of frustration and powerlessness were palpable as he told this story. He felt that he could not push the doctor for more information because the doctor had the power to withhold services from Prakash’s mother if he came across as too demanding.

[Your] hands are tied. At the end of the day if the doctor doesn’t want to give you the information, he will not. And if we try to press it out, then you have a very good chance of getting, you know, escorted out with security.

Unlike previous times of disagreement with physicians, Prakash did not have another doctor to turn to for support or advocacy in this instance. He was less confident to influence or make care decisions. Furthermore, he had too much to lose in this situation if he asserted himself too forcefully. He could not take the risk of jeopardizing his mother’s care by alienating the physician responsible for it. He was compelled to step back and acquiesce to the doctor’s decisions.

When I asked what he thought accounted for this doctor’s behaviour, Prakash offered several explanations. He proposed that the doctor may have had some negative experiences with individual patients before and, therefore, was defensive in his

interactions with new ones: “The other patient, the other patient could have been obnoxious or something so...the doctor may be OK, but the client was [obnoxious] and then [if] you start on the wrong foot, he’s got this bias already.”

He also emphasized that doctors have “a high pressure job” which may excuse their behaviour. Sometimes health care professionals are just in a “bad mood” as a result: “Sometimes the nurses would be, you know, quite rude just for no reason at all. I’ve seen that happen.” For the most part, Prakash viewed these negative interactions as isolated incidents and not reflective of broader cultural attitudes. “So I can’t blame doctors. Pure and simple thing of life, you know, it just happens.”

Prakash did express the possibility that in some cases health care providers may demonstrate negative attitudes toward patients because of their affiliation with particular cultural groups. For example, Prakash suggested that this can occur when a new patient belongs to the same group as a previously “obnoxious” patient.

[Like] you get a drug addict as a patient, and then you have a bad experience with [him], the next time they bring [a drug addict] in the emergency you’ll be, you know, you’ll be a little more [careful] because you had a bad experience with them [before].

Prakash thought that this might also occur if the public stereotype of an ethnic group was negative.

[It] depends on what’s going on [at] the present time and which community is going through what. Sometimes you get painted with the same brush and all that, right? So some doctors are quite [careful], you know, ‘Can I trust this guy as a patient in my room all by myself here?’

In such instances, Prakash was inclined to attribute this wariness to the cultural prejudices of a small number of individual professionals. He suggested that there are always a few people in society who demonstrate such negative attitudes towards particular groups. “There is always maybe one or two percent of people who don’t like to, you know, deal with [a] certain group of people. Basically that’s what it is.”

The idea that cultural prejudices extended beyond the attitudes of a few individual caregivers ran contrary to Prakash's primary belief that everyone is treated the same in health care settings. Prakash believed that system protocols would ensure that all care recipients are treated equally and receive the same services. This perspective was evident in Prakash's story about what he thought occurred when a minority person requested assistance at an emergency department.

They have certain protocols, right. So, like, if you go out to triage you have to take the time and they'll assess the cases — not by who comes first but [by] how serious each case is.... So a lot of people don't realize [that and] they get, you know, all hifty-nifty in there. Because, you know, they are there to take care of us...they're not playing a game on you just because you are different or whatever. It's the severity of the case. But once you're inside there you just, you know, you have the same [treatment] as the other person who's sitting [there]...they're following their protocol.

When people did experience inequities and gaps in service, Prakash suggested that such incidents were exceptions that were inevitable in large institutions.

In the bureaucratic system, you know, sometimes things will fail. Or, you know, slow down because it's a huge apparatus, whole structure. So sometimes there are hiccups. But, you know, no system is perfect. So you have to live with that. We have to accept that too in a way.

Again, Prakash did not view these "hiccups" as reflective of systemic discrimination: "that shouldn't be, and I don't experience [treatment that is] anything less than reasonable." This perspective allowed him to hold on to the explanation that his negative experience with the emergency physician regarding his mother was an isolated incident that was unrelated to his cultural position.

This point of view was further reinforced by the fact that Prakash did not perceive himself as different from the majority of Canadians. Even on a physical basis, he did not see himself as distinct from others.

Half the time people don't know where I'm from [cough]. They think I'm from [the] Philippines or Mexico or...some Arab country or something. So [it's] very hard for them to figure out where I'm from so I says, "I'm just a Canuck."

Prakash's depiction of a generic Canadian identity appeared to include the primary characteristic of diversity and, therefore, he saw himself "just [as] a Canuck" among other "Canucks" who were also visible minorities. Prakash went on to make the point that even Canadians of British and European backgrounds were all culturally different in the end, which made them "Canucks" like all other Canadians.

We are a little bit different, but at the end of time, we're [East Indians] still in the big picture of Canada too. I say, basically, I can say this for about 80 percent of the Canadians in Canada. All Asians, Caucasians and all that...the British, the Scottish, the Italians and, you know, when you go to the bottom you still find they all got their culture. Even though it's latent, or anything they're not expressing that much...but at the end, deep down, they've still got their, you know, [heritage] They've adapted too, but they still haven't forgone their roots.... At the end of the day, they're still Canucks just like us. That's what I mean.

Prakash viewed himself as a typical Canadian — "a mixed bag" who had retained traditional beliefs and practices and adopted new mainstream Canadian ones. He was a cultural hybrid among other hybrids, which mitigated the perception of difference from the majority and the subsequent possibility of being treated otherwise because of it.

Main Points

Prakash's story highlighted several key aspects of care that are significant to living with a life-limiting illness. First, Prakash's experience underlined how important it is for health care professionals to provide as much information as possible to individuals about their diagnosis and terminal prognosis. From Prakash's perspective, to have all the "facts" about an illness allows individuals to be informed participants in medical decision-making. People's confidence to be actively involved in meaningful care

planning is further enhanced when their goals are acknowledged by physicians as primary objectives to achieve. With this knowledge and support, individuals can weigh the costs and benefits of various treatments options in relation to their care needs and personal expectations of an acceptable quality of life. For Prakash, to be a leading partner in this process was vital.

Furthermore, prognostic knowledge is crucial to seriously ill persons because it is relevant to their lives immediately and in the future. With this information, they are given the opportunity to review and reorder their plans and priorities. According to Prakash, the provision of this knowledge by health care professionals to patients is fundamental to responsible care. This information prompted Prakash to move some goals forward and give others up. He completed his financial and legal affairs and made arrangements for his funeral. He became more attentive to various relationships with friends and family, and lived his life with a different sense of daily gratitude. Although these latter activities reflected Prakash's previously existing cultural values, their importance appeared to become more pronounced after his cancer diagnosis.

Prakash's experience also revealed how individuals may draw on various cultural resources to deal with a serious illness. He described how he was empowered by his cultural beliefs and practices when the curative limits of conventional medicine had been reached. He turned to his spiritual beliefs to make meaning of a dire prognosis and employed prayer and meditation to enhance his health. Prakash's story showed how cultural knowledge and practices sustained him and nurtured his hope for continued well-being when biomedicine seemed to have little more to offer. The confirmation that the limits of mainstream medicine had been reached allowed Prakash to draw more extensively on his cultural beliefs and strategies to make meaning of his illness and to respond to its progression.

Finally, Prakash's story illustrated the utility of learning how health care systems work in order to benefit as fully as possible from them. This information can be used by culturally diverse individuals to adopt strategies that will help them to effectively navigate system procedures. Prakash's stories also highlighted his perception that any episodes of poor treatment in mainstream care settings were the consequence of

inappropriate behaviours on the part of individual care providers rather than reflective of broader systemic prejudices or problems.

Prakash lived his life with a positive philosophical attitude. He viewed his illness and eventual death as a natural part of living. As he walked me to my car after our last interview, we were admiring the flowers in his garden. He explained that he picked a flower each morning to include in his daily prayer. The flower reminded him that all belongs to God and all returns to God: “We are only borrowing what he lends to us.”

Chapter 5. It's Only Natural to be Hopeful: The Story of Fiona Lee

An Introduction to Fiona

I arrived at the front door of a four-storey condominium in an older neighborhood in a city in the Lower Mainland. When I pushed the intercom button and introduced myself, a voice responded with the single-word instruction of 'upstairs'. I walked into the foyer and took the stairs to the third floor. I looked down the hall for the apartment number and saw a door open. A Chinese woman looked out and waved me over. I walked down the hall to meet Fiona Lee.

Fiona was in her late fifties and about five-foot-seven. I was struck by her height because she seemed tall to me for a Chinese woman. She wore glasses and was dressed in matching pants and sweater. She smiled warmly and shook my hand. Fiona invited me into the apartment while quickly explaining that Deborah had not yet arrived. Deborah was Fiona's hospice volunteer and she had agreed to act as an interpreter for our interview today. My communication with Fiona had been mostly by email so far, although we did speak once on the telephone. I thought Fiona's English was very good, but she felt less confident about it so she asked Deborah to join us. Although I offered to arrange for a professional interpreter, Fiona said that she would be more comfortable with Deborah in this role because she had known her for over four years.

While we were waiting for Deborah, Fiona showed me into the dining and living room area. Chinese books and magazines — as well as various Sudoku puzzles — were spread out on the dining and coffee tables. Fiona enjoyed solving Sudokus as well as creating them — an interest directly linked to her career as a physics and math teacher. She explained that Sudoku served as a good “distraction” and “[kept] her mind active.” She often worked on them when she was eating because swallowing food was a very slow and tedious process for her — she had no saliva or taste anymore because of the various treatments she had received during the past few years for cancer.

[My] throat hurt — very, very dry. Swallowing is difficult, yeah, swallow — very difficult to swallow. Another one — not much taste...taste is gone. It becomes a duty to eat rather than an enjoyment.

Doing Sudokus helped to make this “duty” more palatable. As we talked while Fiona showed me around, she apologized several times again for “not speaking English very well” even though I did not have difficulty understanding her. She relaxed about this concern after Deborah arrived. In fact, Fiona continued to speak English during most of the interview with only infrequent changes to Mandarin for Deborah to translate. After Deborah’s arrival, we seated ourselves on two sofas that surrounded a coffee table. Fiona sat on my right side because of hearing loss in her right ear — an outcome of multiple radiation treatments. Fiona explained that the sound of her voice, which is quite low and gravelly, was also a consequence of those same treatments.

At the beginning of our interview, Fiona shared some of her background. She was born in Mainland China in a rural community close to Shanghai. After the Cultural Revolution in China, she was given the opportunity to attend university where she studied physics. She became a teacher and taught for many years before immigrating to Canada. She moved with her husband to Canada in 1989 because of the increasing government repression in China, which publicly culminated in the events of Tiananmen Square. This became a tangible symbol of their frustration and gave further impetus to their decision to leave China.

Fiona and her husband had no children and they were the only members of their families to immigrate. Fiona’s husband had also died two years previously. Consequently, Fiona had no immediate family support in Canada. She was still strongly connected to her siblings in China and visited them every year. Although Fiona described herself primarily as Chinese, she knew she had also “changed” and become more Canadian: “[I have] different idea of thing[s] because I been here twenty years.” She laughingly reflected on how her siblings called her the “foreigner” whenever she returned to China to visit them.

Fiona taught in a Chinese school for most of the years that she lived in Canada — she only stopped working recently when she became too unwell to continue. She was

diagnosed in the fall of 2004 with nasal pharyngeal cancer. She underwent over 30 radiation treatments over a three-month period immediately after her diagnosis and returned to work in early 2005. Unfortunately, the cancer recurred and spread to her lungs the following year. Since then she received ongoing rounds of different chemotherapies.

Fiona was referred to my study through the local community hospice program. She had received volunteer support from this agency for several years, as did her husband before her. She was motivated to participate in the research project because she wanted “to help improve the system,” particularly regarding interactions between patients and physicians. The information I gathered about Fiona’s experience derived from a primary interview with her, which were supplemented by several email and telephone communications, as well as two conversations with her hospice volunteer. In all, I spoke to her and her volunteer for about four hours. Although I had planned for at least two interviews with her, her condition started to decline soon after our first interview and she was too unwell to meet again. About six weeks after this interview, Fiona returned to China to be with her family. She died there two months later.

Diagnosis and Treatment: Continuous Cycles of Treatment

When I asked Fiona about her illness, she started her story at the point of diagnosis. She was very precise in her recollection of the chronology of events.

October, 2-0-0-4, I got the nasal pharyngeals cancer. Cancer in the na, the nasal passages. And then, radiotherapy. It start November, 2-0-0-4 to, ah, January, 2-0-0-5. Yeah, 33 times, three months. Yeah, then, um, nothing to do. No other treatment. Then in May, 2-0-0-5, I go back, I went back to work, yeah. In January, 2-0-0-6, I found I got a little cough and the mucus just like the [inaudible] blood...little, very little blood in the mucus. Then I went to the [Cancer Agency again].

It took some time and a series of tests before the recurrence of cancer was confirmed. Fiona underwent an x-ray and CT scan, but neither detected the presence of cancer.

However, “the doctor don’t believe the examination” and he ordered an additional guided biopsy that did confirm that the cancer had returned and had spread to her lungs.

Then radiologist say, “Yes, changed into the lung.” Yeah. This is April, 2-0-0-6. Yeah. And started, started chemotherapy in May 2-0-0-6. And then until now.

Since the recurrence three years ago, Fiona had had multiple cycles of chemotherapy that often included six to seven weeks of intravenous treatments. These were followed by two-to-three month breaks with subsequent tests to determine the impact of the medications. In Fiona’s case, the cancer continued to progress, which led to ongoing rounds of new chemotherapies. Many of these latter treatments were experimental and part of larger clinical trials.

H: *So you’ve had several cycles with some breaks in between.*

F: *Yeah, interval. Every now and then changing the medication.*

H: *So have you just been on a break then or are you in the middle of a cycle right now?*

F: *Last cycle finish in, in, um, January 14 this year. But February 17 take x-ray. Check lung. See growth...ah, tumour growth. So start chemo — next Wednesday on March 4th.*

H: *March the 4th.*

F: *Yeah, change the medicine.*

H: *And how many rounds of chemo will you do this time?*

F: *Doctor didn’t give me certain. He just say, “Try.”...six or eight weeks.*

In a very understated way, Fiona described the chronic fatigue associated with this ongoing cycle of care: “I just feel tired.” From Fiona’s perspective, her oncologist’s interest in her fatigue and other side effects only extended to the point of determining whether they would impede her ability to continue with chemotherapy. Once he completed this assessment by reviewing her x-rays and asking a few questions, appointments would come to a quick ending. Fiona explained that he did not attend to

the treatment side effects himself and instead referred her to other physicians to address them.

Every time I wait a long time, sometimes one hour, but saw him two minutes..."Do you feel sick or vomiting?" I say no. I say no. "That's okay, continue chemo." His main concern is the dosage of the chemo, how to cure that. Anything else you talk to him is nothing, no, none of his business. For instance, if I was complaining about the nose getting stuck and the throat getting dry or the ear not hearing now. Is not his area. And he will send me to another specialist.... Just the, take care about the chemotherapy.... He's specialize in this one, this area. He's just concentrating in this area. He doesn't want to get distracted or do anything else.

Based on her experience, Fiona believed that physicians were too narrowly focused, which limited the scope of their practice: "They are really too specific that they don't know anything else." The result is that no one person sees the whole picture and coordinates care accordingly. She described how this was similarly problematic for her husband during the final stages of his illness.

Too many specialist[s] and they look after one area...when my husband had the operation and they discovered there was lot of inflammation, ah, so the, another doctor came in and cured that, or stopped that, and he was okay, sent home. And then, um, he was throwing up blood, and hemoglobin, then they discovered [this] he was taken back to the hospital again. Hemoglobin too low. And then, um,...then another doctor found out that blood almost gone up to his brain, and so it was too specific. Doctors have no connection or consultation with each other.

When this occurred, Fiona felt that the care was disjointed and fragmented. On another level, Fiona wondered whether her doctor's lack of attention to her overall well-being (or that of her husband's) was also an indicator that "he just couldn't care."

As Fiona talked about her diagnosis and treatment experience, she returned to her own question of why she had cancer. She wondered how this happened because she

deliberately followed a healthy lifestyle so as to prevent illness: “All the way, all the time, I’ve been very healthy conscious.” Fiona’s family doctor reinforced the value of these efforts: “Before I got cancer, she always say you are really healthy...the blood test always very good.” When she compared herself to her husband, particularly in terms of their diets, she was more confounded about her cancer diagnosis.

Yeah, so I don’t know why because my eat[ing] is very healthy — why I’ve got a cancer.... My husband didn’t eat, didn’t [eat] healthy. [He] like meat very much. [He] like the fries...I always like vegetables and very little meat.

She carried this exercise of comparison further when she considered the habits of her husband’s brothers.

His brothers all drink and smoke — [they’re] all good. All fine in China. The solution isn’t look good, but all fine. He here — no smoke, no drink. So he [used to] sometimes give his brothers advice, “Don’t drink, don’t smoke.”. I say, “Don’t say that, you are not good example [laughs].”

Fiona expected that her efforts and those of her husband to minimize health risks would protect them from serious illness — a common-sense belief that they shared with those around them, including their doctor.

Although these activities were not enough to prevent cancer, Fiona continued with many of them. She was still conscientious about what food she ate and how she prepared it. She drank a “smoothie” everyday, which “help[ed] me to eat more fruit and vegetable” and she prepared many foods by “steaming rather deep frying.” She also walked everyday — “I did exercise before [cancer], but, ah, not as persistent. But after the illness, I am doing it everyday.” By taking these actions, Fiona felt that she was doing what she could to make a positive difference to her well-being. Fiona’s continued efforts suggested that the overall benefit of actively engaging in the fight against illness was greater and more important than the final efficacy of the individual strategies.

The Experience of Care: What is Important

Weeding and planting at the same time

As Fiona described above, the focus of treatment at the Cancer Agency was aimed exclusively at battling the cancer. Little attention was paid to the impact of this approach on her total health. Therefore, Fiona took the initiative from the start to combine Chinese medicine with Western therapies to counter the negative side effects of these aggressive systemic treatments. She learned about this tandem approach in China.

[In] China, [you] use the Chinese medicine and the Western medicine together...Chinese medicine can give, help you, uh, disappear the side effects...I guess it may be weeding at the same time and planting seeds, or giving nutrient, nutrient at the same time...rather than just using one way without the other. So if your immune system is not built up simultaneously, you could [go] lower and lower...[it is] more holistic.

The idea is that the body's own defenses can be fortified by the "seeds" and "nutrients" of Chinese medicine while the cancer is "weeded" out by Western treatments. For example, Fiona explained how she used Chinese remedies to mitigate the fatigue produced by the rounds of chemotherapy. By doing this she was able to tolerate the treatments better.

I with the chemo, uh, take Chinese medicine. So energy level was better. But now I stop, um, August last year to now. Yeah, I stopped it. So I feel it [tired] again.

Fiona stopped taking the Chinese medicine because she could no longer afford the cost of it "because the Chinese medicine in [Canada], just need to pay by myself...it's not covered by the medicine [plan]. Yeah, here the Chinese medicine is expensive, expensive."

Recently, Fiona consulted with a Chinese medicine doctor again, who was also trained in Western biomedical care. A friend of Fiona's arranged for this appointment because Fiona was so upset after receiving the news that the tumour in her lungs was continuing to grow. "Last week...I got the x-ray result. I'm very sad. I really want to give up. So a

friend gave me the fax and introduce [me to] a Chinese medicine doctor [here].” Fiona’s fear that she could not physically withstand the impact of these ongoing treatments without the reinforcement of additional holistic medicines was confirmed by this doctor. She was becoming systemically weaker, which she believed was the reason the cancer was spreading further.

[This] doctor was reading my report and saying there were two, ah, indexes. One, the reading, one is very low and the [other], about my liver, which is bad. But nobody, nobody has told, ever told me until this doctor...the first one [index] is about my immune system which is really low and that is why my, my cancer is uncontrollable. And then the second one [index] is about the liver. The liver is bad and nobody ever told me either.

Fiona’s conclusion was that the exclusive focus of the treatment regimen on reducing the cancer combined with the lack of consistent monitoring of its side effects had left her seriously vulnerable otherwise. After speaking with this doctor and receiving some new Chinese medicine, she felt more optimistic: “Yeah, she encourage me and gave me a little medicine...and already, right away, I felt better.”

Incorporate other assessments

Not only was the chemotherapy detrimental to Fiona’s physical status generally, she also questioned whether the type and dosages of the treatments prescribed were appropriate choices — she wondered whether they were based on sufficient information.

[The doctor] check the, um, lung cancer, either big or small and [whether] the growth are down — always depends x-ray. No the other examination. Just the x-ray. And the doctor watch the x-ray...but no the blood test, no the CT. No the other one. So sometime I confused...because why use [so] much medicine, many chemo, and didn’t it change...not a big changing...so non-effective.

Fiona explained that it was “always the doctor” who decided the treatments for her based on this information without further investigation or discussion with her. However,

Fiona wanted more than this: “I really want [him] to give me the more examination. More tests. Because always x-ray, x-ray, x-ray...[I want to] have the broader tests.”

Fiona did challenge her oncologist’s assessments and subsequent treatment decisions on two occasions. She did this by seeking a second opinion from physicians in China. These initiatives were not well received by her oncologist in Canada.

[I] finished the radiation therapy, back to China to see, uh, doctor in Shanghai. They are, uh, cancer doctor. They gave me advice. Say you should take a little chemotherapy. There’s still something wrong they assumed, they believe. But I can’t stay long time in China. Another reason if I in China to take, um, chemotherapy I need to pay by myself. So I come back here. I need to work. So I came to here. See [cancer] doctor. I give him this advice. I say, “Chinese Shanghai doctor say dadada, and here doctor say needn’t do it.”...Another example in 2-0-0-6, I got the lung cancer, uh, I get the x-ray for Shanghai. Let doctors see something. They gave me some advice. I [take] report to here. Doctor very, very unhappy [that I had consulted with the doctor in Shanghai again]. So I did from now, from that time, I didn’t say any word about the Shanghai [advice]. I always depended [on his recommendations] — “your decision, your decision.”

The doctor’s reaction appeared to reflect an implicit hierarchy of expertise that placed the Western physician’s knowledge above that of his Chinese counterparts and Fiona. Furthermore, Fiona heard a clear message in his reaction, which was to not question his treatment plans and to maintain instead a passive role in any related decision-making. She wondered whether things would have turned out differently if her oncologist had incorporated the Chinese recommendations: “Just I think if in the first time after radiation [he] gave me the chemotherapy, maybe cancer changes [after] that...we don’t know...[it’s] always a question.”

Fiona accepted the dynamic of this relationship for two reasons. First of all, she had traditionally respected the authority of doctors so questioning their recommendations felt like she was breaking a rule “because when you go to doctors, we, we are from the

culture that we don't ask doctors questions." Secondly, she felt that she did not have any other options for medical care: "I really want to change my doctor but I know in the [clinic] only two person — two doctor who can take care of the [cancer]. So if the other doctor is worse than him I [have] no way. So I stop." Fiona found herself between a proverbial rock and hard place — because of limited resources she felt that she must accept her doctor's approach or end up with no services or even someone less helpful than before.

Despite her doctor's attitude, Fiona did continue to seek the advice and use the remedies prescribed by Chinese medicine doctors when she could afford them. What changed was that she did not share their recommendations with her oncologist because of how he might react: "He is a very opinionated man...and I'm afraid to tell him." Fiona felt compelled to compartmentalize her treatment strategies, which ran contrary to her desire for coordinated and holistic care. Consequently, in some instances she struggled alone with treatment decisions. For example, she stopped using Chinese medicine for a while when her chemotherapy was changed because she wasn't sure whether they were compatible with one another: "I afraid, they, they didn't match." Unfortunately, she might have been able to combine the two approaches safely but she did not feel comfortable or safe enough to discuss her concerns with her oncologist and so she was not able to benefit from his knowledge.

Stay hopeful

Fiona experienced other major differences between Western and Chinese approaches regarding the focus of care. Her stories showed how Western physicians emphasized prognostic information regarding the incurability of her cancer while Chinese doctors tended to minimize this perspective so as to lessen their patients' stress and worry. They focused on treatment possibilities instead.

In China, doctor didn't give patient any [prognostic] information.... They don't want the patient to know. It's too much worry. They don't want you to worry about it. They just keep on treating you.

The frequent and consistent message Fiona heard from her oncologist was that her cancer could not be cured. She understood that informing patients about this information

was part of Western health care and she tried to adapt to this process of truth-telling. However, she found the ongoing emphasis on it redundant and discouraging.

But here, doctors always tell you [that cancer can't be cured]. Even your lifetime is only three months. So now I change my idea. Here I can know about my truth. But I don't like doctor always give me, always say, like, ah, my cancer two-month start [again]...doctor always give me one sentence. "This can't cure. We cannot cure you." Always say this way.

She found that the repetition of this message “aggravate[d] the condition” and added more “worry” for her. Each time she expressed some optimism about the potential of a new round of chemo treatments, her doctor responded with the same words: “You won’t be cured.” Fiona’s story showed that her oncologist’s sense of obligation to tell the prognostic ‘truth’ overrode her need to be hopeful about a cure in the face of this truth. She felt that there was “no compassion” in this answer so she stopped asking him about the possibilities of improvement. She also wondered whether he had given up, which may have explained to her why he was not using more aggressive treatments. “Maybe from his point of view, this people [with cancer like hers] are just ready to die, waiting to die. This is about maintenance only. It’s only a matter of time.”

But Fiona fundamentally rejected this passive and narrow position. She wanted the doctor to shift his approach to one that was more encouraging — to be hopeful about the positive possibilities of treatments. “[He] don’t have to tell, keep saying that it can’t be cured, [but instead say] ‘we trying, we trying. It’s hard to cure but we’re trying’.” She contrasted her oncologist’s attitude with that of a Chinese doctor, who was his resident.

And he would, uh, looking at, say, looking at the same report, he would say, “Oh yeah, it’s not too bad. Um, we still have a few kind of medicines that we haven’t tried. There may be some miracle or something.”

Fiona’s Chinese medicine doctor presented a similar perspective recently. “I ask the Chinese doctor, say, uh, ‘shall I be cured, would I get better?’ And the doctor said, ‘of course’. Even this is not true, but give me that hope.”

Fiona was aware that she might not survive this illness. However, she was, along with these doctors, able to hold both prospects at the same time — the possibility that she might die with the hope that she might be cured. Although Fiona acknowledged that this position might reflect the perspective of individuals, she believed that it was rooted in a broader Chinese cultural attitude: “It’s also cultural too. Very cultural. Yeah, you just keep giving people hope.” For Fiona this was a compassionate and appropriate response because “it’s only natural for patients to hope to be better, to be cured.” Fiona’s persistent hope for a cure translated into a corresponding desire for more aggressive treatments.

If [I] were in China, the Chinese doctor would use every single means to cure the cancer and never give it a chance to survive. For instance, the doctor’s suggestion about getting another chemo [after the radiation treatment] would have happened, right, but here they, the doctors believe in giving you the quality of life [so] they try to be milder and gentler.

Fiona continued to expect interventions aimed at lengthening her life rather than only enhancing the quality of what remained of it.

Fiona’s experience revealed an apparent major misunderstanding about the goals of her care. The objective of curative care in this instance would be to eradicate the cancer. The aim of palliative care would be to slow the cancer’s progression and/or manage the symptoms associated with it so that quality of life could be sustained as much as possible as the cancer advances. The fact that Fiona’s doctor kept emphasizing the incurability of her disease after its recurrence suggested that the experimental chemo treatments were intended as palliative measures. However, it does not sound from Fiona’s story that this was clearly explained to her and/or that she understood the care plan in this way. Furthermore, the use of chemotherapy for palliative reasons is not widely understood, which may have added more confusion to the mix. Unfortunately, efforts to mitigate the side effects of these treatments and manage symptoms associated with disease progression were not included in this ‘palliative care’ approach.

These may be some of the reasons why Fiona described the chemo treatments as “ineffective” because from a curative perspective they did not achieve their goal. From a

palliative viewpoint, they may have actually added months or even years to her life by slowing down the progression of the disease. However, Fiona's apparent lack of understanding of the purpose of the treatment left her with a chronic feeling that her doctor did not care enough to do more.

Fiona wanted her care providers to share the belief that a "miracle" was still possible and strive towards achieving it. She ended the interview by sharing a story about her husband's doctor, who advocated for more aggressive treatments for him at the end of his life when others opposed it.

My husband, he was lucky. He had a, ah, good doctor. He, uh, two years, two and half years before he died, a doctor, young doctor, woman doctor, who was, uh, Middle East or Indian doctor and she, when she discovered that he had, uh, something wrong with his lung, she insisted that there should be an operation [to remove it]. So she talked to the specialist and in the beginning that doctor was not in agreement. But because of her persistence he was able to live for two more — more than two, two and a half years.

Although a cure was not achieved, the pursuit of one accomplished the palliative goal of securing some additional quality time for him. Just as Mr. Lee was "lucky" to get a doctor who kept hope at the forefront, Fiona concluded that "maybe [I'm] unlucky to come across [one who doesn't]."

Main Points

Fiona's experience revealed several key aspects of hospice palliative care. She underlined the importance of respecting the healing traditions of individuals and combining different knowledges and practices when dealing with a serious progressive illness. Specifically, she recommended the use of both Western and Chinese medicine to enhance total care outcomes. She highlighted the value of simultaneously using interventions derived from these approaches to maximize their individual and synergistic benefits. Fiona believed that the holistic scope of Chinese remedies could augment the efficacy of radiation and chemotherapies while offsetting their detrimental side effects.

Fiona sought opportunities to integrate these treatment agendas. She consulted both Western and Chinese physicians and communicated their recommendations to each other. By sharing this information, she intended to initiate discussions about integrating treatment options where “there could be some input from her” as well. She underlined how important it is for individuals to participate in identifying and deciding treatment choices. Fiona also called for a coordinator of care — a physician who would monitor all treatment strategies and regularly assess their benefits against any negative consequences. This approach would ensure that modifications to care plans and goals would be relevant and timely.

The primary theme that emerged from Fiona’s experience was how important it is to nurture hope even in the face of disease progression and the creeping awareness that death may be imminent. From Fiona’s perspective, physicians can provide encouragement to their patients by sharing their belief that improvements can happen no matter how remote the possibility. When I reflected on this idea, I remembered a story I had heard at a palliative care conference a few months earlier. A speaker at the conference related a conversation that she had had with her husband’s doctor a few months before his death. She had asked him, “Do you think that Bob [her husband] will survive this?” The doctor turned to her and said, “Every doctor has a miracle patient, I hope that Bob is mine.” I believe this story captures Fiona’s sentiment exactly. Palliative care does not need to preclude a belief in a miracle — in fact, supporting this belief may add quality and meaning to the time remaining in an individual’s life.

In many ways, Fiona’s experience ran contrary to these expectations. Fiona’s oncologist did not acknowledge the importance or relevance of her cultural beliefs or practices. He conveyed the message that the knowledge of Western medicine, as embodied in his expertise, was superior to that of other approaches. He demonstrated this by minimizing and/or ignoring the suggestions of the Chinese physicians Fiona had consulted and by expressing his dissatisfaction to her for seeking out other opinions generally. He did not engage Fiona in discussions about treatment plans or explore care goals with her. Furthermore, he repeatedly squashed her hope for survival by reminding her of an incurable prognosis. This appeared to be an example of the discourse of medical truth-telling overriding a discourse that values hope and optimism.

The result of these responses was that Fiona eventually shut down in her interactions with her doctor. Over time she did not feel that it was safe to share her beliefs or expectations and so communicated less and less with him. There was an emotional thread of sadness, fatigue and resignation running through Fiona's story that seemed iatrogenic. As she pointed out, the doctor's attitude "didn't help much for the healing process" and created more suffering for her. Fiona identified several ways to provide good health care at the end of life, but they were mostly unmet for her. Perhaps Fiona returned to China because she believed that she would receive a combination of Chinese and Western care there that could balance the challenge associated with treating a life-limiting illness with that of maintaining her hope to still overcome it.

Chapter 6. From the Place of Difference: The Story of David Nolan

An Introduction to David

I wait patiently at the door of the suite. I can hear the slow shuffle of feet from the other side. It seems to take a few minutes and if I had not heard the movement in the apartment before, I would have knocked again by now. Eventually, the door is opened and I am met by David Nolan. David is a 45-year-old Caucasian man. He is dressed neatly in jeans with a pressed, button-down shirt. David looks thin and his clothes hang loosely on his frame. When I say hello, he follows the sound of my voice and looks at me directly. He greets me warmly and invites me into the apartment.

The reason it took a few minutes for David to answer the door is because he is blind. As I follow him down the hall, I see how he slowly feels his way along the wall to guide himself. We pass a bathroom on the left and then reach an open space that starts with the kitchen and dining area, which then eventually becomes the living room. When David reaches the end of the wall, he begins to furniture-walk through chairs and side tables until he reaches the couch where he sits down. He had been listening to the TV earlier and now feels for the remote on the coffee table to turn it off.

David's partner, Barry, is also home. David asks Barry to show me around the apartment. The suite is overflowing with furniture and various bric-a-brac on counters and tables and ledges. There is a large entertainment cabinet in front of the couch with a television in the centre. I notice a rowing machine on the other end of the living room with some free weights lying around it. Pill bottles line the kitchen counter along with containers for spices. As I look around at all these items, it does not seem to me that the suite has been particularly organized to accommodate David's blindness.

David invites me to sit down on the couch. He asks if I would like something to drink and offers a choice of coffee, tea or water. I choose a glass of water, which he asks Barry to get for me. David is very much the attentive host even though he is limited by his blindness.

I have known David for sixteen years. I first met him and his previous partner, Peter, when Peter was admitted to the palliative care unit at a large urban hospital where I worked. I was a social worker with the AIDS Care Team then and it was in that capacity that I met David and Peter to assess their home care needs and to develop a discharge plan with them. At that time, both had already been diagnosed with full-blown AIDS.

After that initial meeting, each was admitted to the palliative care unit several times and I worked with them on each occasion. They were both patients on the unit when Peter died in 1996. David reminded me that his family doctor had predicted then that he had only a few weeks remaining in his life as well. “[Dr. T] is always reassuring, but, you know, he’s never really scared me except for the time that he told me after Peter passed away that he thought I was going to be going within a couple of weeks [too].” At the same time as this prediction, David started a regimen of new AIDS medications that marked a significant breakthrough in the treatment of HIV infection. These medications were especially effective for David. They slowed the rapid progression of David’s disease and pulled him back from the precipice he was facing then.

David is still a palliative patient because he continues to live with two incurable progressive diseases — AIDS and renal failure. The kidney disease he developed is an outcome of his AIDS diagnosis and treatment, as is his blindness. He has been dialysis dependent for several years now, which is a treatment that cannot be sustained indefinitely. He does not expect to be cured of these illnesses and he knows that he will die from one of them. Although David does not look for a miracle of cure in the same way that Fiona Lee did, he does share her hope that he can stay a step ahead of his illnesses for a while longer.

I’m not expecting to go into Dr. T’s office and him offer me a magic pill, like, anytime soon — [a treatment] that’s going to clear up everything because that will never happen. I’ll always have kidney disease. I’ll always be blind...I will be going on with AIDS for, you know, a while anyway...

David lives within the shadow of uncertainty cast by these diseases all the time. Any new symptom can potentially herald a life-threatening situation.

I mean with AIDS you don't know, like even, you know, with this past cold I had [last week], I mean I thought I was dying, just like I did the first time I got sick when I found out I was HIV, I thought, well, this is it.

David's doctors have called his health "fragile for the last few years," which has increased his sense of vulnerability even further. Moreover, he has no new options for AIDS medications beyond his current regimen: "I mean, like right now, I'm on salvage therapy."

David became aware of my research project through a third-party recruiter at a hospital clinic where he receives his AIDS medications. David has spoken publicly about living with AIDS before and he saw this as another opportunity to promote a greater understanding of this experience as a gay man. Because David and I already knew each other from previous interactions, he was comfortable with me and with the research process. He described how he had been joking with his sister earlier that I was "coming over and that [he] was working on [my] PhD." I had some initial concerns about how much energy David had for the research interviews, and I reminded him that we could stop at any time if he became too tired. However, this was unnecessary and David remained very engaged and participative during our meetings. I interviewed David twice and followed up with him by telephone to clarify various points of information on several occasions. The time I spent with David in these interactions totaled about five hours.

Diagnosis and Treatment: Will I Survive?

I don't need that test

Although David had been suspicious for several years that he might be HIV positive, he did not want to be tested to confirm that possibility. He had engaged in unprotected sexual activities in the 1980s and experienced various sicknesses during that time that made him wonder whether he had contracted the virus.

I kind of suspected that I probably was [HIV positive] because of my behaviour and because of certain illnesses that I'd had back east, which I mean were not necessarily HIV related but could have been, you

know...and at that time I didn't want to know. [It] was something that I just kind of blocked out of my mind...

David's family doctor encouraged him several times to have an HIV test, primarily because he was a gay man and thereby a member of a high-risk group. Health care providers commonly argued that early detection of the disease offered an opportunity to start treatments that would slow down its progression so that people would live longer. However, David's belief was that a positive result could only mean ominous news — that you were going to die soon: “[Like] it was kind of one of those things that if you found out then, you know, you'd get really sick and go, really quick.” This was a prevailing discourse in the gay community in the 1980s and early 1990s, and for that reason many men did not get tested. Furthermore, because there was so much fear and stigma attached to AIDS, people did not talk about having it or testing for it.

[People] back [east] really didn't talk about it so I didn't know who was or who wasn't or who could be or who couldn't be...I remember there was a friend of mine that I had, that I had no inkling at all that he was HIV positive but then after I moved out here I found out that he'd died from it...[and we had] never talked about it. Like people just didn't seem to talk about it a lot back then.

Consequently, David “resisted getting tested” because he did not want to deal with a confirmatory result and its implications. “Like when my doctor back there brought it up, I'd say, ‘Oh no, oh, I don't need that. I'm not going to do that right now’.” David's anxiety about the potential results outweighed his doctor's recommendation each time. It was not until David moved out west and met Peter in 1990 that he decided to get tested. Peter had already tested HIV positive and he offered David support based on his own experience. Peter's doctor also emphasized that there were promising reasons to establish his HIV status because of new treatments for it. When David told the story about getting tested almost twenty years ago, his ambivalence about it and his emotional reaction to the results still spill out with significant intensity.

And [Peter] said, “Well, why don't you come with me and I'll introduce you to my doctor and maybe you'll feel more comfortable knowing, you

know, knowing that I'm positive that, ah, you'll be more positive to get tested for it." So, um, I was introduced to Dr. T, ah, I guess it was January of 1990. And, um, we talked about, you know, the whole HIV test and what the positives and negatives were — even though at the time most of us knew that — most of us didn't know that there were any positives at the time. We were just more familiar with the negatives, you know, going on the drugs and eventually passing away from it, and, you know, at the time most people were passing away fairly quickly from it. And, ah, so anyway I got tested and I remember the day, ah, that I got tested we were walking, you know, by the park up here and I just, I just broke down, you know, [I] couldn't deal with, you know, the knowledge and, you know, immediately thinking that it's a death sentence and that I'm going to be, you know, I don't have much longer and, you know, and I'd just met Peter, and, you know, that, you know, even though we hadn't known each other that long that, you know, that, you know, that I wasn't going to have that much longer with him...and, ah, so it was a pretty rough time that period of probably, I guess for, ah, maybe, must have been a couple of years...

Tell me what you know, but spare the details

When David tested HIV positive, he felt all the fear and apprehension he had been trying to avoid for several years. However, once the diagnosis was established, he turned around in terms of his desire for information about it. Since then he requests regular updates about his illnesses and their progression, even though he is not interested in the specific medical details about them.

...I ask certain questions [about diagnoses], but, um, I don't go into great detail, you know, like I guess I want to know, like, the basics... I think there are people who want to know every little detail. And there are people who run home and go on their computers and look up everything. I've never been like that. 'Cause, you know, I know enough, I don't need to know every little detail about it...

At a certain point, the level of detail about test results and disease indicators is meaningless to David and potentially stressful to him if he becomes too focused on them. He questions whether even the doctors understand all this diagnostic information.

[Like] the viral load, you know, like to me, I mean [the test results] are just numbers and they are numbers that are, like, you can't ever really imagine. Like, [what does a] 200,000 viral load mean? Like I don't know what that means, you know, and I don't really know what under 50 means...so whereas some people are, like, 'Oh, my God, my viral load is 60 or 70 or 200' and it's, like, it's just a number and, like, I can't think about it that way because like it's something that I can't really wrap my mind around to what it really means, and, you know, I don't even know if all the doctors really even know what it means. So, like, I'm not going to, you know, stress myself out about worrying about whether I have a 55 viral load as opposed to under 50, you know.

On the other hand, what is important to David is full prognostic information about his survival.

[If], you know, something comes up with me and I, you know, I get an infection or something, the first thing I worry about — and it goes back to when I first found out that I was HIV positive — is whether or not I'm going to die from it. Or whether or not, you know, it's really serious or whether it's something I can, you know, um, get over or get treated for, you know, because I think that, that may be my biggest fear, you know.... I mean if I have, you know, three months to live, I'd like to know so I can get that ticket to Hawaii [laughs].

David appreciates that his family doctor provides this information to him in a direct and supportive way: “He’s got a good bedside manner, you know, like, yeah, I mean he’s not, he doesn’t candy-coat it or anything, but, you know, he explains it to me in a way that I understand it and, you know, he’s always reassuring.”

David expects similar direct information about the potential positive and negative outcomes of the medications offered to him. This is especially important to David

because his approach to dealing with AIDS has been to try virtually every HIV drug available — experimental or otherwise.

I first started on AZT. It was my first course of treatment for HIV and then from that point on throughout the '90s I was on pretty much every HIV drug that they came out with and was in several drug trials for new drugs that, um, they were going to see whether they were going to be effective or not. DDI, DDC and, um, oh, I can't remember the names of all of them and I don't think all of them, you know, came to being used as treatment, but...pretty much all the drugs that came out, my doctor put me on...

The Experience of Care: What is Important

The doctor knows best

For the most part, David has relied on the proficiency of his physicians to determine treatment choices. He describes a hierarchy of knowledges wherein the expertise of specialists tops that of his family doctor and his own.

Well, treatment [options] — pretty much I rely on the doctors to decide, um, pretty much for me. I mean when I see Dr. R [AIDS specialist] over at the hospital, I mean, I kind of see him as the be-all-and-know-all of HIV. I mean, you know, maybe he's not, but I mean in terms of, you know, where I am in terms of [HIV] healthcare right now, I mean he, he's the one I would look to for the best advice. And, ah, I mean even Dr. T [family doctor], you know, goes by what Dr. R says. I mean Dr. T really can't overstep what Dr. R decides.

Not all the recommendations about treatments have been helpful to David and he knows that some have had iatrogenic consequences. “I think sometimes in the past — [and Dr. T's] admitted this himself that, you know, I've gone on pills that haven't been good for me, you know, and that have done more bad than good when I've taken them.” In some instances, serious irreversible consequences occurred when doctors made decisions about aspects of care that were outside of their realm of expertise. David

describes how his previous nephrologist made changes to his eye medications that may have contributed to the loss of his sight.

Dr. K [nephrologist] had been intervening because I had been developing problems with my kidneys. And so he was trying to figure out what was causing the problems with my kidneys...then all the doctors started to play around with all the drugs I was on trying to see which drugs might be, you know, interfering with my kidneys. And then Dr. K was the one that kind of hit on thinking that it might be the gancyclovir [eye medication] so that's when...they started kind of playing around with the dosage with gancyclovir. And, like they, like initially I was taking one [pill] twice a day, and then they'd take it to one and a half twice a day, and sometimes they'd take it down to one [pill] once a day. And I, I would, like, I got really nervous the more they were decreasing the amount of the gancyclovir because I know, well, I knew that up until that point that it had been helping me...and even up until this day, and I mean who can say, but like, I mean I don't know whether if I'd stayed on the gancyclovir — like the full dose that I'd been on — whether I'd still be able to see or whether or not, you know, them cutting it back the way they did interfered with me losing any more of my sight than I would have [otherwise]...it's something I always wonder and probably always will.

David did not express his apprehension to the nephrologist at the time because he believed that Dr. K, by virtue of his physician role, knew best what to do: “He’s a doctor so I mean, you know, he just did, I guess, what he thought was best for me at the time.” David trusted that Dr. K’s medical knowledge was adequate for the problem although in hindsight he “wish[ed] there’d been a bit more, you know, consultation with the eye clinic and people there than there probably was.”

Similarly, David has relied on his doctors to interpret the emergent significance of new symptoms for him. Even in the face of their progression, he would follow the care plan recommended by his doctor rather than seek a reassessment on his own initiative. This

occurred when David lost sight in his left eye and then again in his right eye a few years later.

[At] first I thought it was just an eyelash that was, you know, stuck in my eye and I kept rubbing my eye and I thought, oh well, it's just sleep in my eye or something that I can't get out. So I went to see Dr. T and, uh, he said that he, you know, couldn't detect an eyelash or see anything in my eye but that I should go and see the eye clinic at the hospital. This was a — I think it was a Thursday I saw Dr. T and he said we'll get you into the eye clinic on Monday, the following Monday. And by the time I got to the eye clinic, my left eye—my sight had gone completely...that was pretty devastating to say the least.

[Losing sight in my right eye] all of a sudden happened. And, um, so then I went to Dr. T and he said, "Well, we'll send you to the eye clinic again." And so I went to the eye clinic and again it was like a day delayed or something and they said, "Oh, we'll send you to the university clinic for them to take photographs of your eyes." And I'm thinking, well, what's the point? You know, like, here we go again.

In neither instance did David push for immediate action or go to the emergency department at his local hospital for another evaluation while waiting to see the ophthalmologist. He trusted his family doctor's appraisal that these symptoms did not require an urgent response. David's stories show that the common belief that the physician knows best guided his decisions and actions in each of these scenarios. They highlight how the physical experiences of patients are not considered acutely serious until deemed so by a doctor.

My point of view is important too

Because of these events and others like them, David eventually adopted a more assertive role in decision making about his health care. He now questions the primacy and comprehensiveness of physician knowledge, which he previously had taken for granted. For example, he requests more specific information about the potential negative outcomes of new medications so he can decide whether trying them is worth the risk —

he expects “honesty about, you know, what the potential of the pills I’m taking could do.” If David has concerns about possible treatment effects, he may refuse a recommended medication or delay its start until a later time. David describes how his AIDS specialist has responded positively to his regular participation in decision-making.

I’ll say to him [now], “Well, I don’t really know if I want to do that drug or go on that drug because, you know, I’ve heard different [negative] things about it”...and he’ll say, “Well, you know, okay, if you want to [delay] that for a couple of months, that’s fine.” He’s been very, like, you know, okay with me with things like that.

Some of the other treatment aspects that David considers when making decisions are those that may diminish his quality of life. The primary disagreements that he has had with health care providers stem from the tension between their agenda to meet specific medical needs and his goal to maintain an acceptable quality of life. This divide has been especially evident between him and his nephrologist regarding the frequency and duration of his dialysis runs. David undergoes dialysis three times per week “and it’s something I dread doing everyday I have to do it.”

It’s just so boring, especially that I’m blind. Nothing, there is nothing I can do except listen to a TV—and I mean there are talking books and all that stuff, but, you know, the ward is noisy. It’s so noisy. People say, “Oh well, why can’t you sleep?” Well, I mean, there are people that sleep there but they’re probably 70 or 80 years old and they all snore and I can’t sleep up there.

David finds the routine of dialysis extremely tedious and, therefore, he requested a shorter run. However, his doctor argued that longer and more frequent dialysis is medically indicated: “She thinks that, you know, everyone should be at least having four hours because you need the four hours to have a complete, you know, filtration of the body.”

Although David acknowledges that this may be a valid medical practice and the “right” thing to do from that perspective, he still struggles with this mandatory routine in his daily life.

I'm wrong in the way I'm thinking because [the nephologist has] always explained it to me where I understand her point of view, and her point of view to me when I see it is the right point of view — it's just hard for me to deal with and accept it, if that makes sense.

He has expressed his frustrations to his doctor, but when I asked him whether he thinks she has heard his point of view about diminished quality of life, he's not sure.

I don't know. If she does, she doesn't pay attention to it. Because I mean, she's still got me on three and a half [hours] which is fine, but she said to me one day, she made a comment not so long ago, she said, "I'd have you doing dialysis every day if I could." And I don't know whether that was just like an offhand remark or whether she was serious about that or what.

Although David did eventually reach an agreement with his doctor, he said it "was quite a fight" to resist her medical authority. He had "to stand pretty strong" and "bulldoze" his way through her agenda for his perspective to be accepted. In the end, they both compromised. "It was either three or four [hours for dialysis]. So I compromised for three and a half and I guess she did too."

David has experienced similar interactions with other specialists when he has not felt heard by them.

You don't really think that they hear or understand what you're saying or where you're coming from, you know. And what you're trying to get across. And, uh, they just kind of go ahead, full steam ahead, with what their plan of, ah, course of action is.

As a result, David is not always successful in convincing his doctors to incorporate his treatment wishes. He has asked his psychiatrist several times to increase his antidepressant medication, but so far the doctor has refused to do so because he believes that David can address his concerns in other ways.

He's not a big one for prescribing drugs and I wish he was because I really feel like I need more than I'm getting because I'm just on a minimum of Paxil and I mean I think it's 20 mg or whatever. You can take

up to 60 mg of Paxil...[he] thinks that I should be able to work things out on my own without, you know, medications, but so far I haven't been able to.

When I asked David how he feels after such exchanges, he said, “I get kind of discouraged, you know, and think, well, you know, no one seems to be able to help me and I don't know how to help myself.” When his experiences and ideas are not acknowledged, David feels alone with his problems and less confident that they can be resolved. He desires an “understanding for where I'm coming from.”

Work together as a team

David rejects the common medical assumption that physician assessments and care plans should supersede the knowledge and goals of patients. David advocates for a more collaborative approach “as opposed to, like, the doctor-patient [hierarchy] kind of thing. You know, working together as a team sort of thing — you know, as for the good of, you know, the patient. I don't know if there's a word for that.” In fact, there is a word for this in health care — it is called patient-centred care. It is a model of care that actively includes patients in medical decision-making and planning. The fact that David is not familiar with this term suggests that it is not an approach to care that his care providers have described or presented to him.

At the same time that David promotes patient participation, he points to the busy workloads of physicians as a barrier to it.

I think the health care today is so frantic and, you know, fast-paced that there's not the time to sit and talk about stuff like that, you know. You're in and out pretty much. You know, like when I go and see, you know, Dr. T, I mean he doesn't sit down and say, “What do you think would be most helpful for you, you know, in the way I treat you?” or whatever. Like I'm there for a reason and I guess he's there to help me with it and I guess it's not something he thinks about asking.

David gives examples of rushed appointments with other doctors that impede such discussions.

Dr. P is short and sweet. Oh yeah. She doesn't — you don't stay long in her office. And the same with Dr. R. You don't stay long in his office, no, he's pretty turnstile...but I mean he's got — they both have such huge workloads, I'm sure.

David sees the practice of running patients quickly through appointments as the norm, which leaves little opportunity for them to have full exchanges with their physicians. Moreover, when appointments are this fast-paced, there is rarely time to address psychosocial concerns, which are part of the holistic purview of patient-centred care. This appears to be a structural barrier to this type of care.

Appointments are just for physical problems

Based on David's experience, the focus of the medical appointment is primarily on physical problems, and exploration of other issues is not part of that interaction. Even when it was determined that David had lost his sight permanently, the ophthalmologist offered no emotional support to him or suggestions for resources to assist him to adjust to this life-altering news. David describes this loss as “devastating”, but the expectation that he would receive additional support from his doctor was ruled out by the doctor's busy schedule.

D: *I said, “So I'll always, I'll never have sight again?” He said, “No.”*

H: *And he never checked out how you were feeling about that?*

D: *Like afterwards?*

H: *Yeah.*

D: *Oh no.*

H: *Or just even in that moment?*

D: *Oh no.*

H: *No, eh?*

D: *No. Then I guess the last time I saw one of those specialists, he said, “Oh well, you've got glaucoma in the right eye. Nothing can be done for that.” And that's that.*

H: *Do you expect them to provide any kind of emotional support or even some suggestion around that?*

D: *I couldn't really even consider that they would.*

H: *No, eh?*

D: *No. I mean they're so busy.*

David's family doctor will take extra time with him: "[He'll] spend however long I need. I've been in his office for 40 minutes sometimes." In some instances, they talk about emotional concerns, but usually only at David's initiation.

H: *Does he check in to see how you're doing emotionally or mentally? Is that part of what you talk about?*

D: *No, I'm usually the one that brings up that stuff.*

H: *You're the one that usually does. What is his focus generally?*

D: *Whatever health concerns I have.*

H: *So whatever symptom or physical concern that you have?*

D: *Yeah.*

David generally keeps to the rule of focusing only on physical concerns when he meets with his doctors. In fact, when he does not have a specific physical issue to review with them, he often feels that he is "wasting their time" and that he "should just call and cancel the appointment so someone else can go." He has learned that emotional concerns do not warrant their own time slot. "I don't want to take up [Dr. T's] time, like, with stuff like that because I figure I [should be] there for, you know, a physical thing."

Seek psychosocial support elsewhere

Consequently, David has turned to other services for psychosocial support. For example, he joined a hospital support group for HIV-positive men. However, the group did not meet David's goal to work through some of the issues he faces living with AIDS. Like Brenda, he found that the tone of group meetings was very negative and that there

was no exchange of positive and practical ideas to cope with the daily challenges of living with AIDS. It also did not meet his secondary goal of making new friends.

It was always the same stuff talked about every week. And I'd come out of there more depressed than I did going in because everyone was talking about all the negative stuff, and I never really found that I got any real solutions for the stuff that I was talking about...and we went out for coffee and stuff afterwards sometimes and I guess I always wanted to make friends there, but I never did...and then, so I guess I stopped going.

David also sees a psychiatrist, but he has been disappointed in his work with him as well. "I don't know whether I was expecting too much or what I was thinking, but I guess going to see a psychiatrist you hope to feel that they're going to help you, like, emotionally, and feel better about yourself and, you know, your life and things that are going on." This has not been David's experience.

David's preference would be to address his psychosocial concerns with his family doctor because he has a longstanding relationship with him marked by comfort and trust. As David notes with some irony, "I have not known [my psychiatrist] nearly as long as I've known Dr. T [family doctor], and Dr. T and I can talk about everything. Dr. T could be my psychiatrist, I imagine." However, health care protocols do not allow him to draw on that cache during his appointments.

The Culture of Being Different

When I asked David about his culture, he reflected on it in various ways. First, he talked about culture in terms of class and ethnicity, and then sexuality. He described growing up "in a lower-middle-class family" of English background. "My mom's parents are from England and my dad's parents were from England [too]...I just had a fairly English upbringing." When asked what this meant, David laughingly referred to the routine of "roasts on Sundays." He went on to say that it included a:

[Keeping] up with the Jones' kind of attitude, you know, if that makes sense in terms of culture. You know, like there's always this need that, uh,

you've got to have a bit more, and your grass has to be greener than your neighbour's.

David also talked about being gay and how he learned early on that this was a deviant way of being. David's perception of gay culture initially reflected the negative stereotypes of mainstream society that depicted it only in sexual terms. "[I had] negative images from what people would have thought back then — you know, like gay bars and bath houses and, uh, you know, promiscuity." From an early age, he learned that fitting in with the mainstream and being successful in it are important cultural imperatives.

David's reflections about culture shifted quickly to the theme of being different from the majority around him. When David talks about his culture, he does so primarily from the position of not fitting in or belonging to the mainstream — of being on the outside of it. He starts by describing how his family was different from the middle-class English families in his neighborhood. As David points out:

My dad left us when I was, ah, ten and he wouldn't give my mom enough money to keep the house kind of maintained. And so we had a field of dandelions for our lawn, whereas everyone else in our neighborhood had golf-green lawns.

David's family did not meet the social expectation of keeping up materially with the 'Jones' all around them. Furthermore, David's parents were divorced, which also set them apart from the norm of two-parent families. David was acutely aware of this disparity and was "teased a lot for it — like [our family] wasn't the Beavers, that's for sure."

Similarly, growing up gay in a heterosexual world separated David from his peers at a young age. He did not fit in with the majority in his cohort. Being different in this way made him a regular target for bullying.

I'm not really quite sure [why] but people pegged me at a very early age that I was gay...like maybe eight or nine or ten. And, you know, I remember, you know, being chased home at lunch hours. Having like, you

know, dirt balls thrown at me and, you know, being jumped on and beaten up and stuff like that from people, you know, assuming that I was gay.

These homophobic actions kept David on the outside of many mainstream activities while growing up. He remembers deciding not to attend his high school graduation because of these experiences. “Instead I went downtown to a gay bar at — I don’t know what age I would have been — sixteen or seventeen or eighteen, I guess. So I didn’t go to my graduation. I didn’t get my diploma. They mailed it to me.”

David’s entry into the gay world was also initially marked by a sense of not belonging to it. Gradually this changed: “I think of [gay men] as a kind of a community [now] more than just kind of [a group of] individual[s]...I guess maybe because I’m part of the community now whereas before I was kind of an outsider looking into it.”

Categories of difference

David believes that being gay is a primary category of difference that eventually led to more categories of difference for him. “If I wasn’t gay I most likely wouldn’t have AIDS and most likely wouldn’t be blind and most likely wouldn’t be on kidney dialysis.” David now belongs to a sub-group within a sub-group — he is not only a gay man, but he is a gay man living with AIDS (and renal failure), who is now also blind. He strongly resists this latter membership because it has profoundly exacerbated his sense of separation from mainstream society.

I have a real hang-up about being blind and what people are going to think about me, like I almost feel like a non-person and I told Barry that I feel awkward so much of the time now because of being blind and having my cane.... I don’t really want to hang out with blind people cause it just — I don’t know — there is something about it that just reinforces the fact that I’m that, too. And I don’t — and I know this is stupid to say — but I don’t want to be blind. Blindness is the worst thing that could have ever happened to me. You know, worse than finding out I had AIDS.

David longs to feel normal — to do ordinary everyday activities with regular friends. He does not want his differences highlighted by his dependence on care professionals.

Whereas I wish, you know, there was someone I could phone up and say, 'do you want to go for a coffee or do you want to go for a walk or do you want to come with me to the grocery store' or something like that, but there's no one. I mean there are services that would do it for me, like people like my homecare worker, but that's not the same, you know. I don't want to go to Safeway with my homecare worker, you know.

David feels that being blind has not only set him apart from mainstream society, but it has moved him to the periphery of the gay community as well: "I don't see it as very accepting of me anymore." To illustrate this point, David described his experience at a pub night for HIV-positive gay men that he and his partner have attended on several occasions before.

And Barry said, "Do you want to go tonight?" And I said, "Oh no, nothing for me there." No one talks to me there either. [I] sit on a stool and Barry goes and plays pool and not a soul says a word to me and that's because of my blindness and my white cane, I'm convinced...I almost feel like a non-person.

Consequences of difference in health care

David has had similar experiences of feeling invisible in his health care interactions because of being blind. Health care providers often do not speak to him directly now either — instead they talk to Barry as if David is not present.

At dialysis, people will go through Barry about things regarding me as opposed to asking me — who's, like, lying right there on the bed — which I find quite odd...it makes me feel like I don't exist...and it's like, I'm right here, you can ask me. I'm not dumb. I'm not a mute. I'm blind, you know. You can ask me...and it's stuff like that that makes me feel less of, you know, what I am.

On the other hand, David does not feel that he is treated differently by health care professionals because he is gay. David describes the hospital where he receives his

primary care as “a gay-friendly hospital.” When David attends clinics elsewhere in the city, he is also treated like any other patient.

I think pretty much at all the other clinics that I go to I'm just another patient, you know, like when I go to Dr. T's office, I'm just another patient there, you know, and they don't treat me any different [and] I'm sure they know I'm gay.

David believes that any difficulties that occur in interactions with care providers are isolated events related to individuals rather than a broader homophobic attitude. This perception is similar to Prakash Gupta's explanation for negative exchanges with care providers. “I [may] feel differently at different clinics but not because I'm gay. I don't know why, but just probably because the receptionist or whoever have, you know, problems in their lives or whatever...” David believes that his sexuality is less a focus of difference in a large urban setting because “people are pretty used to that [here] — mind you, if I went to some clinic in, you know, I don't know where...somewhere up in the boonies, in the north, I'm sure I'd be taken as different there.”

David does believe that some behaviours associated with being gay contribute to negative stereotypes, and he consciously excludes them from his own social presentation.

I'm not outlandish, you know, in the way I dress or behave like some people in the gay culture can be. You know, like some people in the gay culture can be pretty flamboyant and I don't see myself as that way...I don't have a problem with people who are that way, but on the other hand, I think that, that people who have been that way or are that way have maybe given the gay culture not such a great impression over time.

Although David admires gay men for “being themselves” so openly in these ways, and in some instances even wishes that he “could be like that,” he does not incorporate this ‘out there’ approach into his interactions with health care providers. “I think about it, but I never do it. I'm too self-conscious to do stuff like that and...I'd think to myself, ‘Oh well, they wouldn't take me seriously, you know’.” Therefore, David minimizes various behaviours associated with gay stereotypes in order to meet the mainstream expectations

of his care providers. From David's perspective, to be 'too gay' can be counter-productive if he's not taken seriously as a result.

David has also observed that many gay men are provocative in their interactions with health care professionals; they "go in there with a kind of confrontational attitude, you know." When that happens, the physician is "going to get all annoyed with the patient," which can perpetuate further negative interactions. David links this attitude to unrealistic expectations about treatment outcomes — a viewpoint that he believes is commonly shared among gay men.

There seems to be so much...bitterness among gays towards, you know, healthcare or the doctors, or I don't know, bitterness or disappointment maybe that they're not cured or that they're not, you know, well, or something.

David distinguishes himself from this position: "I don't have those expectations — like I know I'm never going to be well." Therefore, David's interactions with care professionals are less strident because he has accepted their medical prognoses about his illnesses. He is respectful in his interactions with care providers because he has learned that "what goes around comes around" in future exchanges otherwise.

Care is about the person, not the patient

However, despite these efforts to fit in, David does wonder periodically whether his health care is short-changed because he is blind, gay and palliative.

I think maybe they don't give me as much care and attention as others because I am gay and I am blind and I'm not going to be able to get a kidney transplant so they kind of, like, write me off, sort of.

This thought has occurred to David at various times when doctors have appeared disinterested in his changing health status. For example, David shared a story about a recent episode at the dialysis clinic. At the beginning of his dialysis run, he told the nurse he was very sick with pancreatitis. He heard her share the information with his nephrologist and he was disappointed when the doctor did not then come to inquire about his welfare herself.

Dr. B was there, standing right close to where we were, and I heard [the nurse] go to her and tell her about my pancreatitis and everything, and she didn't bother to come over and say 'how are you feeling' or anything like that.

David questioned whether her lack of response indicated that his needs were less important than those of other patients. When doctors make the effort to conduct direct assessments, David feels more cared for by them.

[In the renal clinic] there's [often] no direct contact really between doctors and patients unless something, you know, significant comes up...you tell the nurse [something] and the nurse will write it down and then, you know, if the doctor thinks something is necessary to see you about [then] they'll come and see you. Otherwise they don't see you. [Seeing them directly] makes you feel kind of like you're a bit more being watched over and taken care of, you know.

Similarly, David has wondered whether his previous nephrologist was personally affected when David went blind — whether he has any feelings about his potential role in that occurrence.

You know he sees me hobbling around with my white cane and everything and, you know, [I wonder] whether he has any questions about that.... But I don't know whether, like, he feels it the way I do or whether he just sees me as a patient that lost his sight and that he followed the course of treatment that he would have followed with anyone.

The question for David is whether the doctor views him as just another patient with a progressive illness or whether he was touched by what occurred. It is important for David to have a human connection with his care providers that goes beyond professional boundaries — to know that what happens to him as a person is meaningful to them. When care professionals respond to David as a unique individual, he feels very cared for by them.

Like the other day when, you know, I was coming home with Barry from [the hospital after] seeing the resident with Dr. C [internist] and, you know, seeing the nurses that were there at the time in my dialysis, and the nurse practitioner came by and, you know, I left there, and I said to Barry, “You know, where else would I get this treatment, you know, this kind of treatment with all these people, you know, sitting around and being concerned for me and, you know, wanting to, you know, make sure I’m okay and everything?”

This attention reassures David that his well-being is truly important to the people who care for him.

Main Points

David’s story reveals how cultural identities are relevant to health care. David identifies himself according to positions of class, ethnicity, sexuality and (dis)ability that contrast dominant categories. They reflect the experience of being different to, or other than, those of the majority. Some identities have been imposed by mainstream discourses and others have emerged by circumstance. David is gay, blind and palliative in a world where most people are straight, able-bodied and healthy.

According to David’s experience, individuals may draw on categories of cultural difference, and the common beliefs associated with them, to explain events in their lives. David has attributed diverse negative experiences to mainstream attitudes about being gay or blind or having AIDS. He shows how singular shifts in cultural identity influence relations with members of other cultural groups. To be labeled as gay altered David’s relationship to heterosexuals just as being HIV positive affected his association with gay men and being blind changed his interactions with both groups.

David’s experiences demonstrate how the meanings of cultural identities are not static — they vary depending on their discursive contexts. People resist, modify or accept cultural identities accordingly. For example, during the early years of the AIDS epidemic, a positive HIV test signaled an opportunity to medical professionals to initiate aggressive treatment, while it was viewed as a reason for discrimination and a harbinger

of imminent death to gay men. For those reasons, David resisted HIV testing because he did not want an identity marked by stigma and impending demise.

In another example, David illustrates how people manipulate their different identities by forefronting them in various contexts according to the meanings attributed to them. In his interactions with heterosexual care providers, David avoids any demonstration of stereotypical gay behaviour for fear he will not be taken seriously in his exchanges with them because of heterosexist or homophobic attitudes. Conversely, he promotes the gay connection he has with his family doctor because of the support and “sense of comfort” that he derives from their common sexuality. According to these experiences, individuals appear to strategically decide whether or not to highlight particular cultural identities according to how mainstream health care providers might interpret and respond to them.

Individuals can revise identities imposed on them as well. When David was first diagnosed HIV positive, he assumed the traditional patient role that reflected a passive acceptance of the medical goals determined by a physician. Over time, David has reshaped this inert position into one that is much more active. He has defined a new patient identity that demands a collaborative partnership with professionals that takes into account his ideas about best care. The impetus for this change stems from experiences in which medical goals determined by others compromised David’s overall quality of life.

However, based on David’s experience, it is evident that substantial resolve is required to disrupt the traditional role of patients in mainstream healthcare, and the results are not always successful. Consequently, individuals choose their battles for change according to what will make the most positive difference to the quality of their everyday lives. For example, as much as David wants his primary doctors to consider his psychosocial concerns equally alongside his physical problems, he does not overtly challenge the health care protocol that relegates them to the periphery because of the energy such effort requires.

Individuals who are perceived as different from the mainstream because of sexuality or illness or (dis)ability may feel vulnerable in health care settings. David expressed this vulnerability through his worry that he does not always receive full attention from his care providers because he is gay and blind and nearing the end of his life. According to

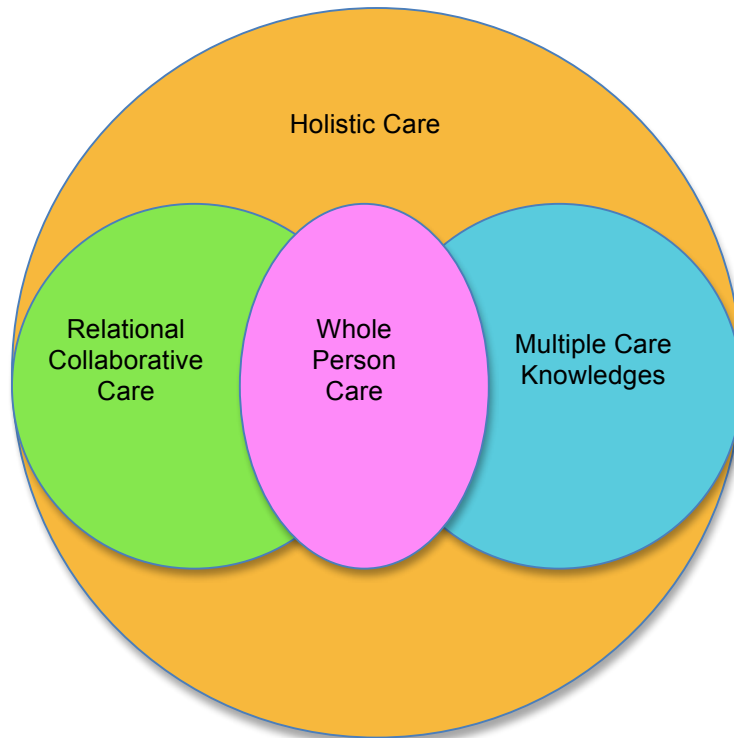
this perspective, care providers need to be sensitive to the real and perceived disparities associated with these positions of difference. These feelings can be further intensified against the backdrop of chronic uncertainty associated with living with serious progressive illnesses. What is interesting in David's story is that he did not view his other identities of being white, middle class and male as positions of privilege that could counter the disadvantages associated with his marginalized roles.

David's experience underlines how important it is for health care professionals to listen carefully to what patients identify as significant to their well-being and to integrate this information into care plans. This also includes communicating directly and clearly about diagnoses and treatments, and interpreting the prognostic implications of new symptoms as accurately as possible. David emphasizes the need for care providers to convey compassion and interest consistently in their interactions with patients. In the end, people must feel that they are thought of, and cared about, as individuals. They need to know that they make a genuine difference to their care providers despite their cultural differences.

Chapter 7: The Kaleidoscope of Whole-Person Care

As I constructed the four paradigm cases, I reflected on the participants' experiences one at a time and then compared and contrasted them. Several main themes emerged through the course of this analytic process as discussed above. My next step involved further exploration of these themes in the stories of the other six participants. Whereas the paradigm cases represented a means to contextualize the data, this activity aimed to organize information from all the study participants categorically. As this occurred, I gradually imagined a conceptual picture of whole-person care that reflected three primary dimensions based on the viewpoints of all the research participants. These dimensions include holistic care, integration of multiple care knowledges, and prioritization of relational collaborative care (see Figure 1), which I will discuss in this chapter.

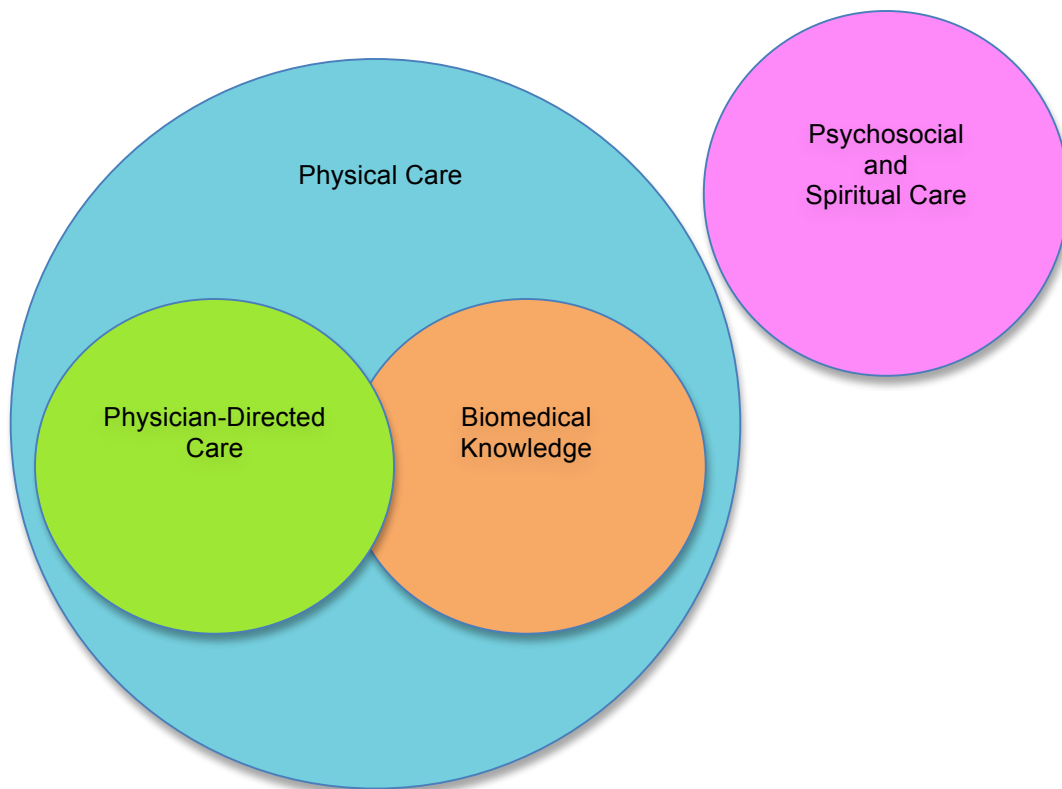
Figure 1. The Ideal of Whole-Person Care



This picture of whole-person care (Figure 1) represents the ideal for the participants — for most of them it did not reflect their lived experiences of mainstream health care. Instead, the delivery of their care reflected a configuration of dimensions that highlighted biomedical knowledge and physician-directed care. In this arrangement, there was a greater focus on physical concerns that subsequently displaced psychosocial and spiritual care to the side (see Figure 2).

The ideal depiction of whole-person care described in this chapter will encompass a thematic description of the key dimensions of whole-person care noted above and will include a review of the ways in which they were promoted or constrained in the participants' experiences (see Table 11).

Figure 2. Study Participants' Actual Experience of Care



The Dimensions of Whole-Person Care

Holistic care

We are more than our bodies

As I considered the theme of holistic care, I was drawn back to Brenda Harper's ideas about health and how it comprises more than the management of physical dysfunction. She described how it also includes attendance to our mental, emotional and spiritual needs, which together contribute to our overall well-being: "We are more than [our physical status]. We are, we are four parts, right? We have mental, emotional, spiritual and physical [parts]."

She uses the Medicine Wheel to remind herself to pay attention to each of these areas of her life and to address any difficulties or gaps within them. She believes that health care providers should consider these aspects of their patients' lives and suggested that they use the Medicine Wheel as a template to do so.

[We] use the Medicine Wheel, right, which is just a circle divided into four and looking at the four aspects — physical, mental, emotional, and spiritual. And then looking at what, maybe what the needs are within that circle, right. It would be so simple [for physicians] to begin a dialogue with it... [It] would be beneficial for more people if the doctor said, "How are you looking after your emotional [needs]? And your spiritual [needs]?" You know, like just [using] these simple questions.

Other participants also spoke about the relevance of mental, emotional and spiritual components to their total well-being, and how it's important for physicians to include these in their assessments.

[If] the [doctors] could make the little bit of time and start absorbing different [information] — what's happening in their [patient's] life — not what disease they are having but rather what's happening in their life, then, you know, they can see a broader picture [of] what could be bothering the patient. Could it be psychological [reasons] why he's having an ulcer? Not because he's eating [this] or not eating [this] —

[maybe] he's got stress now. It's like, what's activating it? What's the reason behind it? Not, "Okay, I'll give you this, take this, and it should be okay." ...Sometimes, you know, it would be the simplest of things [to ask these questions].

Maybe the doctors should ask whether, you know, whether you believe your religion is helping or not...[or] do you have a family support and things like that? Do you have friends or people who are in touch with you because people get into isolation, you know...[All] these things come into play, right — how your family is dealing with it and how you are dealing [with it], you know, when you are having problem. — Prakash Gupta

[I wonder] does she [oncologist] know actually how I'm doing physically and mentally...[or] emotionally...[all these things] — it's a really big impact...[and it] looks like, you know, it's kind of not looked after that well. — Theresa Wong

Sarah described undergoing such a comprehensive assessment at a holistic care centre. She compared it to the assessment she underwent at the cancer agency. She explained how it addressed a range of factors that she thought was pertinent to her experience of cancer.

[When] I saw the medical doctor [at the holistic care centre] she not only asked me typical question like, "Do you smoke, do you drink, do you use, like, birth control?" She asked me about my diet. She actually asked me to write down a chart of my seven days diet and bowel movement too. She asked me about my spirituality. She asked me about my stress in terms of, like, relationships at work. Um, and, like, you know, my exercise [routine]. So [all these things] were brought up by the medical doctor in the [holistic care centre], but it was never brought up at the Cancer Agency.... [Lifestyle] choices — it's something to me [that's] so relevant to cancer and your well-being, but it was never discussed at the Cancer Agency.

Generally, the study participants appeared to accept the narrow focus of mainstream medical assessments. They did not expect their doctors to address their mental or emotional needs. As discussed earlier, neither David nor Brenda included psychosocial concerns on their list of items to review during their appointments. David expressed concern about “taking up” his doctor’s time with non-physical issues: “I don’t want to take up [Dr. T’s] time, like, with stuff like that because I figure I [should be] there for, you know, a physical thing.” Brenda’s assertion that “it just stands to reason” that doctors will be annoyed by patients who arrive in the office with emotional concerns suggests how this narrow perception of the doctor’s role is commonplace in mainstream health care.

Well, it just stands to reason...if I haven’t dealt with my emotional stuff and I go in there [doctor’s office] to try to get that met at some level — if I’m [looking for] pity or whatever, I think it irritates doctors.... I’ll have a list [of physical concerns] of whatever I have to get done, okay. I don’t take up their time [otherwise] ...

Frida did receive emotional counseling support from her family doctor, but she was careful not to overuse this unanticipated bonus.

I didn’t expect it, but when I got it, I used it sparingly [laughs]. I thought I was blessed with a gift. I was blessed with a doctor that not only had time for, ah, for the sore throat or the lung problem, but had time for my, um, emotional needs...

Busyness limits the scope of care

Various reasons were offered by the participants to explain why physicians do not generally provide a broader range of care. The primary explanation is that they are simply too busy. As Theresa points out, “They don’t have so much time, you know, to sit with you and, um, talk to you about all those [emotional] things.” Speaking from her position later as a chemotherapy nurse, she reiterates this assertion. She described how she tries to sit down with patients and “talk to them...as a whole, to see how they’re doing...but it’s just somehow so busy.” As mentioned before, David talked about how

“health care today is so frantic and, you know, fast-paced that there’s not the time to sit and talk about stuff like [emotional concerns].” Prakash shared a similar perspective:

Well, the thing is the doctors are quite busy right now, right. They barely have time [to check] blood pressure and all that. So, you know, they don’t have that much time [for other inquiries].

Martins stated that, “It’s very hard to get to them [physicians]. They are very, very busy.” The perception that doctors are very busy was generally shared by all the participants. Their stories showed that physician busyness was usually accepted as a viable reason for not providing comprehensive care, which subsequently neutralized any expectations for a broader scope of care from them. As noted above, several participants, such as David and Brenda, were very conscious about not “irritating” their doctors or “taking up their time” with emotional concerns when they were already so busy attending to their physical needs.

Lack of awareness also limits care

Other ideas were also put forward as to why doctors do not address psychosocial concerns. Brenda suggested that physicians are not in touch with their own emotions or spiritual beliefs and, therefore, are not likely to initiate discussions about them with patients. She saw this as a reflection of a broader social discourse that values intellectual activities.

They [physicians] just don’t have an awareness of [the emotional or spiritual]...I mean it’s constantly up here [pointing to her head], isn’t it? [It’s all] intellectual. That’s our society though, isn’t it?

Similarly, physicians may not ask about a patient’s emotional well-being because they do not want to tread into a discussion about topics that patients may find uncomfortable. Prakash suggested that people do not want to talk about death and dying and so doctors stay away from the subject because it may upset them.

[Maybe] the doctor says, “Oh, I don’t want to bother because a lot of people don’t want to talk about it,” right. They get very depressed so maybe the doctor says, you know, “I don’t want to, you know, bring the,

bring the issue [of dying] up because not too many people want to talk about it.”... I guess a lot of people do get depressed when they find out that [they’re dying], you know, when they get on palliative...[So] the doctor must be saying, “Well, you know, he’s got other things to do now.” People don’t want to talk about it [death and dying] and the doctors basically don’t follow up on it too.

Brenda raised the point that physicians and other health care providers may not have adequate training to lead difficult conversations that are emotionally laden, which may be another reason why they do not broach them.

I don’t know to what extent the social workers or doctors address the emotional. I know they attempt to because of the social worker being there and stuff, but I don’t know how effective they are...I certainly didn’t find [the one I saw] to be very effective. I don’t know if they don’t have the time or they don’t have the training. I wonder.

Finally, the participants’ experiences revealed that the lack of a holistic focus for care also stems from the division of specialized care providers and the lack of communication among them. “[Medicine] has evolved in such a huge array of specialties, of sub-specialties, and sub, sub, sub, sub-specialties, and, um, no doctor can have all the cards” (Frida). Prakash suggested that care professionals need to share their information and perceptions with each other to create a comprehensive picture of a patient’s situation and needs: “The dots should be connected. Right now, [they’re] not.”

Side effects are minimized

The participants’ stories also showed that their doctors tended to have minimal concern regarding treatment side effects and their impact on the participants’ overall quality of life. Physicians portrayed side effects as unavoidable consequences of necessary medical treatments. What seems implicit to this perception is the expectation that patients should accept side effects as a temporary inconvenience in the pursuit of the greater goal of cure or symptom management. This ‘grin and bear it’ attitude is also reflected in some of the patient literature about cancer treatments. The following section is the opening paragraph

of a chapter titled “Side Effects of Chemotherapy” in a book about breast cancer that several participants were given after their diagnosis.

All drugs, even antibiotics or headache tablets, have potential side effects. What counts is that the beneficial effects of a drug outweigh the problems or discomforts of its side effects. Knowing that a particular drug or combination of drugs can effectively destroy the cancer, you may be more willing to tolerate the side effects, especially if they're temporary.

Olivotto, Gelmon, McCready, Pritchard & Kuusk, 2006, p. 149.

This expectation was frequently reiterated in the language and actions of the participants' physicians.

[When] I go back to see him, I do find whatever complaints I have regarding the side effects, he would say, “You tolerate it [chemotherapy] very well,” or “you're doing well.” Um, pretty much I feel he's very focused on my cancer. If he doesn't feel [anything], you know, he would say, “Oh, it's very regular in your breasts. I can't feel the tumour,” then you're doing well [according to him]. But even though I have been having diarrhea since I had chemo or...fatigue, um, like anything about the side effects or my overall well-being except the tumour, um, I don't feel he cares a lot about it. — Sarah Mah

[The doctor's] main concern is the dosage of the chemo — how to cure that area. Anything else, you talk to him is nothing — no, none of his business. For instance, if I'm complaining about the nose getting stuck and the throat getting dry or the ear not hearing now — [he says] is not his area... Just take care about the chemotherapy. — Fiona Lee

[They] did five sessions of radiation...yeah, for symptom management — pain. And, uh, that went according to them [cancer doctor and nurses] very well. [But] according to me, I was sick as a dog and it took me weeks to recover. I was quite sick and they say that I shouldn't have been...I was terrible, feeling sick and weak — it was just dreadful. — Frida Bahena

I found [the chemotherapy] is really brutal. Because, um, myself as a chemo nurse...I do educate, you know, all my patients regarding the chemotherapy, you know. But of course, you know, every medication have a whole list of side effects. I have to tell my patients those things so I know them really well. And then, actually when they work on me, it's brutal. It's just brutal. [The doctors and nurses focus on] whether you are fit for your chemo. Your readings are okay, everything is okay...but there's still, you know, actually lots of discomfort...Even though I mention it [to the doctor], it's just kind of expected, those things. 'Okay, we'll maybe give you some medications.' So yeah, kind of like every time you have a whole list [of side effects] and they, they'll say, 'it's expected' and that's it. — Theresa Wong

All the participants were inclined to accept the discourse that side effects are a small price to pay for possible life-prolonging treatments — at least in the early stages of their illness. Mary Kovacs described how she felt that there simply was not “much you can do” to avoid them and that her role as a patient was to deal with them as best as possible.

I had a very difficult time with chemo — a very difficult time — it took almost 12 hours [each time] to go through six different kinds of, ah, liquids or whatever. And, ah, it was tough for the family, but it's not much you can do, you just have to keep working at it and, ah, try your best...I had to accept everything that come with it. I had no choice.

Even when treatments were presented as an option, participants felt the pressure to comply with the recommendation made by their physicians. To decide not to take a treatment because of anticipated side effects was not usually considered a sufficient reason.

They [physicians] would tell you, “You do this treatment — it will reduce the recurrence by 20 percent, um, but it's your choice.” But you can see that they are, they are really serious. They, they really want you to proceed with the treatments...[but] I do question every treatment. Like you know before chemo or before radiation, I do question, do I really have

to go through this, um, because there are side effects and they do compromise my overall health, um, not just temporary but it can damage something like for permanent. So I do ask, you know, “How necessary is this and what are really the benefits?” And I can feel they are, um, I don’t want to say pushing, but I can say they, they would be very concerned if I am, if I decline a treatment [because of the side effects].

Side effects are not always worth the price

Several of the study participants eventually pushed back against this expectation, however. This usually occurred in the context of advanced illness when quality of life carried increasingly more weight than uncertain treatment benefits in the care equation. Even Mary, who had previously accepted all the treatment decisions made by her oncologist — “just do what you have to do, I’m in your hands” — resisted his recommendation for ongoing chemotherapy as she neared the end of her life.

And I told the doctor, I don’t want any more chemotherapy because I was sick and I would not recover. And I make a decision then...I said, “What I’m going to win with that [treatment] — is only a couple months suffer more, you know. It’s, it’s for me, for my family, ah, I thought, no, I’m not going to do this...who wants somebody [to] suffer, you know. I wouldn’t.

Mary’s doctor referred to her decision as a ‘brave’ one, although he did not accept it initially and he scheduled an appointment to start chemotherapy anyway. Mary was not swayed by her doctor’s opinion nor did she feel obliged to follow his medical recommendation. It appeared that she felt that she had nothing to lose by challenging him because she knew that she was going to die soon with or without the treatment.

M: *I didn’t care what he say, what he said, brave decision or not. But, um, I just suffered too much.*

H: *So you weren’t concerned whether he agreed with it or not?*

M: *No, I, I am already decided. But he did make appointment for me. He said two weeks later you can come back and we can start...but the change [with the treatment] is not going to be much...maybe a few more months. I*

said, “If I don’t have a treatment how long I will have without treatment?” So he turned around and said, “About six weeks.” And when he said that, I said, “I understand,” I said, “I’m still like to stay in my decision.” And then he says, “I’m going to make appointment for you anyway.” And then after a week, I call him back and I, I said, “I thank you very much, but I’m not going to take that [treatment].”

As discussed earlier, David also accepted his doctors’ treatment choices for many years without question even when the side effects were profound. However, as his illnesses progressed, the importance of quality of life increased for him. He started to challenge his doctors’ recommendations: “Well, I don’t really know if I want to do that drug or go on that drug because, you know, I’ve heard different [negative] things about it.” Consequently, he declined various AIDS medications because of the potential side effects that might compromise his everyday life. Similarly, Prakash stopped taking some drugs because the combined side effects were “too much for [him]” on a daily basis. Frida also declined further chemotherapy because the nausea and fatigue associated with it would prevent her from joining her family on a cross-country trip that they had been planning for some time: “I don’t want to go for chemo now when I have this [trip] that I want to do. Because three month[s] having fun is much better than living three month[s] in misery.”

Seeking psychosocial care elsewhere

The lack of attention paid by physicians to the broader impact of treatment side effects, or to psychosocial needs generally, affected the participants in different ways. Theresa described how she had been psychologically “hurt” by a profound sense of personal inadequacy regarding her lack of ability to manage her side effects better — particularly because she was a chemotherapy nurse herself. Theresa did not feel that she could share this private concern directly with her doctor, partly because of her embarrassment about it.

[The side effects I experienced] actually psychologically — it hurt me. It hurt me actually deeply...I just feel stupid, you know, actually a nurse, a chemo nurse cannot look after her own [symptoms], you know, side effect

of chemo therapy. I just feel a shame going to the hospital...I think I should handle it better than anybody.

Other participants also felt alone with their worries. Nathan said it was “frustrating” when his doctors did not offer any emotional support to him as his illness progressed and Frida described how she was left “hanging” emotionally by her oncologist after she was first diagnosed.

[The] oncologist...call me and says that I have, ah, cancer of the bones too. Metastases to the bones and that meant a stage four and that meant that there is no treatment. Of course, I thought I was going to die within a month, within a year at the most. And, um, and then she said she was going to take a vacation.... So I was hanging there for about two weeks with no treatment, with nobody to talk to me, and not knowing what side was up.

In most instances, the study participants were left to find other ways to deal with their emotional reactions and worries. Some resources were available in mainstream health care settings, although the participants generally did not hear about them from doctors or nurses. The participants’ stories suggest that care providers did not make referrals for psychosocial support because their attention was primarily focused on treating physical needs instead.

The participants learned about psychosocial services through handouts and posters and word-of-mouth. For example, Frida received a written list of counseling services and support groups at a cancer clinic when she first started to receive treatments there. Sarah’s father noticed a brochure about a support group for women in the reception area at the Cancer Agency, which he passed on to her. Similarly, Theresa’s husband saw a poster about counseling services and arranged an appointment for her: “I think he saw the poster and then, ah, he contact, you know, the counsellor and he brought me over there.” Sarah sought out counseling services at the agency and saw two social workers there: “One is a vocational counsellor. The other one is a more regular emotional counsellor. Just because I am having some issues with my workplace, I felt a need to see

a counsellor.” Nathan saw an agency counsellor as well, whom he heard about from members of an outside support group.

All of the participants highlighted the importance of attending to their mental, emotional and spiritual needs at the same time that they addressed their physical ones. Many drew on longstanding cultural beliefs, knowledges and practices to achieve holistic care — most of which were not part of mainstream healthcare. As Sarah explained, “I go to the Cancer Agency to take care of the cancer, the tumour, the disease. I go [outside] to the [holistic care centre] to help build up my well-being...[for] the positive goal of being healthy.”

The rich contribution of many knowledges

Western medicine to the physical rescue

The participants’ stories revealed that they all utilized a combination of mainstream and local cultural knowledges to attend to their physical, mental, emotional and spiritual needs. Although they drew on a range of practices for different purposes, they identified Western medicine as the best approach to treat their physical ‘disease’.

I believe the Chinese or traditional medicine, it's more natural so it take care of the well-being. But when I already have a tumour developed, I feel that it's at a stage you need not be maintaining well-being, but you need to rescue a situation. And then in this case I, I went with the conventional approach because I felt that they, they use more aggressive approach. Because I feel...when tumour is already developed and you need to reverse this process, um, then I feel that conventional medicine, it's more aggressive and maybe more capable in this time-sensitive case. Because I feel that Chinese medicine may be too slow to stop this process.... We always say, like, the Western medicines are more bossy or dominant...they're more aggressive...so we always feel it's always the conventional treatment who would dominate everything else [to treat the disease]. — Sarah Mah

Martins talked about the limits of non-Western treatments in the face of a cancer diagnosis as well: “Folk remedies sometimes work wonders. Ja, ja, they do, but [with diseases that] are so strong like cancer...it’s, it’s a waste of time.” Fiona also spoke about how she relied primarily on Western medicine to aggressively “weed” out her cancer.

I can then add other things to help myself physically

The study participants described in their stories how they also turned to other medicines and practices to reinforce their physical strength so they would benefit fully from mainstream medical treatments, and in many instances, to offset the negative side effects caused by them. Sarah talked about both of these reasons for using Chinese medicine.

[Chinese medicine] is not to help you kill the invader, either it’s flu, cold or tumour, but the philosophy is make you strong so that you can fight the disease — that’s the philosophy behind Chinese medicine. And I think that has, ah, a big influence on how I approach battling cancer. [I use Chinese medicine] because of the side effects I got from Western medicine. I think the pain was my biggest motivator.

Similarly, Fiona used Chinese medicine to boost her immune system: “If your immune system is not built up simultaneously [while taking chemotherapy], you could go lower and lower.” She also used it for “planting seeds” to mitigate the side effects caused by the intensive “weeding” associated with chemotherapy. Frida consulted a Mayan Indian doctor, who also practiced Chinese medicine, about symptoms and side effects. He put together an herbal remedy for her, which she drank as a tea.

He put a bunch of herbs together and I have to boil them and drink twice a day. It didn’t taste bad actually [laughs]...and for sure certain symptoms he has gotten rid of [through this tea]. See, this arm was swollen, it was swollen, swollen. I couldn’t bend my hand here and, um, he treated this and it’s gone...[he] did that and, um, he has helped me with pain or digestion, that kind of thing.

Theresa started glucosamine to treat her arthritic pain, which had become exacerbated by chemotherapy. Her doctor had prescribed an anti-inflammatory medication for her previously, but it caused her a great deal of stomach upset. Theresa is a nurse, who is fully committed to Western medicine so it was unusual for her to turn to complementary treatments to manage her symptoms. However, when they were not helpful, she broadened her approach to care to include alternate strategies out of necessity.

[I'm] totally Western. I'm a nurse [laughs]. I'm giving Western, you know, medicine, okay...but I can keep my mind open actually about those things. I can give you an example. I've been taking glucosamine. It's not really a Chinese medicine, but still my opinion actually [is that it is] something, you know, actually other than conventional. And, um, I do lots of research on it...I need information on these things, even [whether] I should take it. Because at that time I'm taking the anti-inflammatory things for my arthritis. And I said — oh my God, those, those medicines really, you know, giving me a bad, hard time, you know on my stomach. So I said —I really have to try out something [else].

I also include ways to help myself mentally, emotionally and spiritually

Many of the participants also described how they utilized cultural practices to enhance their emotional, mental and spiritual well-being. Frida explained that she started to drink the herbal tea regularly to also improve her mood: “I start feeling maybe not too much more energy but feeling better about myself, being a bit more happy, being able to enjoy whatever was going on.” As mentioned before, Brenda would pray and take sweet grass with her when she went for radiation therapy. These rituals provided additional support to her while she received her treatments.

I didn't know that [then], but looking back in hindsight now, I realized I was looking after my emotional [needs by praying and smudging].... So I wanted to obviously look after my emotional and my spiritual, okay. And my mental when I was there obviously. [That's] my thinking.

Many of the participants drew on their faith to help them cope with living with a serious illness. Prayer was especially important. For some participants, it had already

been a regular part of life for a long time, which they now used to deal with the challenges of sickness. Mary showed me the rosary that she had at her bedside in the hospital. She prayed with it regularly to help her deal with her illness and its progression. Daily prayer had always been an important part of her life and continued to be so: “[My Roman Catholic] belief is as strong now as when I was little girl. I’ve been praying since I know how to eat. And I have a rosary — I have it here with me — I got it when I was seven years old.”

Mary stated that it was her faith that helped her to carry on in the face of her increasing limitations and decline. She said that this attitude to carry on was rooted in her “religious thoughts...sometimes life just knock you, you know, you fell down, but you just have to get up, you just have to get up.” She said that this mind-set was reflected broadly in Hungarian culture: “We did [the same] in 1956 too [during the Hungarian Revolution] ...we fell down and we tried to get up and, ah, I think it’s part of our culture.”

Martins also talked about the resolve that he drew from his Christian beliefs to keep going each day: “It gives you extra strength to get through it.” Nathan shared a similar perspective about Judaism, and Sarah said that her Christian faith has “played a vital role in [her] whole journey” of living with cancer. Theresa returned to her religious roots when she was diagnosed with cancer to help her to cope with it: “I was a Christian, but just I didn’t go to church for quite a long time. So I start actually praying when I was sick. So I decided to go back to the church.” Prakash drew on his Hindu beliefs and started each day with a prayer to cope with his illness.

I wouldn’t call it a medicine but a way of, you know, curing it [cancer] in my own way...that’s what I, you know, sort of planted—that, God bless, everything’s going to be okay and I have no problem. So that’s how I start my day every morning.”

Brenda talked about how a “reliance on a higher power and strength in that belief that I will be okay” helped her to move forward each day as well. Martins remembered that every night before going to bed, his mother would say to him, “Let’s sleep with God, tomorrow will be another good day maybe.” He explained that “[life] was taken like it is

[in all its parts]. God is there to help along.” Although he was ninety when he shared this story, he said that he still recited the same prayer.

A discourse of acceptance of whatever life brings appeared in the participants’ stories. Several participants connected this attitude to broader cultural beliefs about the natural cycle of life and death, which helped them make meaning of their illnesses. Martins talked about the natural rhythm of life that he learned about growing up in a small country in northern Europe.

I was born out in country and my country was 75 percent farmers so kids grew on farms and, of course, growing up on farm comes very much folklore about many things — not only about life and so on, but about religion...[and I learned that] everything goes around and around.... So the whole universe is tied up in a certain, you know, rhythm.

Prakash also talked about how the events in our lives fit into a pattern even if they appear to be haphazard. This knowledge helped him to make sense of his cancer diagnosis.

So we have to accept, you know, that your illness is for some reason there.... We all going to die. What’s the difference from dying from cancer or from something else? I’m looking at everything as a random, but, you know, things may look chaotic but in every chaotic state there’s a, a order.... So you should not be afraid of death. You should start accepting it.... Life is a journey and, you know, no matter what you do, you’re going — at the end of the cycle, it’s going to end.

Similarly, Brenda lives with the “awareness that we’re only going to live for a certain length of time”, and, therefore, each of us will die of something at the end.

The participants’ stories showed that they took for granted many of the beliefs and practices they were using because they had drawn on them more or less for most of their lives. For example, as Theresa said, “You know, it’s kind of part of our living [to use] the Chinese herbs.” Similarly, other strategies such as regular exercise, sleeping well,

taking vitamins and eating a proper diet were viewed as everyday common sense ways to be healthy.

I did some vitamins...I watch my diet and I eat healthy and make sure I take my medicines...you eat right and exercise and, you know, sleep well and this is also very healthy. — Mary Kovacs

Many of these activities cut across cultural knowledges as well — particularly regarding the use of herbs and foods that were considered medicinal.

Certain herbs, condimental things have the same use in many cultures. An example is, say cumin, say cardamom, say mint...oregano is another one...you see oil of oregano [here] for infections and things, but oregano has been used for years in all of Eastern Europe for cramps, for menstrual cramps, for, ah, premature birth.... Food too, food is another thing — most cultures have an idea that certain things are good for this, certain things are good for that. I always like garlic and onions [because] their ability to be easily digested and, um, helping with healing. We use, ah, garlic for a bunch of things — as medicine in my country...[although] we don't eat the amount of garlic that the Chinese people eat [for example]. — Frida Bahena

What appeared to change for some study members after their diagnosis or as their illness progressed was more frequent and conscientious use of these approaches. As Frida pointed out, “I always eat garlic and onions, but now I eat them conscientiously.” Fiona increased her exercise routine — she started to take a walk everyday. “I did exercise before [cancer], but, ah, not as persistent. But after the illness, I am doing it everyday.” Sarah explained how she had historically only used Chinese medicine sporadically because of its bad taste and the inconvenience of preparing it. This pattern changed during her treatment for cancer.

[During] this treatment path, I've learned to grow stronger in the belief of natural approaches. I'm familiar with natural approaches and I, I'm not sure how to explain it...like Western medicine taste better than the Chinese medicine [laughs]. So sometimes for the convenience sake or from just

emotional state, I would pick Western medicine [before — like] for a cold it's very convenient than boiling the Chinese medicine. Even though I have the belief [in Chinese medicine], I may still just give up this belief and take something for convenience sake. But then now, chemo is such a painful treatment, you know, and I think at that time then it really tests my will. Then I really don't mind making the effort of making Chinese medicine and drinking this bitter black stuff. Yeah, so [using Chinese medicine] grew during the treatment.

Brenda also started to attend Native healing ceremonies as often as possible after her lymphoma diagnosis: “[Now] I go every time I can.” Prakash initiated regular practices of prayer, meditation and visualization when doctors told him that, “Nothing [i.e., Western treatments] will work for you, unfortunately.” Similarly, Frida explained that she used complementary remedies more frequently when she moved “into the home stretch of serious cancer.” Frida has no illusions that either Western or complementary medicine will cure her, but she believes that combining the approaches may allow her to live a little longer.

I don't think that, ah, going to the herbalist or going to the acupuncturist will cure me. The same as I don't think that [the Western] medication that I am receiving is going to cure me, but for sure if I can put in a little bit and I can gather up a few other things, and my doctor can give me some treatment — I'm going to live a longer time than I would otherwise.

I'm fighting this damn thing

Perhaps most importantly, the participants' experiences revealed how the deliberate application of local knowledges and strategies to combat illness gave them an opportunity for active participation in managing their health, rather than passively receiving treatments determined solely by their doctors. As Sarah said, “I think there are lots of things I can also do [in addition to taking medications]...I wouldn't [act] as if I don't have any responsibility in making myself healthy, in making myself well.” This approach was reflected in Fiona's story as well. Frida emphasized that when she adds her cultural strategies to the mix: “It's help[s] my attitude [because] I'm fighting this damn thing.”

Taking charge in this way also appeared to be a way to resist the discourse of biomedicine that recognizes and values only Western knowledge and treatments.

I am of a peasant origin and we did all kind of things [treatments] because there was nothing else to do.... So I need to have a little room for myself — [so] for my stomach ache I don't need to take Pepto-Bismol — maybe I go and get a couple of herbs from the garden [instead]. And I'm fine for that. What are you going to say about that? What are you going to do about it? That's how I see it — as, ah, as adding something [to my care]. — Frida Bahena

Learning the 'Canadian' (mainstream) way

Many research participants shared stories about how they sought to learn as much as they could about mainstream health care systems so as to benefit from them as fully as possible. Several paid particular attention to the expectations of health care providers and protocols, and then deliberately altered their performances to meet them. For example, Brenda and Sarah learned to prepare for medical appointments by creating a list of priority items to discuss to make the most of the time allotted to them. Brenda also learned to be “much more verbal” in her interactions with doctors and nurses. She became more proactive by asking questions and expressing her concerns to care providers. Brenda's experiences revealed that this direct approach was more likely to elicit the information and action she required. Brenda explained that she developed this assertive approach after her cancer diagnosis — she pointed out that it is different from the traditional ways of many Native people.

Oh, I'm much more verbal [since my diagnosis] A lot of our people I think are very [quiet]...they don't verbalize a lot. I think I'm probably a bit unusual [in this way] with our First Nations people, especially at my age.

Theresa also described how she is much more direct and assertive in her communication with doctors compared to older Chinese people. She explained how her mother will not express her complaints to her doctor, and how she views Theresa's push to do so as the 'Canadian' way.

T: *Like my mom. She has a Chinese family doctor. But I tell you, whatever the doctor [asks], she said is okay. Even if they talk in Chinese — okay, everything is okay. I said, “Mom, it’s not okay, you know. You do have something you have to tell him because you don’t feel well, you have to tell him it’s not really always okay.” Like, you know, [she] get a pair of eyeglasses from him...she came back [from the appointment] and she said, “Oh, this thing is not really quite right, keeps sliding down.” I said, “Why you didn’t tell them at the time?” She said, “Oh, maybe it’s okay.” I said, “It’s not okay.”*

H: *So the doctor does a certain kind of treatment, or like provides eyeglasses, if it’s not okay, she won’t say.*

B: *Oh no, they won’t say. They won’t say. Especially the elderly ones. You know, ah, basic Chinese cultures — they won’t complain.*

H: *Now what about you though — will you say?*

B: *Oh, yeah. Because, well, I am in Canada. If in Hong Kong, I think maybe I will complain but not that much..... [My] mom said, “You are so different...”*

H: *So she sees the difference, she sees the changes.*

B: *Oh yes. She sees the Canadian culture [in me], you know.*

Prakash also assumed new ‘Canadian’ behaviours. He learned that it was not helpful to “rush” health care professionals or to circumvent existing protocols, but rather to respect existing mainstream systems and work with them. He discovered that there was a “right way and wrong way of doing things.” Mary adopted a similar attitude when she was admitted to the hospital. She perceived that her role as a patient was to adjust to the routines of the unit and the care providers, and she made a conscious decision to do so to make it easier for herself there.

[You] have to accept your surrounding and try to be patient...you have to accept it, you know. That’s what is at present and you better be happy about it.... I have to make a decision with myself and, and that’s what I try

to do, you know. Accept the people around me and accept the way they behave and how we are.

Theresa and Frida were already familiar with the ways of hospitals and clinics because of their professional nursing knowledge and experience. They had an insider understanding of protocols and systems, which helped them to manage effectively within them. As Theresa said, “I’m a chemo nurse so I know all those things, you know.” Similarly, her background as a nurse promoted smooth interactions with her doctor because she already knew so much about health care treatments and practices: “Because the oncologist knew that, you know, I’m a nurse...we have no problems.” Frida explained that her nursing knowledge also facilitated positive interactions with health care providers because she not only knew what to expect in mainstream health care, but she also knew the limitations of the system.

I know the limitations [laughs] and I am used to live with them [as a nurse]...my profession taught me that there are things, things that you don’t do in healthcare regardless of the, of the circumstances.

Cultural identities are fluid and versatile

From these stories, I observed how cultural identities comprise diverse parts, and how the participants fore-fronted different aspects of them in different contexts. They adopted new beliefs and learned other practices, or maintained or modified previous ones depending on the circumstances. As Theresa said, this is how a “merger with the Canadian culture” occurs — “your view changed and your thinking changed, you know, [although] not totally.” She tells a story that illustrates the fluidity of cultural practices in her family. Theresa broke from Chinese tradition by openly discussing her diagnosis and prognosis, as well as her funeral plans, with her husband and two daughters. However, she does not talk about these things with her elderly mother because it is not the “Chinese way” to do so.

For Chinese, we don’t talk, they never talk about death. Especially like in my mom’s generation, you know. They don’t, don’t talk about it at all. So like a secret, okay. They hide it. They would never talk about it. And then, um, when I knew that I was sick, you know, well, I talk with my

husband actually — well, this topic needs to be talked [about] okay, even though I don't know how many years I will live, you know. And then, um, I like to have, you know, all the preparations done. All those things, you know. And I talk to my daughters, you know, about it, all those things...this is kind of like a Canadian way. It's quite different from our Chinese way. And then, um, definitely every time I talk about it, my mom said, "No, no, I don't want to hear anything about those things, you know." Yeah, that's the traditional [way]...a restriction to talk [about] those things. So [my mother and I], we are just talking about pleasant [things], you know.

Frida also spoke about how she is made up of diverse cultural parts and practices and that she continues to add new pieces and let go of other ones. Culturally, she described herself as an “unfinished quilt.”

[I am] an unfinished quilt. I don't think of myself as [one identity]. I know I am Chilean, I love many things about my country...and there is a bunch of things I like in Canada.... [I am] an unfinished quilt with all the new pieces. I keep on adding and taking away and redoing it...[I have] Russian pieces and Mexican pieces and Indian pieces and Chinese pieces because there are relationships, and you get to know people and, ah, you like things and you kind of incorporate them.

This reflects what Prakash talked about as well, which I discussed earlier. He viewed Canadians as a “mixed bag” of cultural identities that include traditional beliefs and practices and new Canadian ones.

[All] the people [in Canada] are immigrants or second, third generations even today. They've adapted to Canada, but they still haven't forgone their roots, too. I've noticed Italians, Chinese, Vietnamese — they all still holding [onto some of their traditions], even the newer generation, even though they may be modern Canadian, whatever, born [here]. They still hanging onto the tradition...[but] at the end of the day, they are still Canucks just like us. That's what I mean.

Paradoxically, what makes us the same is that we are all made up of different cultural parts. From this perspective, the significance of difference diminishes. Brenda said that First Nations peoples reflect a similar integration of many cultures.

We're integrating more, before we were very separate. Like different religions. But now everybody's borrowing each other's things and their ways and stuff. Yeah, it's much more than it ever was...I don't know why — maybe because we're not so isolated with our differences.

These experiences show that cultural identities are dynamic and shifting. They include an evolving combination of different beliefs, knowledges and practices, which the participants drew on variously at different times and circumstance to manage their health and illness.

Mainstream medicine is best for you

The participants' stories showed that most of the professionals who provided care to them were not generally receptive to the idea of combining local cultural knowledges and practices with mainstream medicine. The responses of care providers to diverse approaches ranged from benign indifference to active rejection.

In most instances, doctors were simply uninterested in the participants' beliefs regarding their illness or the complementary actions they were taking to address it. David said that "as a general rule" he had never been asked about these things: "I mean I've never heard them ask anyone." Nathan said that the only person who ever asked him about his Jewish beliefs and practices was a care aide: "She was sort of curious, but the nursing [staff] and that, no, not really. There is no connection there with regards to that [type of thing]." Prakash said that: "Nobody has asked me about [these things], period, until today." Brenda suggested that some care providers are simply indifferent about patient activities that fall outside of their experience. For example, when she brought sweet grass to her radiation treatments, she said that the technicians did not react: "I don't think they even cared or noticed hardly."

It was also apparent from the participants' experiences that some doctors viewed complementary approaches to care as inferior to Western medicine. Nathan experienced an interaction with his oncologist that reflects this perspective.

[My] oncologist really isn't into alternative medicine... "Relaxation," she says, "yeah, that's great, but, you know, the naturopath or, you know, all [this] other stuff [you're considering], it makes you feel good, but" — and this is the first time I saw her — "it makes you feel good but in the end you come back to us."... So I wasn't very impressed with that.

What appears implicit to this attitude is the belief that the 'doctor knows best'. Moreover, this notion of being the expert with the most relevant knowledge may apply to more than complementary medicines — it can also supersede the knowledge of other Western health care providers, and that of patients themselves. Nathan shared a story about how his surgeon dismissed the assessment of another medical doctor, several nurses, and Nathan, regarding some complications he experienced after a colectomy.

N: *I had the surgery and I, immediately I was having complications called pouchitis, which is inflammation of the pouch. [It's] just like having colitis in the pouch. I went to the surgeon and he's like, "Oh no, no, no it's not pouchitis," even though all the nurses, like the ileostomy nurse, and my GI (doctor) all said, yeah, it's pouchitis because it's quite common for that to happen [after this type of surgery]. He said it wasn't, so basically I had this pouch, but it was constantly inflamed.*

H: *So he just didn't take other people's interpretation of this as valid?*

I: *Yeah, yeah basically.*

H: *Nor your opinion?*

I: *Yeah, exactly. He's the arrogant, typical arrogant surgeon, right — very good at what he does, but no listening skills, you know.*

Like Nathan, Sarah also did not feel that her doctor took her assessment of her new symptoms seriously.

S: *I felt bone pain and I'm very concerned about bone mets, [that it's] metastatic and I feel that it's a big thing. It's big enough for me to call the oncologist three times, and I didn't even get a phone call [back]. [So] I went to my family doctor and requested a bone scan. [But] I wasn't able to reach [my oncologist in the meantime] or to set up any appointment earlier than my next scheduled one.*

H: *So you went to your regular appointment and he had the bone scan results...what did he say?*

S: *He said, "Yeah, it's nothing, it's good." That's it [laughs].... He didn't even explain why he didn't get back to [me]. I said, "I called you three times, did you get the message?" And then he said, "Yup. And your bone scan result is fine, so it's clear."... I always feel, I don't know, speechless, like, from his response.*

Sarah's story revealed an unfortunate indifference on her doctor's part to her worries and interpretations.

On the other hand, Frida's experience demonstrated an exception to this attitude — her family doctor appears to value her knowledge and expertise.

I think my relationship with my doctor is, uh, is unique...it has been developed over the years.... [There] is a trust that builds, that was built through the years. So if he hears me pushing for an appointment, for example, he said from the back [of the office], "Let her in." Because he knows I won't be pushing just because I peel a knuckle. He trust my, my, judgment and the importance of what is, what is necessary. But the other is that I respect my doctor. I respect his time, I respect his, his judgment and, uh, and he respects mine too.

Similarly, Brenda described that her doctors became more interested in her opinions and cultural activities, and she became more inclined to share them, as their relationships evolved positively. This usually occurred over time as they got to know one another: "We just developed a [positive] relationship so I would tell them." Brenda took special

Native medicines and attended healing ceremonies regularly, and she would talk about these activities with her care providers if they were respectful of them: “If they asked me, sure I would [talk about these things].” However, she did not share this information when she thought that they might judge her cultural activities, which to Brenda are “too precious for me to have [them] negated, misunderstood, or whatever.”

Judgment stops information-sharing

The experiences of other participants also revealed that they stopped sharing information about cultural strategies they were using when health care providers minimized their practices in some way. At those times, they appeared to resist the discourse that the ‘doctor knows best’ by continuing to use complementary medicines without telling their physicians about them. For example, as noted earlier, Fiona continued to use the remedies prescribed by her Chinese medicine doctors, but she stopped telling her oncologist that she was doing so because of his negative judgments about them: “He’s a very opinionated man.” Sarah thought this practice of not disclosing information was widespread. She believed that many Chinese patients use some type of Chinese therapy without necessarily telling their Western doctors because of their anticipated disapproval.

They may not necessarily disclose that [they are using complementary therapies], or even if they do disclose and got objections, they may continue [using them].... [For example], there’s some capsules, you know, Chinese medicine capsules. Like a lot of the Chinese cancer patients strongly believe in those and we are taking them despite the oncologist either they recommend or go against it.... There’s also — it’s some sort of mushroom pills...that I can almost say 99 percent of the Chinese patients I’ve known are taking them if they are diagnosed with cancer. Um, and despite the fact that the oncologist would say no to it, they would take them secretly.... We just go for our preference. Yeah, I think that. If we are cancer patients and we are Chinese almost, I would say 98 percent, they see their Chinese doctor or acupuncturist or they would see a Qi Gong.

The stories of several participants also revealed that they did not share cultural information because they did not feel that they required approval or endorsement from their doctors regarding the appropriateness and/or relevance of their cultural beliefs and practices to their health care. This was apparent in Brenda and Prakash's experiences as well as Mary's. She shared information about her religious activities with her home care nurse when he "caught" her praying, but otherwise she did not feel a need to share her beliefs or practices with him. "I share with him...because he always caught me...when he came and I had a rosary [and was praying]...I said this is what I do and that's what gives me strength, that's all."

The participants' stories showed that they shared the perspective that there are various ways to address their holistic care needs based on a range of cultural knowledges and practices. Mainstream Western medicine offers an important contribution to this care, but there are also other valid local cultural approaches that can be effectively combined with it. Frida highlighted this point during our last interview:

[What] the cancer agency offers me is — how can I say — rock bottom, the baseline of the care that society can provide for us. [But] there is many other things that are out there that we little people start or create...it may sound weird, but if so many people think the same weird thing it might be right. So I'm taking some of [those] medicines [too].

Relational-collaborative care

As I listened to the participants tell their stories, I kept hearing how important it was for them to have positive and collaborative relationships with their health care providers. These appeared to occur with professionals who were respectful, compassionate, sensitive and fully engaged in their interactions. Positive relationships were further developed when health care providers took the time to review the participants' health status and their treatment options, and involved them to the extent they wished in care planning. The study participants also felt reassured when physicians were consistent and easily accessible to them. The combination of these attributes and actions appeared to promote health care partnerships that were cohesive and collaborative.

You are dealing with an individual

The participants' experiences revealed that the creation of positive and collaborative relationships started when care providers recognized them as unique individuals. Martins spoke about how health care institutions are so "very, very big" and how patients can "get lost" as individuals within them. Nathan emphasized how important it was to be viewed as "a human being [and]...not just another number" in these large systems. He talked about his experience at a local hospital where he felt like he was just one of many patients who needed to be moved through the system as quickly as possible. "When I was at [the hospital] they couldn't wait fast enough to throw me out. It's like you're treated as a number." Brenda also felt like a generic patient when she received her radiation treatments. She said that the technicians were "very unaware of [her]. It was almost like automation," which left her feeling "objectified" throughout the therapy. Similarly, Frida talked about medical residents and nurses who were so focused on completing routine tasks or reviewing information about patients that they missed the opportunity to make a connection with them.

[There] are some [residents] that they are just walking [in] and say, 'hi, you are so and so and blah, blah, blah, blah and your lab work is blah, blah, blah' and they don't even know who [the person] is [they are talking to]...that happens also with the nurses...the last three times the nurse who comes to get me to [take me] to the room doesn't even say his name. And, ah, not that you're going to remember most of the time, but you remember the ones who didn't tell you [their names].... Most of the time I find, particularly with all the new technologies, that we forget that we are dealing with a person.

Theresa was also reassured to be seen as a single individual and not just another patient on the assembly line of health care — to know "that somebody is really looking after you as a whole...[that] you're not just, you know, some body coming in."

He makes you feel that he has all the time in the world

The participants identified several ways by which professional caregivers can recognize and connect with patients as unique individuals. As discussed earlier, Brenda

stressed how important it is for care providers to be present and engaged in their interactions with patients. The ability to connect in this way is a skill that can be acquired “because you can [learn to] make a patient feel like, ‘wow, you have my undivided attention right now’ — there is a way of doing it” (Frida). Brenda’s oncologist had this skill: “It’s not very long that we’re together, but when we do he has the ability to connect [with me].” In her experience, this capability comprised eye contact, active listening and physical touch.

[When my doctor] is with me, okay, he is present for that very short time...because he will shake my hand and he will look at me and say, “How are you, Brenda?” And ask me whatever. And then I know...he is there with me.... And it, [it’s] just a feeling I get that he’s completely involved in my case.

Theresa also spoke about how physical touch conveyed the message that her doctors cared for her — that they were there for her.

Sometimes they will give you a hug, you know, they have some body touch [which says] you know, ‘okay, actually we’re here for you and we know you are sick’...

Sarah described quite a different experience. She found that her oncologist was not engaged with her — he often appeared as if he had already moved on to his next activity in his mind.

[He] might just come in [to the appointment] and sit and like, as I said, I always have questions prepared, right, and I might ask a question and two questions and [he’ll] say, “Is that it?” You almost feel like he wanted to leave. Ah, and he would answer, he would give you quick answers. So you can feel like, you know, he doesn’t have time and also I can feel like [it’s] as if he has something to do next and he’s rushing.

Similarly, Nathan recognized the cue that his doctor had disengaged and moved on to his next task when he repeats the question, “Is that all, is that all?” Nathan felt then that he “get[s] short shrift” in terms of attention and time.

Moreover, the participants revealed in their experiences that when doctors do not engage and take the time to review medical information with them, they are left feeling confused and uncertain about their status. For example, Martins did not know how much of his liver had been surgically removed because no one had taken the time to explain the disparate pieces of information he had received from different doctors about this procedure.

I don't know how much they cut out...I read somewhere that they say 'left removed' and [then I read] 'right removed'...[and] according to [other] doctors there was a tiny bit, very small [part removed]...and so I never had a really clear picture.

David had been similarly confounded when doctors moved through appointments quickly and communicated only in medical language.

There's been some times in the past that I've had doctors where, you know, I've come out of the office feeling kind of like I didn't really understand a word they said, you know, because they talk a lot of medical talk and medical jargon and medical terms.

When doctors did make time for the participants and stayed engaged with them, they felt that they received good care. Nathan described aspects of positive interactions with health care providers — he specifically identified enough time with them as a key ingredient.

They're approachable. You can have a conversation with them. They give you the time. My GI [gastro-intestinal specialist] is a perfect example. I go in there, I can have a conversation for — whether it's five minutes, ten minutes, 20 minutes. I'm not rushed out, you know.... I had excellent care [at his clinic]. The nurses were excellent, the doctor was excellent. Because they took the time.

This was also his experience with home care nursing — “they give you one-on-one care, they take the time, they listen to you.” Frida echoed this theme when she talked about her relationship with her radiologist.

F: *The radiologist that I have seen is a very — he's a very thorough man, human, person. He's, he makes you feel like he has all the time in the world.*

H: *He does.*

F: *Yeah. And, um, I was very, very comfortable [with him], you feel very comfortable talking to him, asking him questions and giving him the answers and being there one way or another — [the time it takes] doesn't bother him.*

H: *Okay. So you don't feel rushed there?*

F: *No, no, no, not at all. No, I don't have a complaint in that regard. I have heard bad stories but they haven't happened to me.*

Although David had experienced some of those “bad stories” when he had been rushed through appointments by specialists, he also stressed how helpful it was when physicians slowed down and took the time to explain his health status. For example, he was impressed when his internist drew a picture for his partner to illustrate what was occurring to David's pancreas during a recurrent bout of pancreatitis.

He even drew a diagram for Barry. I mean that's pretty unusual to sit down with a marker and a piece of paper and show him what the different parts of the pancreas were and, you know, what happens [with them]...the extra time that some doctors take to explain certain things to you [is helpful], you know, because they've got to know we don't read, you know, medical dictionaries.

He also appreciated the attention and time that his family doctor readily provides to him to review his concerns: “[He'll] spend however long I need. I've been in his office for 40 minutes sometimes.”

Respect is fundamental

The participants' stories highlighted that another important feature of a positive relationship is the presence of respect in interactions with health care providers. Frida

identified respect as essential to good care and she suggested that to be disrespectful of a person's sense of self can be iatrogenic at a very fundamental level.

I think something that I consider is very important is the respect. To me it seems that any interaction between people there is something that we all share and that is the little kernel of our beings that cannot, that should not be hurt. Because that is the one that helps us heal and recover and be who we are.... And I think it's, it's a boundary that shouldn't be crossed, doesn't need to be crossed...don't, don't touch my soul, kind of thing.... That is for me very important — in health care like in everything else, I guess, but I think in health care it is very important.

Frida also reflected on her experience as a nurse and how she felt that the respect she showed to patients contributed to their progress and recovery: “[In my] interaction [with patients], for example, they feel respected. They feel, uh, safe. They feel that I am helpful...[and] they can trust you in such a way that they go forward.”

As noted earlier, Brenda stressed how vital it was for care providers to respect her cultural beliefs and practices because they are part of her identity and “too precious” to be judged or minimized. For similar reasons, Theresa expected care providers to respect her experience as a nurse, and acknowledge its relevance to her care. She concluded that respect for patients is important whatever their background.

I think, you know, if they [care providers] ask me, I would tell them I think they have to respect me. Especially [that] I'm a nurse. I know all those [medical] things too, you know.... I think they, they should respect everybody, you know, even if they are not a nurse.

The participants' stories revealed that when health care providers showed respect to them, they felt a greater sense of equality between them. Theresa highlighted this point when she compared her experiences as a patient in Hong Kong to those in Canada. She found that doctors in Canada were more respectful of patients than their Chinese counterparts, and subsequently less authoritarian.

In my culture, I think it's even worse.... I think, you know, here all the doctors, nurses — they, they really respect their patients...but in Hong Kong, the degree of respect is [less], hmmm, they just treat you like patients...and they are doctors — [they] are really high, high up there. They just come in, you sit down, and they just tell you [what to do].

It is important to know you matter

The participants' stories showed that this hierarchical gap was further reduced when care providers revealed that they were personally affected by their patients' experiences. When they shared their feelings in this way, they demonstrated that patients mattered to them as individual people. Fiona told a story about a doctor who shared her sadness about a palliative patient in her practice.

There's a Chinese doctor I met who's telling me that [she's] looking after this person [and] she's still okay, looks okay now, but we know that [she will decline]. [She said], "It is very difficult." She said, "Sometimes I cry alone because when I see this patient she's still okay today, but we know that she has only a few months [left to live]." So from that incident you can tell that the doctor, uh, that doctor or some doctors take practicing medicine as a mission rather than just a duty, rather than [just] a job.

It appeared that part of feeling cared for is to know that health care providers are not just fulfilling a professional role, but are also touched personally by what happens in the lives of their patients. This display of vulnerability highlighted their humanness and made them less remote.

This may also occur when care providers acknowledge their mistakes and their impact on patients. As discussed before, David still wondered whether his nephrologist felt any sense of responsibility for David's blindness or whether he was untouched by what occurred and simply viewed David as just another patient with an unfortunate outcome. "I don't know whether he feels it the way I do or whether he just sees me as a patient that lost his sight." Similarly, Nathan was disappointed that his surgeon never acknowledged that mistakes had occurred during Nathan's first surgery. He believed that the common

assumption that doctors do not make mistakes precluded a candid admission of responsibility and a related expression of regret.

[There] is a lack of accountability. No one wants to take responsibility for their mistakes or even admit they made a mistake.... [This] thing, you know, [of] putting the doctor up on a pedestal like they can do no wrong is long gone for me. I don't think I ever had that association, but that's what some doctors still want you to think.... I had that with the surgeon that did my initial surgery. You know, he's a good surgeon, but in terms of admitting wrong — forget it. It's never going to happen.

Frida challenged this physician location and attitude. She resisted the discourse that places doctors hierarchically beyond reproach. She did so because she wanted a relationship with a doctor wherein she could safely express her concerns and expectations. “I thought — well, am I going to have a doctor that I am afraid to raise subjects [with] or am I going to have a doctor that somehow fulfills my needs?” Frida put aside the assumption that her physician would not accept criticism. She explained to her doctor how she felt unhappy about the way the doctor had previously treated her and she received a very personal and positive response.

But when at the next [appointment] she came in like nothing had happened [during the previous interaction], I say, “Well, well, well, before we start this business, let's talk.” And that was it. And the best thing was that she apologized and she says, um, she just said, “Would you accept my apology if I said I'm sorry?” She didn't try to make excuses. To me it meant like she recognized [her mistake].... And it was a very positive outcome and I was very, very happy with her response. And, uh, I have never felt sorry about my decision. She, she was all I wanted.

The participants' stories also showed that the connection between patients and care providers was strengthened when they put aside their designated roles and related boundaries, and occasionally acknowledged their personal sides. Brenda expanded her relationships with her doctors by deliberately relating to them on this personal level.

I took some time to say, “How are your children,” or something like that. And I would give them — I would buy them flowers or a card quite often. And then I watch the doctors and they said the same thing — that they like people sending them a card or something, acknowledging them. I guess their humanness is always there.

These experiences showed that it was important for the participants to see their care providers as whole people who cared about their work and them.

Compassion, sensitivity and hopefulness

When participants and care providers connected at this personal level, greater degrees of trust and comfort developed. Several participants identified these as important attributes of caring relationships along with sensitivity and compassion. When David talked about his relationships with doctors and nurses, he said that “compassion [is important]...and sensitivity and trust, and, um, being comfortable with, you know, one another.” Sarah noted these as well in the care she received from her chemotherapy nurses: “They are all very compassionate and very sensitive and, yeah, very caring.”

The study participants also identified encouragement and hopefulness as important aspects of compassionate care. As discussed before, Fiona wanted her doctor to focus on optimistic possibilities rather than dire prognoses. “[The doctors] don’t have to tell, keep saying that it can’t be cured, [but instead say] we [are] trying, we [are] trying. It’s hard to cure but we’re trying.... So I think doctors should encourage the patient.” Prakash also stressed how care providers should not keep the focus only on the inevitability or imminence of death: “You don’t have to focus it on me, [that is], ‘now you’re going to die, now you’re going to [die]’, just tell them once.” Similarly, David described good care as a combination of clear, sensitive and encouraging communication about the seriousness of his status. He explained how his family doctor provided this support to him.

He’s got a good bedside manner, you know...I mean he’s not, he doesn’t candy-coat it [medical information] or anything, but, you know, he explains it to me in a way that I understand it and he’s always reassuring.

Continuity promotes excellent care

The participants' experiences revealed that the continuity of care providers made a positive difference to their care. Nathan saw the same doctor for many years for colitis before his cancer diagnosis. "[I] saw my GI [specialist], you know, every month and a half and, you know, I had excellent care there." Longstanding relationships with care providers also contributed to comfortable interactions between them. As David said, "Dr. T [family doctor] and I can talk about everything."

When continuity was lacking, quality of care appeared to diminish significantly for several participants. Nathan described how the absence of his oncologist negatively affected his experience of care.

[My oncologist's] been away pretty much the whole time [since my diagnosis]—the past two years on sabbatical so I haven't been, I haven't been getting continuity of care because I'm always having a substitute oncologist fill in for a couple weeks so no one really knows my whole history. I mean she's back now, but to be honest, it's been pretty piss-poor. I mean how can you get good care when you are constantly seeing a different person every, every two weeks or every month?

Martins also described how his care was delegated among several doctors — most of whom did not follow up with him.

M: *And they choose themselves three or four doctors who will look [after me], to follow [my care], and nobody showed up.*

H: *How do you mean, 'nobody showed up'?*

M: *Well, I saw from one [doctor] eventually...his job was to look [after me] after the operation, to guide me, look after me — [but] he didn't do anything.*

When there was a lack of continuity among care providers, several participants described how they felt an added burden to keep track of all aspects of their care to ensure that mistakes were not made and nothing was missed. As Nathan described, "You've got to be on your toes, you basically have to be your own advocate," which he

says takes a great deal of effort. “It’s really appalling the amount of effort that I’ve — [that] me and my family have had to [expend] just to get things right.”

Theresa also felt that she had to assume a vigilant role in her care to ensure that it was provided properly by her different care providers. Frequently, she disclosed that she was a nurse, which appeared to add credibility to her concerns and suggestions. She described an incident when this disclosure was necessary to support her request for a different dressing for her intravenous catheter.

They [the clinic nurses] said, “Oh no, it’s [a particular dressing that’s] supposed to be [applied].” They have to use this kind of dressing [for the catheter]. I said, “Well, I tell you...I know my skin is allergic to that.”... I just hate, you know, [to] tell them I’m a nurse, okay, [but I did]. Because, you know, every time I told them I’m [a] nurse and then they are, “Oh, okay, then we’ll do those things” [that I suggested].

Theresa’s point was that she did not want to take on a nursing role while receiving treatment. She just wanted to be a patient, who would be taken care of capably by the professionals around her: “I just want to be, I just want to put my nurse role aside and I just want to [be] here to be a patient.” The experience of feeling cared for seemed to occur when the participants could confidently rely on the skills and knowledge of the same care providers over time.

To see the doctor is (most) important

The participants’ experiences showed that their confidence and sense of security in their relationships with their health care providers also increased when they were easily accessible to them. For example, Frida spoke about how she appreciated her family doctor’s availability. “Any time I want to see him he’s available and he has given me time and, ah, long appointments if I need to. All those things help [my care]. [He’s] very, very accessible.”

Conversely, participants described feelings of frustration and anxiety when their care providers were not available to them. For example, Nathan spoke about how he was frequently frustrated by the lack of access to, and slow response of, local doctors to his

concerns. This feeling was exacerbated by the fact that an oncologist he had consulted in the United States months before continued to respond to his questions promptly. “If I have a concern and call up [the doctor here], it could be days before I get a response. Whereas, I’m still in contact with the oncologist in [the U.S.] — for the most part he’ll respond within an hour, you know, or within a couple of hours.”

These feelings of frustration and anxiety were also conspicuous in Sarah’s earlier story of when she developed a new symptom of bone pain. It is a symptom that can indicate the recurrence of breast cancer.

There was [an] incident [when] I experience some bone pain. It was really painful on the ribcage on the side where the breast cancer occurred so I was really worried it’s a metastatic cancer so I was really anxious. So I, I tried to call my oncologist hoping I can arrange a time to see him, and I try to call three times...three times I left a message. I say, “Please tell my oncologist so and so,” and my oncologist never, uh, get back to me. And the third time I was like, I was really anxious. I was, like, I really hope to see him at least—even though if he strongly believe it’s not a bone metastas[es], I like — it would be a relief for me if he tells me in person after doing some examination.

Sarah needed to have access to his expertise sooner rather than later — it was his assessment and reassurance that she required to ease her worry.

Even when other health care team members were available to the participants, direct access to physicians was still very important. Several participants talked about how they were reassured by personal examinations by doctors — their assessments and recommendations generally superseded those of other care providers. For example, David explained why he would like to see his nephrologist more often in the dialysis clinic.

D: *I rarely see my [nephrologist] there. The only time I see her is if there is a problem with my blood work or if she needs to increase my goal weight or, you know, something like that.*

H: *And how would it be helpful to see her more frequently?*

D: *Well, I don't know. It just makes you feel kind of like you're a bit more being watched over and taken care of, you know, instead of [at a distance] because everything goes through the nurses to the doctors [otherwise]. There's no direct contact really between doctors and patients unless something, you know, significant comes up...you tell the nurses and the nurses will write it down and then, you know, if the doctor thinks something is necessary to see you about and they'll come and see you. Otherwise they don't see you...the nurses can come around and do whatever, but it's when the doctors come around I feel a lot more secure [about] the information I'm getting from the doctor than I do from, you know, a nurse...the doctor is the one that ends up making the final decision anyway so I guess, you know, especially if I'm not feeling well or something, you know, I just want to see the doctor.*

Although Sarah also desired easier access to her cancer doctors, she did try to adapt to their busyness and inaccessibility by turning to other team members when possible. However, she pointed out that not all doctors have teams to contact, and those who do, lack continuity within them.

S: *In general, I found that they [doctors] are very busy persons...the nice thing is they have assistants around them to help. For example, like my surgeon, you know, she also has a nurse who joined her in the discussion. And I found that the nurse had more time to explain things and to talk to me. Or if I have question I can call her and ask... [With] my oncologist I find it's hard because I don't even have a direct person I can talk to in his team.*

H: *[There] was no nurse on his team?*

S: *No,...he also has different, um, I would say assistants or intern students or residents, but they are always different.*

H: *Because they are always rotating through.*

S: *Yeah, they always rotating. Like, you know, they always different so I don't have familiar faces within his team or any direct contact with any of his team. And so that's why I feel, um, a much better relationship with my surgeon's team than with my oncologist team.*

Furthermore, Nathan suggested that health care facilities need to expand the times when care providers and services are available to patients. He pointed out that medical problems and symptoms do not follow a Monday-to-Friday schedule.

N: *[Part] of the problem is it's a nine-to-five attitude. The Cancer Agency — I don't know if you know this — the pain clinic [at the agency] is closed on Friday.*

H: *No, I didn't know that.*

N: *There is no one there. I mean there is the on-call person but it's not open. So pain takes a day off on a Friday apparently. I think it's absurd.*

The participants' experiences showed how the opportunity for them to connect directly with doctors—or at least with the same members of their team—in a timely manner was very important to their care.

I believe in working hand in hand

Although the study participants depended very much on the expertise of health care providers, this did not mean that they were content to be passive players in the determination of care plans and decisions. Many stressed the importance of actively keeping their goals at the forefront and working closely with care providers to achieve them. David described this partnership as a process “of working together, you know, as opposed to, like, [the] doctor-patient kind of thing [i.e., the doctor makes all the treatment decisions]. You know, working together as a team sort of thing, for the good of the patient.”

Many participants expressed this same aspiration in their stories. Fiona wished that “there could be some input from me for future treatment.” Theresa expressed a desire for information about treatment options and to participate in choosing them: “I really want to know what, you know, treatment they are going to give me and then whether I agree to

those things.” Sarah also stressed the need for physicians to fully explain treatment decisions to her. This was especially important because she would be the one who would live with the consequences of them.

S: *[On the] one hand, I know they [health care professionals] are very experienced, they saw many, many cancer patients before me and they have a lot of knowledge on, you know, cancer and things. Um, but on the other hand, because it's my body and my health and I'm the one who would have to face the consequence of all these procedure and treatment, um, I, at least, I like to find out why you made that decision. Umm, I believe in working hand in hand so I trust the expertise [of health care professionals], but [that] doesn't mean that I would be very hands off, you know, and ask no questions.*

H: *So you would like to have the rationale for that decision?*

S: *Yeah, yeah. I think that's the balance — um, like I love to agree with them, but sometimes I would need some information so I can agree with them.*

H: *Right. So [receiving] more information...*

S: *More information or just provide, like, how you came up with this, with this recommendation, um, so at least we can work in partnership. So it's not like you made all the decision and I'll just, phhh, leave it in your hands. And at the same time, I do need, I understand I need to rely on their expertise and knowledge...but the [final] decision, I like it to be me making it actually...I trust the professional expertise, but I think I do want to get involved somehow in the process.*

As discussed before, Prakash held similar expectations about his involvement in care planning. He wanted the doctors to fully inform him about his health status and the treatment options available to him, and then he would choose how to proceed.

Don't keep me in the dark, it's my life. Give me the facts. Don't matter how good or how bad, but give me the facts...and then I take it from there.

In this case, truth telling helped Prakash understand the limits of mainstream medicine, which allowed him to determine how to incorporate other cultural responses for meaning-making and management of his illness.

At the same time, the extent to which the study members desired to participate in decision-making did vary among them according to their health status and needs. In some instances, they wanted full involvement and in others they expected their doctors to make treatment decisions entirely. The latter tended to occur in situations of medical urgency. For example, as discussed before, when Prakash underwent emergency surgery to remove his lung tumour, he relied on the surgeon to make the best decision in the moment — “of course” the doctor decides what to do in such cases. Similarly, Martins accepted without question his doctor’s recommendations for investigations and treatments when he was admitted to the hospital for acute liver failure.

M: *I arrived in hospital, they saw me yellow [jaundiced] and...my doctor phoned...and you go take pictures and this and that and they check your heart and they check everything...and they decided [what] to do, and it just happened, that’s it.*

H: *So the doctors decided.*

M: *Doctors decided. We had nothing to [decide].*

H: *So you had nothing [to decide] — you or your daughter?*

M: *No, we would take everything [recommended] — [because] you want to live.*

In other situations, treatment choices were neither offered to the participants nor expected by them because established protocols were automatically initiated based on their type of disease and the stage of its progression. Theresa described the clinical pathway she followed after her cancer diagnosis, which precluded active decision-making on her part.

T: *[There was] not really much decision [to make]. It’s kind of, like, that is the way. When I was diagnosed with cancer and...I went to see the surgeon, he didn’t give me the option. He said, “Well, that is the case —*

you will have the surgery first and then you will have the radiation later.”... Then when I saw my oncologist, you know, basically he said, “It’s because according to all those [surgical] findings you are getting this protocol [chemotherapy]. So this protocol is for you.” So it’s a, it’s the oncologist decision, you know, which protocol I’m getting and so I don’t really have a decision on that...

H: *Because the protocols are already mapped out.*

T: *Yeah, it’s just according to this, ah, stage and type of cancer and the, the size of the tumour — all those things, you know.*

Sarah also depended on her surgeon’s assessment to determine whether a lumpectomy or mastectomy was most appropriate for her when she was first diagnosed with breast cancer. It seemed sensible and reassuring to her to follow established practices given her emotional state at the time as well.

S: *I went to see my surgeon and, ah, she didn’t give me a choice of either lumpectomy or mastectomy...she did an examination and then she asked me some questions and afterwards she pretty much say, “I’m going to give you a lumpectomy and I will remove some of your lymph node.” She pretty much told me what she’s going to do. I did ask her, “Well, what about a mastectomy? What do you think?” And she said, “Well, you’re a young woman — we’ll give you a lumpectomy.”*

H: *So there was no discussion.*

S: *There was no discussion. I mean I’m not complaining. In some way, I think it’s comforting. I don’t have to make a choice, um, because at that time I was pretty devastated. I, I wouldn’t think I could make any good decision.*

However, the desire for more complete information and discussion regarding treatment choices increased as the participants became more knowledgeable about their illness and the different ways of managing it. For example, although Sarah accepted her surgeon’s

decision to perform a lumpectomy, she learned later that other options were possible, which in hindsight she would have liked to explore.

[But] after I read the books and learn more about choices, I did question how come she never gave me the choice [to have a mastectomy]. And also how come she didn't use the — there's another technique [where] you can use dye before removing your lymph node — you can use dye to verify if any of your lymph nodes contain cancer cell and then if it does, then remove the lymph nodes. Um, she didn't give me that choice either...um, so when I went home, I read the books [and] I know about the different choices. I actually call my family doctor and discussed with her — I said, "Can I actually get a second opinion? How come I was never given a choice? I like to talk more about, like, other choices."

David also expected to influence treatment decisions when he learned that a particular medication has negative outcomes or side effects associated with it.

[If] I've heard something about one of the drugs, you know, that [there is] some kind of negative [outcome] or side effect or something that I really don't want to deal with, uhm, I'll talk to him [AIDS specialist] about it and, you know, he understands my view and he'll say, "Well, that's okay. We'll go with what we have for now." Or else he'll have another option that I'll be more comfortable with.

The participants' stories also showed that they sought more participation in decision-making as their illnesses progressed and the desire to maximize quality of life outweighed the desire for possible cure or longevity. For example, as discussed earlier, Mary made the decision to not continue chemotherapy when she realized it would diminish her well-being without gaining more time for her: "And I told the doctor, I don't want any more chemotherapy because I was sick and I would not recover. And I make a decision then." Until then, Mary had relied on her physician to make all treatment choices for her. Similarly, Frida had followed her oncologist's treatment recommendations until she felt that their consequences outweighed their benefits in the context of an incurable illness.

My oncologist is the one who makes most of the decisions. And I agree with them. She has sent me to see the radiologist a couple of times and a couple of times I accepted radiology, radiation therapy. But the last time I say 'no', and I think my decision was right and the doctor agreed that maybe I didn't need it...I think she understands my point of view. I want quality of life. I want to live the good days. So I want, I want the treatment for that, not vice versa.

What these experiences revealed is that the participants wanted to be informed about their medical status and the treatment interventions that were relevant and available to them. However, the extent to which they desired and were able to participate in making actual treatment decisions varied among them. Some wished to participate fully while others expected their doctors to make the final decisions based on their experience and expertise. Their experiences also revealed that their degree of involvement in decision-making also changed according to their position and experience of quality of life along the trajectory of the illness.

The study participants' stories highlighted how positive relationships between patients and care providers are fundamental to excellent health care. The participants wanted to feel cared for by health professionals — they wanted to know that their well-being mattered to those who provided services to them. This feeling occurred when they were recognized as individual and unique, and when their hopes, beliefs and practices were acknowledged and treated with respect. They expected compassion and sensitivity from their care providers, and they were reassured by the knowledge that they would be consistently available to them. Finally, they desired a dynamic partnership with care professionals that was inclusive and collaborative.

It is Not Only the Medicine We Give, It is How We Give It

In this chapter, I have described several key dimensions of whole-person care, and the ways in which they were encouraged or impeded (see Table 11). Holistic care is the backdrop to this conceptual depiction. The application of a cultural analytic lens highlighted the picture of whole, multi-faceted individuals, who have a range of needs that extend beyond physical concerns. They include mental, emotional, and spiritual

aspects of everyday life that also require attention when living with a serious progressive illness.

The cultural diversity of the participants was further reflected in the various ways in which they responded to the challenges associated with living with a palliative diagnosis. Although all the participants relied primarily on Western biomedical treatments to counter their physical problems, they also drew on local cultural knowledges and resources to augment these efforts and to address additional psychosocial and spiritual concerns. All participants combined a variety of beliefs and practices to meet their various needs, and described the application of both mainstream and minority approaches as another key aspect of whole-person care.

Finally, the participants emphasized how important it was for health care providers to actively include them in collaborative planning. This calls for care providers to inquire about the full range of patients' needs as well as their beliefs and practices regarding health and illness. This approach brings the perspective of patients into the process of decision-making. When this occurs, care goals are developed according to individual desires and contexts. The participants described how this partnership is enhanced by personal and relational attributes that include respect, compassion, optimism, continuity and accessibility. They underlined how relationships with professionals that reflected these characteristics affected the quality of their care positively.

Table 11. Dimensions and Themes of Whole-Person Care

DIMENSIONS	THEMES
Holistic Care	<p>Addresses physical, mental, emotional and spiritual needs.</p> <p>Health care providers may not provide because they are too busy, lack awareness, and/or underestimate the impact of treatment side effects on the overall well-being of patients.</p> <p>Patients often seek holistic care outside of mainstream care settings.</p>
Integration of Multiple-Care Knowledges	<p>Combines mainstream and minority cultural knowledges and practices to address range of physical, mental, emotional and spiritual needs.</p> <p>Patients develop fluid and versatile cultural identities that incorporate mainstream and minority cultural beliefs and practices; these are drawn on strategically to achieve care goals.</p> <p>Health care providers may view minority cultural care knowledges and strategies as inferior to those of mainstream medicine.</p> <p>Patients may continue to use minority cultural care strategies without disclosing them to their primary care providers.</p>
Relational-Collaborative Care	<p>Active collaboration between health care providers and patients to determine care goals and best ways to achieve them.</p> <p>Relationships are characterized by respect, compassion, sensitivity and engagement.</p> <p>Collaboration may be impeded because of lack of continuity among health care providers and limited access to them.</p> <p>Patients value opportunities for consultation and input regarding care goals and treatment plans although degree of desired level of collaboration may vary according to health status and needs.</p>

Within this kaleidoscope of dimensions, it is possible to create a complete picture of whole-person care by highlighting any one of these lenses (see Figure 1). They overlap with one another so the action of adjusting one lens correspondingly initiates the turning

of the others as well. For example, when the focus of care is holistic, different perceptions of the total impact of the illness from the perspectives of patients and health care providers are considered and responses to it developed together. Similarly, if the initial focus is on building collaborative relationships between health care professionals and patients, their various experiences and expertise will be sought and incorporated, which then broadens both the focus and approach to care. Finally, if care planning starts with the recognition that there are a variety of relevant health care knowledges, patient and professional viewpoints regarding these will be equally considered in relation to a range of needs and desired outcomes. The effect of each alignment is the construction of a final picture of whole-person care.

I end this chapter with a quote from Frida's last interview. She described how whole-person care is a combination of knowledge and attitude. It includes both the medicine we give and the way we give it so that patients feel respected and cared for whatever their cultural identity.

Medicine is not just to give the pill. It's how you do it, too. It's the interactions — you cannot separate the two of them. It's the attitude...it's the way you enable the person to take care of herself and to accept whatever you have to offer to them — being it a pill or being it a bed bath...even the strokes you do to wash their back has to have that ingredient of caring and loving for human kind. You don't have to love the person per se, but [you] have to have that human understanding of the need to feel dignified.

Chapter 8. Discussion and Implications: Whole-Person Care — (Re)claiming all Parts

The dying need the friendship of the heart — its qualities of care, acceptance, vulnerability; but they also need the skills of the mind — the most sophisticated treatment that medicine has to offer. On its own, neither is enough. — Dame Cicely Saunders, Founder, St. Christopher's Hospice

I see health care providers as the people who really need to put together the art of healing [with the practice of medicine].... You are dealing with a human being. — Frida Bahena

In this study I explored the experiences of health care of culturally diverse persons, who had been diagnosed with a life-limiting illness. The purpose of my research was to describe these experiences and to understand the ways in which mainstream and minority cultural discourses influenced them. I wanted to learn what culturally diverse persons value in health care and to identify ways for social workers and other health care providers to meet these expectations.

As I highlighted in the first chapter, this research is important because trends in Canadian demographics reflect a growing multicultural population that brings unique challenges and opportunities to mainstream health care professionals. Specifically, the provision of culturally relevant services is one of the most important tasks facing social workers in Canada today (Bernard & Moriah, 2007).

This study validates, challenges and extends our understanding of the phenomenon of cross-cultural care in several important ways. In this chapter, I will discuss the key findings and ideas that emerged in response to my three research questions. For the purpose of clarity, I introduce these points individually in relation to each question even though there is overlap among them:

1. What do culturally diverse persons consider important to their health care?

- The participants' stories affirm once more the importance of whole-person care for individuals living with a terminal illness. The description of whole-person care that emerged from the participants' experiences closely reflects the discourse of conventional Hospice Palliative Care (HPC). It also validates what previous studies have described as key components for comprehensive care at end-of-life. I will review the requisites of whole-person care identified by the participants, and briefly discuss their connection to the conceptual framework of HPC as well as to other research outcomes.
- What is immediately striking about the participants' description of whole-person care is that cultural competency is not named explicitly as an individual component even though the participants' stories reveal how cultural beliefs and practices influenced all dimensions of their care. I will discuss this point more fully as well.

2. What are the experiences of mainstream health care for culturally diverse persons living with a life-limiting illness?

- Although the descriptions of the key requisites of whole-person care represent important findings, they are not new or surprising. What is noteworthy, however, is that the study participants' experiences reveal that they did not receive whole-person care uniformly. Some participants experienced parts of it, while others not at all. This is especially intriguing because whole-person care reflects the scope of conventional HPC. The participants' stories also showed that their cultural beliefs and practices were not perceived by health care professionals as especially relevant to their care outcomes.

3. In what ways are mainstream and minority cultural discourses enacted in the context of health care, and how do they affect the experience of care?

- The participants' uneven experience of whole-person care raises an important point for consideration: What impedes the full delivery of whole-person/HPC in mainstream health care to patients living with life-limiting illnesses? I draw on

ideas from Foucault's theory of discourse to make sense of this contradiction of care that was experienced by the study participants. I use Foucault's ideas to understand the ways in which both mainstream biomedical discourses and minority cultural versions influenced the care experiences of the participants.

- Within this section, I also examine how culture is conceptualized in the discourse of mainstream health care. Specifically, I review how the cultural identities of the participants appeared fluid and dynamic in their stories, which is contrary to the primary conceptualization of patient culture in mainstream health care that portrays it as static and unchanging. I also challenge the acultural portrayal of biomedicine and put forward the notion that it is a distinct culture among others. With these different perspectives in mind, I suggest ways to re-think the notion of culture in mainstream healthcare and re-imagine corresponding approaches to cross-cultural care.

As I underlined earlier in the methodology chapter, hermeneutic phenomenology is a phenomenology of praxis that promotes a spiral motion of knowledge and action. Therefore, throughout the discussion, I identify implications for practice for social workers and other health care providers. I summarize key practice recommendations under specific sections titled "points for practice." I conclude the chapter with suggestions for future research.

The Requisites of Whole-Person Care

As discussed in chapter seven, the study participants identified whole-person care as essential to good health care. Several key requisites for whole person-care emerged from the participants' stories, which I review below. They include comprehensive assessments, clear communication, continuity and accessibility, respectful and compassionate interactions, supporting hope and optimism, and collaborative decision-making. These ingredients of care are validated by similar notions of HPC described in other studies, which I identify in the descriptions of each requisite. They are also reflected in the Canadian Hospice Palliative Care Association's (CHPCA) conceptualization of palliative and end-of-life care. As noted earlier in the methodology

chapter, this type of affirmation offers a “phenomenological nod” to the findings that enhances their credibility.

The CHPCA’s definition begins with the statement that HPC “is *whole-person health care*...that strives to help patients and families to address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears” (Canadian Hospice Palliative Care Association, n.d., para 2). The aim of HPC is to maximize the quality of life at end-of-life through pain and symptom management, psychosocial and spiritual support, and compassionate and respectful communication. It is patient-centred and aims to effectively meet individual needs according to the particular context of each person. These components and goals are apparent in the various requisites of whole-person care as well.

What stands out by virtue of its absence from both the CHPCA’s definition and the participants’ description of key requisites for care is a stand-alone point that explicitly calls for cultural sensitivity and competence. The participants’ notion of the scope of whole-person care appears to subsume individual cultural expectations and needs. The assumption that cultural diversity will be identified and addressed as other components of whole-person care are enacted is implicit to this approach to care. This perspective is apparent in the discourse of HPC as well, which also recognizes the pervasive position and influence of culture in all facets of end-of-life care. Like the participants’ description of whole-person care, it also does not set cultural expectations apart from other patient needs. Instead, it recommends that all aspects of care be “provided in a manner that is sensitive to the patient’s and family’s personal, cultural, and religious values, beliefs and practices” (Ferris et al., 2002, p. 19).

Be comprehensive

The study participants’ stories emphasize how important it is for health care providers to explore the physical, mental, social and spiritual needs and resources of patients. They described how a thorough assessment of these various components ensures that the health care provided to them will be relevant to their needs, including those related to cultural practices. Comprehensive interviews that include questions that elicit ‘thick description’ about all aspects of a patient’s life will augment the scope of whole-person care. Brenda

suggested that care providers use the Medicine Wheel as a template to generate this range of information.

Other studies have also underlined how individual, comprehensive assessments tailor care activities that are relevant to each person's array of needs (Gourdji, McVey, & Purden, 2009). For example, several studies emphasized the importance of exploring spiritual and emotional concerns at end of life so that full care is provided (Boston & Mount, 2006; Curtis et al., 2002; Johansson, Axelsson, & Danielson, 2006; Kelly et al., 2009; Sharma & Dy, 2010). Schim and Doorenbos (2010) suggested that several additional dimensions of patient culture that may reflect individual and group variations also be investigated. Specifically, they recommended that health care providers explore patients' meanings of health, illness, family, home, decision-making, and food as part of their assessment.

Communicate clearly

The study participants underlined how information sharing and care planning are improved through clear and direct communication. They described how important it is for health care providers to not only ask patients about the different aspects of their well-being, but to also take the time to listen to their concerns, to answer their questions, and to explain medical information in understandable terms. When this occurs, rapport is enhanced in clinical relationships, as David experienced when his physician took the time to draw a picture of his pancreatic problems for his partner and discussed them in detail with him. Other researchers also report that interactions that include active listening and thorough discussions about the patient's condition and treatment options are very helpful to patients and family members for sharing information and concerns, and planning for end-of-life care (Curtis et al., 2002; Kelly et al., 2009; London & Lundstedt, 2007).

As rapport and trust builds through open and supportive communication, patients may also be more inclined to share cultural information with their care providers. Brenda and Fiona described how they felt comfortable talking about their cultural beliefs and practices with their family doctors because they had had positive exchanges with them before.

Provide continuity and accessibility

Clear communication and relevant care planning are further enhanced by continuity of care among care providers. The lack of continuity of care experienced by several participants highlighted its importance to their well-being. Their stories revealed how poor continuity among care professionals and systems contributed to a corresponding diminishment in their quality of care. Poor integration of care services has been identified in other research as one of the most difficult challenges in health care systems in Canada (Ontario Medical Association, 2010). This is especially evident when the locus of care shifts from general practitioners to specialists, which was also reflected in the stories of several participants.

The experiences of the participants showed that timely access to physicians increased their sense of confidence and security in their care. Frida expressed her appreciation for her family doctor's easy accessibility for consultation when new symptoms emerged. On the other hand, several participants described their heightened anxiety when their primary physicians were not available to them during such times. The participants made several suggestions to improve accessibility that included extending office hours and expanding telephone and email access to their care providers. The Ontario Medical Association (2010) identified similar strategies in their policy paper on patient-centred care.

Be respectful

The experiences of the study participants underlined the principal importance of respect in all interactions between health care providers and patients. The participants described how respect for their full personhood, which includes their unique life experiences and cultural knowledges, promoted positive relationships with health care professionals. As discussed above, several participants explained that they were more likely to share information about their cultural beliefs and practices when health care providers demonstrated respect for them. In Cherlin, Schulman-Green, McCorkle, Johnson-Hurzeler, and Bradley's (2004) study, family members of palliative patients also identified respect for the patient as one of five "outstanding practices" in end-of-life care that enhanced relationships and promoted information-sharing with clinicians.

Several study participants identified that a primary feature of respectful behaviour by health care providers is to be engaged and present in each clinical encounter. They described how ‘presence’ can be conveyed through eye contact, and physical touch and posture, which has been reported by other patients as well (Benzein, Norberg, & Saveman, 2001). The participants also emphasized that respect is further reinforced when care providers take time to be with patients, and avoid appearing overworked and too busy. The value of this approach has been described in other studies (London & Lundstedt, 2007).

Show compassion and kindness

The participants’ stories demonstrated how kindness, compassion, empathy and dignity are primary components of caring interactions. Other researchers have identified the importance of these ingredients to the establishment of positive relationships between health care providers and patients (Bendapudi, Berry, Frey, Parish, & Rayburn, 2006; Gentlewarrior, Martin-Jearld, Skok, & Sweetser, 2008; London & Lundstedt, 2007; Richardson, 2004). Sharma & Dy (2010) specifically recommended that health care providers “use compassion, kindness, and respect to help build trust” with culturally diverse patients and families (p. 4).

Chochinov (2007) emphasized especially how important compassion is to maintaining and enhancing the dignity of persons at end-of-life. First Nations people share a similar perspective and participants in Hampton et al.’s (2010) study recommended that health care providers be taught about compassion because “Aboriginal peoples respond to care offered from the heart” (p. 13). Brenda reflected this same expectation when she spoke about how important it was for her care providers to be authentic in their interactions with her. She used the strategy of asking the question, “If I was your mother, what would you recommend?” to personalize her situation so that health care providers would see her as a person just like them.

Support hope and optimism

The participants’ stories showed how the expression of hope and optimism by health care providers also enhanced the quality of their relationships, as well as their general

sense of well-being. Benzein et al. (2001) similarly found that patients with terminal cancer, who strived daily to reconcile ongoing tensions between living and dying, appreciated the support they received from medical professionals for their determination to continue to “live in hope.” The importance of this intention was very evident in Fiona’s desire for her oncologist to join in her efforts to remain optimistic with each new round of experimental treatments.

Health care providers have observed in other research how their expression of optimism does provide comfort and encouragement to patients (Francis, 2008; Mok et al., 2010). This attitude also helps them to see the various aspects of patients’ lives that engender hope beyond those related only to their illness. However, the obligation that physicians may feel to provide realistic prognoses to their patients can limit their ability to convey optimism for the future (Francis, 2008). Because the cultural value of truth-telling to facilitate informed consent is primary in mainstream health care, physicians are most often inclined to adhere to it.

Decide together (more or less)

The study participants emphasized the importance of establishing a patient’s decision-making preferences. This activity requires that health care providers check with patients regarding their desired level of participation in making decisions about treatment choices and care plans at different trajectory points. The participants’ stories showed that this inquiry did not usually occur. Other research has also found that information about patient and family decision-making preferences are not often elicited (White, Braddock, Bereknyei, & Curtis, 2007).

The participants described how their desired degree of involvement in decision-making fluctuated according to their health status and needs. In acute, emergent events, the participants relied on physicians to make decisions quickly as needed. In other situations, all participants became more involved as their knowledge of their illness increased and/or the illness progressed. Other researchers have also observed how patients have different preferences for decision-making at different times (Kon, 2010). Levels of participation may change according to the degree of risk associated with a treatment decision and/or according to the scope of a patient’s health literacy (Ontario Medical Association, 2010).

Even if they were not inclined to make autonomous treatment decisions, many study participants still expected to be informed about changes in their status and related care options. They wanted an opportunity to discuss medical information and to share their opinions regarding it. This included reviewing treatment suggestions derived from local cultural knowledges that they saw as relevant to managing various aspects of their health. They described a collaborative approach to decision-making that combined their life expertise with the medical expertise of health care professionals, and considered the perspective of each to their unique situation.

The active involvement of family members in decision-making was not apparent in the participants' experiences. This seems surprising in light of the studies I reviewed in the first chapter that showed how a family-centred approach to making decisions and care plans was frequently the norm in many cultural groups. The participants' stories showed that they often discussed medical information with their families and sought input from them, but then they ultimately made the final decisions about next steps in consultation with their physicians. Health care providers should explore the extent to which a patient's family is involved in this process.

Points for Practice

These requisites of care represent a comprehensive description of the primary components of whole-person care that the study participants identified as essential to excellent health care for persons living with a life-limiting illness. There are many practice implications for social workers and other health care providers that emerge from this description. In Table 12, I use the words of the participants to summarize the meaning of each care requisite and offer examples of specific skillful actions to accomplish them.

As mentioned above, the participants did not identify an individual care requisite that speaks specifically to the provision of cross-cultural care. The terms 'culturally competent care' or 'culturally sensitive care' are not included in this template. Instead, the participants described components of care that reflect good healthcare practices generally that would naturally acknowledge cultural diversity as part of the broader scope of whole-person care. These requisites address a range of needs and expectations that

may be commonly shared among persons who are approaching the end of life. An interpretation of this focus on commonality suggests that differences among people may diminish in the face of approaching mortality.

Table 12. Care Requisites and Skillful Actions to Promote Whole-Person Care

CARE REQUISITE	SKILLFUL ACTIONS
<p>Be comprehensive</p> <p><i>I think of what we use most, First Nations, [we] use the Medicine Wheel, right? Which is just a circle divided into four for looking at the four aspects: physical, mental, emotional, and spiritual. And then looking at maybe what the needs are with that circle. It would be so simple to start a dialogue from there. — B.H.</i></p>	<p>Ask questions about the physical, mental, social and spiritual needs and resources of patients.</p> <p>Ask questions about what is meaningful in patients' lives.</p> <p>Use questions that elicit 'thick description'.</p>
<p>Communicate clearly</p> <p><i>[The doctor] even drew a diagram for Barry. I mean that's pretty unusual to sit down with a marker and a piece of paper and show him what the different parts of the pancreas were and, you know, what happens [with them]...the extra time that some doctors take to explain certain things to you [is very helpful]. — D.N.</i></p>	<p>Listen actively to concerns.</p> <p>Take time to answer questions.</p> <p>Explain information in comprehensible terms.</p> <p>Be creative in explanations.</p> <p>Be thorough and repeat information as often as necessary.</p>
<p>Ensure continuity</p> <p><i>Medicine has evolved in such a huge array of specialties, of sub-specialties, and sub, sub, sub sub-specialties, and no doctor can have all the cards. — F.B.</i></p> <p><i>The dots should be connected. — P.G.</i></p>	<p>Keep primary care providers informed.</p> <p>Communicate clearly and often with all care providers especially at transition points of care.</p>
<p>Be accessible</p> <p><i>Any time I want to see him he's available and he has given me time and, ah, long appointments if I need to. All those things help [my care]. — F.B.</i></p>	<p>Respond in a timely manner, especially when health status changes.</p> <p>Extend clinic hours.</p> <p>Create easier email and telephone access for patients.</p> <p>Involve other team members.</p>

CARE REQUISITE	SKILLFUL ACTIONS
<p>Be respectful</p> <p><i>I would tell them I think they have to respect me. Especially [that] I'm a nurse. I know all those [medical] things too, you know...I think they, they should respect everybody, you know, even if they are not a nurse. — T.W.</i></p>	<p>Acknowledge unique experiences and knowledges of patients.</p> <p>Be present and engaged.</p> <p>Take time.</p> <p>Avoid appearing overworked and too busy.</p>
<p>Show compassion and kindness</p> <p><i>Compassion [is important]...and sensitivity and trust, and, being comfortable with one another. — D.N.</i></p>	<p>Learn how to be compassionate.</p> <p>Be empathetic.</p> <p>Be authentic.</p> <p>Be sensitive.</p>
<p>Demonstrate hope and optimism</p> <p><i>[The doctors] don't have to tell, keep saying that it can't be cured, [but instead say], "We are trying, we are trying. It's hard to cure but we're trying." ... So I think doctors should encourage the patient. — F.L.</i></p>	<p>Support patient efforts to "live in hope."</p> <p>Be reassuring.</p> <p>Focus on positive possibilities.</p>
<p>Promote collaborative decision-making</p> <p><i>[I prefer] working together, you know...working together as a team...for the good of the patient. — D.N.</i></p>	<p>Elicit decision-making preferences at different illness trajectory points.</p> <p>Keep patients informed.</p> <p>Draw on patient knowledges and suggestions to develop care priorities and plans.</p> <p>Explore how family members are involved in this process.</p>

Barriers to the Provision of Whole-Person Care:

A Discursive Analysis

The combination of these requisites engenders whole-person care. However, the study participants' stories revealed that they did not receive all components of whole-person care consistently or uniformly, which was especially interesting because it reflects HPC so closely. To make sense of these gaps in care, I have drawn on several key ideas derived from Foucault's theory of discourse.

As I stated in the first chapter, Foucault offers a relevant conceptual lens to understand the ways in which various taken-for-granted discourses influence our everyday experiences. I use this lens to look at how the dominant discourses in biomedicine shaped the care experiences of the participants. I also use this perspective to interpret when and how the study participants resisted the primary protocols of mainstream health care in favour of other minority discourses. Foucault's ideas about knowledge and power are especially helpful to understand the focus and parameters of the participants' clinical interactions with health care providers, and to comprehend the position and influence of HPC within the broad spectrum of biomedicine.

A brief overview of Foucault's conceptualization of discourse provides an important entry point for this analysis. Foucault (1972) explained that discourses "form the objects of which they speak" (p. 49) and "frame our seeing" of them (Lather, 1993, p. 675). They can include collective assumptions, rules, strategies and structural arrangements that order reality in particular ways. They serve to outline the parameters and possibilities of knowledge that privilege certain perspectives while excluding others. Each discursive practice implies "a play of prescriptions that designate its exclusions and choices" (Foucault, 1977b, p. 199).

In this way, each discourse depicts a distinct epistemological framework that facilitates the production of certain kinds of knowledge and corresponding 'truth' claims, while limiting the emergence and influence of other understandings. Foucault specifically linked power with disciplinary knowledge and demonstrated how it flowed through disciplinary practices into the production of institutions and socio-cultural arrangements (Foucault, 1967; 1975; 1977a). This perspective provides a useful starting point to

explore the discipline of medicine and the ways in which discourses associated with it may have contributed to the gaps in whole-person care experienced by the participants.

Biomedicine is true knowledge

From a Foucauldian perspective, biomedicine can be described as a core institution that is firmly anchored in the ‘truth’ of the prevailing scientific paradigm. Although biomedicine encompasses a range of discourses and practices, those that are dominant “turn on expertise, technical mastery over disease and distress, and the prescription of treatments,” which derive from this scientific framework (Kleinman & Benson, 2006, p. 837). They determine mainstream health care and constitute the roles of doctors and patients, and relationships between them. A key outcome of this discursive configuration is that physicians are positioned as experts, which is sustained by an ongoing subscription by patients to the belief in the superiority of medical knowledge and procedures (Lupton, 2003).

This arrangement was evident in the experiences of the participants. Their stories revealed how physicians assumed the role of expert in their clinical encounters with them. In many instances, the medical knowledge of physicians was openly privileged over the knowledges of the participants. For example, several individuals described how treatment ‘choices’ were usually confined to conventional medical protocols that precluded their suggestions for other approaches. This attitude was especially apparent when participants put forward ideas for combining culturally based medicine or complementary modalities with conventional strategies, which I discuss in more detail in a separate section below.

With such hierarchical expertise comes the power to control clinical interactions, which may explain why the participants’ doctors mostly dominated the discussions during appointments, according to their assessment goals. Foucault (1975) underlined that what is important in medical interviews is not so much what patients think as what they say because the primary task of the physician is to translate the subjective observations of patients into the ‘truthful’ objective language of medicine. Similarly, Kleinman (1988) described diagnostics as “a thoroughly semiotic activity: an analysis of one symbol system followed by its translation into another” (p. 16).

This dynamic was reflected in the experiences of the study participants, wherein their connotative discourse was often sidelined in favor of scientific facts and conclusions. There was little time or opportunity for them to ask questions or share other knowledge perspectives and recommendations. Fine, Reid, Shengelia, and Adelman (2010) recently completed a systematic literature review of patient-physician interactions pertaining to palliative care that highlighted similar findings. Five studies in the review reported that doctors use “60-70% of the discursive space (the amount of spoken words) during these discussions” (p. 597). The fact that physicians interrupt patients an average of 18 seconds into the patient’s description of the presenting problem (Frankel & Beckman, 1989) adds a further quantitative perspective to the dominance of physician expertise and interpretation in clinical encounters that was similarly reported by several study participants.

The dominant position of medical knowledge in biomedical discourse may explain how the requisites of whole-person care, such as open and equal communication, respectful interactions and collaborative decision-making, were compromised in the participants’ experiences.

Medical care is care of the body

Within biomedical discourse, the body is viewed as separate from the mind and the social and, therefore, investigation and treatment of it occur in isolation (Rhodes, 1990). From this perspective, it makes sense that the attention of the participants’ doctors was generally directed to their physical disease and not their holistic experience of living with it. The participants’ stories showed that the focus of medical interactions centered primarily on defining physical problems and determining medical responses to them. Interventions were mostly directed to ‘fixing’ their physical troubles, or at least mitigating them.

The participants reported that their doctors generally did not inquire about their psychosocial concerns regarding the disease or its management unless they initiated discussions about them. For example, several participants reflected on how their physicians expressed minimal interest in the psychological and emotional toll associated with treatment side effects and outcomes. Other research also showed that physicians

focus discussions more often on procedures and treatments than on emotional and spiritual issues or quality of life (Liden, Ohlen, Hyden, & Friberg, 2010; Ohlen, Elofsson, Hyden, & Friberg, 2008; Rodriguez et al., 2010). The impact of an illness and its treatment on wider aspects of daily life such as work and social relationships, and one's sense of self, are also rarely discussed (Koedoot et al., 2004; Rodriguez et al., 2010).

Because the diagnosis and treatment of physical problems is principally valued in biomedical discourse, physicians may understandably lack the expertise to address psychosocial and spiritual issues (Chochinov, 2007). Brenda also speculated that health care professionals may not have adequate training to confidently address such concerns because of their primary focus on improving physical (mal)functions. Other research indicates that doctors who feel that they do not have appropriate skills to attend to emotional difficulties are too anxious to initiate discussions about them (Ramirez & Graham, 1996). Physicians generally defer to patients to begin conversations about psychosocial concerns (Detmar, Muller, Wever, Schornagel, & Aaronson, 2001), which is consistent with what the study participants also reported.

It is also understandable that there is a subsequent expectation that the majority of a doctor's time and attention will be used to meet the medical priority of resolving bodily problems. This may explain why many participants felt that their doctors were too busy to inquire about and/or attend to their psychosocial well-being. Other research has suggested that physicians may not initiate investigations about psychosocial issues because they are concerned about the amount of time they will take from physical matters (Chochinov, 2007; Detmar et al., 2001; O'Grady & Jadad, 2010). In some instances, physicians may deliberately project a message of being too busy with more important demands, which discourages patients even further from introducing psychosocial concerns during time-limited medical appointments (Sherwin, 1998). Sarah's feeling that her doctor was always rushing "as if he had something else to do next" may be an example of this strategy.

Many study participants stated that their impression that their doctors were very busy was a key reason why they did not bother them with non-physical issues or information during appointments. The primary focus on physical concerns in biomedical discourse

may explain why the requisite for holistic care that the participants desired was often not met in their experiences.

HPC is not quite real medicine

Mainstream medicine has been criticized for this narrow bio-reductionist discourse that is focused primarily on physiopathology. As a consequence, various medical specialties have gradually adopted a more encompassing assessment of patients that considers not only the physical aspects of their illnesses, but their associated psychological, emotional and social components as well. This approach to care has been variously termed holistic (Porter, 1997), cooperative (Maseide, 1991) and patient-centered (Silverman & Bloor, 1990). These different iterations of care similarly perceive “the patient’s mind, body, and social situation as an integrated totality” and stress the importance of including “the voice of the lifeworld into the voice of medicine” (Maseide, 1991, p. 548). As discussed above, this perspective is integral to the discourse of HPC as well. In light of the experience that many study participants did not receive such comprehensive care, the question arises: What is the position and influence of HPC in biomedicine?

Foucault’s (1979) notion that other discursive frameworks always surround dominant discourses as alternate derivative forms can help us to answer this question. From this perspective, we can see that biomedicine is not a single homogenous discourse, and that it encompasses various discursive modalities instead (Good, Good, Schaffer, & Lind, 1990; Kleinman, 1995). As noted earlier, there is an array of medical specialties and subspecialties within biomedicine that reflect more or less the characteristics of its dominant framework. They are arranged hierarchically with those that are most closely aligned with the traditional focus of biomedicine positioned at the top of the medical establishment. For example, internal medicine and surgery represent the rational and technical pinnacles of medical practice, both of which are highly valued within biomedical discourse (Hahn & Kleinman, 1983). The medical specialties that depend on concrete technical procedures are usually esteemed more than those that rely on talk therapies such as psychiatry. Distinctions are made accordingly between ‘hard’ specialties that rely on interventions that enter the body such as scopes or surgeries, and ‘soft’ medicines that are not so instrumentally based.

According to this discursive delineation, HPC can be considered a ‘soft’ medicine precisely because of the emphasis it places on physical comfort, and psychosocial and spiritual care. Its knowledge and services are viewed as less valuable and relevant than those that aim to achieve the desired goals of cure and restoration that are dominant in biomedicine. In an interesting focus group study, where Hibbert et al. (2003) interviewed doctors from a range of specialties about palliative care, this perception was clearly demonstrated. Physician participants acknowledged their limited interest and ability in addressing the “holistic” and “psychosocial” agendas of HPC, and highlighted instead the importance and priority of their technical expertise.

In the end, death is often viewed by medical specialists as a failure because there is “no alternative to cure in this medical model” (Pierson, 2000, p. 233). As Hern, Koenig, Moore, and Marshall (1998) pointed out, the deeply embedded drive to cure pushes “terminal care” outside of mainstream medicine as something separate and distinct when there is no other technological solution to offer (p. 31). It is when further treatment is considered futile, and the hope for cure no longer viable, that patients are moved into the “marginalized discourse of palliative care” (Wicks, 1995, p. 135).

This perception of HPC as a less valuable discourse of care in biomedicine may explain the study participants’ inconsistent experiences of whole-person/HPC. The participants received care from many different clinicians in a range of settings, and the degree to which they experienced HPC appeared to vary according to the extent to which health care professionals valued the approach and/or saw it as relevant to the situation.

This perspective is especially helpful to understand the experiences of the study participants who received health care in mainstream settings. The goals of care in these locations to cure disease or slow its progression according to the usual discourse of mainstream medicine may reflect what occurs when patients are not viewed as palliative by their care providers. In these instances, interventions continued to be directed to ‘fixing’ the participants’ physical problems. Similarly, this may explain why there was also limited interest in the psychosocial concerns associated with the participants’ terminal diagnosis or its management. This approach to care was especially evident in

David's experience of treatment with ongoing rounds of experimental drugs even though he had been diagnosed with both end-stage AIDS and kidney disease.

The technical mastery of diseases and their symptoms that is central to biomedical discourse also emerged as a primary goal in some palliative care settings. For example, Mary described how much of the care she received on the palliative care unit centered on pain and symptom management. This was certainly an important issue to address, but she did not recall similar attention paid to her emotional, social or cultural needs. Other participants' experiences were similar. Even when their palliative status was acknowledged, the focus of care stayed most often on physical needs unless they brought other concerns forward pertaining to their overall quality of life.

This occurrence may be the outcome of a strategy that has been used to boost the credibility of HPC within mainstream medicine. To achieve this goal, palliative care physicians have deliberately highlighted practices valued by the dominant discourse of biomedicine while downplaying some of the 'soft' sides of HPC (Bruera, 2004; Seale, 1998). They do so primarily through the promotion of their technical expertise, particularly in the area of pain and symptom management. The downside of this strategy is that the principles of HPC "may be subject to dilution from the medical emphasis on physical interventions and traditional professional hierarchies" (Hibbert et al., 2003, p. 278). Paradoxically, this may reinforce the inferior position of whole-person/HPC in mainstream health care. The narrow scope of care that ensues from this strategy may explain the gaps in whole-person care that were experienced by Mary and other participants.

The (lesser) position of non-medical disciplines

Foucault's point that alternate discourses that surround dominant beliefs vary in their authority also helps to explain the secondary role that non-medical disciplines appeared to play in the stories of the participants. Generally, the participants focused on the position and services provided by physicians in mainstream settings. They mentioned the presence and support provided by nursing and allied professionals much less frequently. This observation is noteworthy because a fundamental premise of HPC is the belief that it

“is most effectively delivered by an interdisciplinary team of health care providers” (Ferris et al., 2002, p. 18).

Foucault argued that particular disciplines are shown to be privileged in institutional contexts with the effect of minimizing and disempowering other disciplines (Foucault, 1978; Opie, 1997). In the case of mainstream health care, the priority of addressing physical concerns reinforces the central importance of medical expertise and marginalizes the contributions of other disciplines that may be more focused on addressing non-physical issues. While taking the time to sit, talk and listen to patients and families may be primary tasks for some professions such as social work, “their status as expert activities is contestable in the medical world” (Hibbert et al., 2003, p. 284). This attitude may explain why the participants’ physicians did not actively seek assistance from other disciplines in the provision of comprehensive care to them. Furthermore, as Opie (1997) pointed out, it cannot be assumed that physicians will have sufficient interdisciplinary knowledge to either identify accurately a specific problem outside of their disciplinary domain, or recognize the need for a referral to another professional.

The inferior representation of non-medical disciplines in biomedical discourse, which simultaneously reinforces the authority implicit to the physician’s role, may also explain the participants’ desire to receive care from their doctors for all their needs, including care for their psychosocial and spiritual concerns. This desire has been described by patients in other studies as well (Dowsett et al., 2000). Access to professionals who had expertise in other areas of care did not appear to mitigate this aspiration for the study participants. David demonstrated this perspective when he spoke about his preference to consult directly with his nephrologist rather than with the nurse practitioner because he felt more confident in the physician’s overall knowledge. He also recognized that the doctor, rather than the nurse, would make the final decisions about treatments. This may be an example of a patient co-opting the dominant discourse that ranks the knowledge and power of medicine above other disciplines. The acceptance of this taken-for-granted arrangement serves to reinforce its legitimacy and prevalence. As discussed earlier, the sustainment of the central position of physicians in health care depends not only on their assertion that their area of expertise is most important, but on the reciprocal subscription by patients to that same interpretation.

The (lesser) position of cultural knowledge

The primary components of biomedical discourse discussed so far, which include the beliefs that medical knowledge is true and exclusive knowledge, that care of physical problems is most important, and that physicians are the best experts to determine the most appropriate care, help to explain why the discourses of HPC and other disciplines tend to circulate at the margins of mainstream health care. These biomedical imperatives may also explain why the cultural knowledges and practices of the study participants appeared less valuable and visible in their experiences of mainstream health care.

For example, the discursive assertion that medical knowledge is “real knowledge” and “not merely cultural knowledge” (Taylor, 2003, p. 556) may explain the reactions of the participants’ physicians when they suggested other cultural or complementary strategies to them to manage their health needs. The responses of the participants’ doctors to these ideas appeared to vary according to the degree to which they veered from, or interfered with, conventional medical approaches. It seemed that the “real knowledge” of medicine was the gold standard by which the “rest of the world’s cultural versions [were] seen, compared and judged” (Gaines & Hahn, 1985, p. 4).

When the degree of variance seemed minimal, there was often little or no response on the part of clinicians. Sometimes participants were briefly reminded of the superiority of Western medicine over other cultural practices. For example, Nathan experienced this when his oncologist did not comment on his plans to utilize complementary medicines beyond pointing out to him (in a patronizing tone) that “in the end you [will still] come back to us.” Conversely, when participants put forward ideas for culturally based treatments that appeared to directly challenge the medical expertise of their physicians, reactions were more vocal and definitive. This was especially evident in Fiona’s case when she presented suggestions from her Chinese medicine doctors to her oncologist, which he immediately discounted because they lacked scientific merit.

These may be examples of how the dominant belief in mainstream health care that biomedical knowledge is “real knowledge” can effectively shut down any further discussion of potential benefits of other cultural approaches. These interactions also appear to reinforce the physicians’ position of expert by minimizing that of the

participants or displacing it completely. This outcome may further explain why the participants' expectations for respectful communication, collaboration and shared optimism were often unmet. It may also account for why the study participants were not always comfortable volunteering information to their health care providers about cultural beliefs and practices they were using or considering.

I already know enough about your culture

The lack of explicit interest in the cultural beliefs and practices of patients may also stem from the assumption held by health care providers that they already have enough information about their patients' cultures. Within biomedical discourse, the cultures of patients are generally perceived as tangible ways of being in the world that are static and unchanging. As noted in the first chapter, health care professionals frequently organize these cultural characteristics into categorical lists or factfiles that can be easily consulted as needed. As Dorazio-Migliore et al. (2005) point out, "the list can then be used to inform health care interactions with clients who are viewed as embodying the traits of a specific cultural group" (p. 342). With factfiles in hand, care providers may feel that they have sufficient cultural information about patients when they engage with them. When this occurs, individual descriptions of the lifeworlds of patients may be overshadowed, and neither looked for nor recognized.

This essentialist understanding of culture within mainstream health care may provide an additional explanation as to why health care professionals did not ask the study participants about their cultural beliefs and practices or invite discussions about them. If the participants' care providers were relying on cultural factfiles, there would be no incentive for this line of questioning. Consequently, they were likely unaware of the various cultural strategies the participants were using to make meaning of their illnesses and/or to cope with them. This lack of information further limited the opportunity for collaborative decision-making and care-planning that the participants viewed as an important requisite for whole-person care.

Acceptance and resistance

From a Foucauldian perspective, the priorities and practices associated with biomedical discourses are not necessarily perceived as repressive, but rather as productive forces that provide effective responses to serious health problems. Foucault (1980) argued that power associated with dominant discourses is not just “a force that says no, but that it traverses and produces things” that are frequently helpful and positive to many people (p. 119). Moreover, the rules and expectations associated with dominant discourses are often taken for granted as common sense ways of doing things without a value attached to them. For example, the differential in power that derives from a physician’s medical knowledge is usually considered necessary and appropriate for “effective, consistent and rational practice” to achieve successful treatment (Maseide, 1991, p. 557). This viewpoint helps to explain the study participants’ general acceptance of the discursive relationships and activities associated with mainstream health care. In some instances, the participants, such as Prakash and Brenda, deliberately learned about the protocols of care systems and ‘the right way to do things’ in order to benefit as fully as possible from them. This strategy makes sense from the perspective that patients who meet the discursive expectations of mainstream health care will likely be better served by it.

However, as discussed earlier, Foucault also pointed out that there are at any one time numerous cultural discourses surrounding social and physical phenomena that forefront different knowledges for consideration and implicate different scenarios for actions (Burr, 1995). These discourses may “offer competing, potentially contradictory ways of giving meaning to the world” (Gavey, 1989, p. 464). From this perspective, contestation among knowledges and practices can be viewed as an inseparable and implicit aspect of power relations. As Foucault stated, people have the agency and the critical ‘technologies of the self’ to make multiple choices about which discursive frameworks or strategies to adopt to meet their needs and achieve their goals (Foucault, 1979).

This explanation of how alternate discourses can be incorporated as a way to resist dominant beliefs helps to understand the study participants’ decisions to use minority cultural strategies at different times during their illness experiences. The participants’ stories showed that this type of opposition primarily occurred when the participants

disagreed with the mainstream medical assumptions that: i) the doctor knows best, and ii) quantity of life is preferred over quality of life.

The participants challenged the first assumption that the doctor knows best, and by implication, that only medical knowledge is ‘real knowledge’, by continuing to use culturally based care strategies even when their physicians minimized or disapproved of them. In these instances, they utilized prayer, visualization, acupuncture, herbal remedies and various other approaches alongside, or instead of, conventional treatments. Their stories showed that the impetus for this resistance derived from their belief that there was an array of valid cultural knowledges and corresponding approaches that could be used to augment the effects of mainstream medicine and/or address their needs more holistically. Frida, Brenda and Sarah especially emphasized how traditional cultural medicine embodied a valid collective wisdom derived from the experiences of many people over time. The scope and longevity of this knowledge served as a sufficient basis for its credibility.

Several participants challenged the second discourse that promoted quantity of life as a preferred priority when they believed that interventions would not make a substantial difference to their final health outcomes and/or that their quality of life would be significantly compromised by them. This dynamic was evident early in David’s story when he resisted his family doctor’s recommendation to be tested for HIV infection. David saw no benefit to this medical test because he did not believe that it would prevent or delay the outcome of his death. Instead, he anticipated that this knowledge would only diminish his quality of life because of the worry and stress that would accompany its confirmation. He eventually agreed to be tested when it appeared that there were new treatments that could keep him alive indefinitely. He refused various medications later on again when he knew that their efficacy was limited and their side effects were severe.

Frida declined conventional treatments for similar reasons, and Mary did the same even though she realized that her life would be shortened by doing so. Specifically, their desire to spend quality time with friends and family surfaced as more important than length of life. This change in care goals seemed most likely to occur when participants realized that they were approaching the end of their lives with or without treatment.

From this perspective, it may have seemed that they had less to lose by declining mainstream interventions because death appeared imminently inevitable anyway. At those times, the goal of quality of life emerged as most important during the time that remained. In these examples, the participants also relied more frequently on local cultural approaches as listed above to manage their symptoms and enhance the comfort of their remaining days.

The stories of the participants revealed they shared information about their use of alternate care approaches in different ways. In some instances, they expressed their individual needs and use of minority-care activities directly and assertively to their health care providers. At times when their care providers disapproved of their actions, they often continued to draw quietly on local knowledges and strategies to meet their range of needs without disclosing them. Whatever way they chose, they seemed able to enact other cultural discourses for care when the boundaries of mainstream health appeared too restrictive or unimaginative for them.

Re-thinking Culture and Cross-Cultural Care

I have identified ways in which discourses within mainstream health care impeded the delivery of whole-person care to the study participants. Primarily, these dominant discourses privileged medical knowledge as truth and underlined the exclusive priority of physical care. The primary legitimacy of these perspectives kept the alternate discourses of HPC, and those derived from the cultures of the participants, at the margins of their care.

Nonetheless, the participants' stories showed that they incorporated strategies from both mainstream and minority approaches to meet their needs. The participants described themselves as 'mixed bags' and 'unfinished quilts' of cultural personas and performances, and demonstrated that they drew from a repertoire of various cultural beliefs and practices. Although their stories revealed that they drew from minority strategies more or less throughout the course of their illnesses, this occurred especially at times when mainstream approaches did not meet the holistic range of their needs or compromised their quality of life. The extent to which they did so with the support of their primary health care providers was usually minimal.

These findings challenge us to take into account the various positions and influence of cultural discourses in conventional health care, and to reconsider our previous understanding of them. By thinking more broadly about the meaning and application of culture, biomedical discourses can be de-centred in mainstream health care, which will create the opportunity for other cultural discourses of care to be brought forward as equally viable approaches. The result will be the creation of a new discourse of whole-person care that values and promotes both biomedical and minority knowledges and practices for care at end-of-life, which reflects the participants' vision of it. In this section, I will discuss ways in which biomedical and patient cultures can be reconsidered, and outline several suggestions for different approaches to practice with culturally diverse persons.

Medicine has a culture after all

We can start the process of broadening our conceptualization of culture in the context of mainstream health care by challenging the basic assumption that medicine has no culture. Foucault (1972) stated that the beliefs and practices of dominant institutions are usually so taken for granted that they are perceived as natural. Therefore, they are not thought of or described in cultural language. Instead, culture is a term applied to individuals and groups who are different from the dominant 'norm' (Bhabba, 1990). As Hunt (2005) states, the emphasis on difference positions "the exotic and esoteric against mainstream or conventional beliefs that remain unnamed and unexplored" (p. 134). This perspective may explain why the notion of culture applies primarily to patients in the discourse of biomedicine and not to health care institutions (Kleinman & Benson, 2006; Lupton, 2003).

To expand our thinking about the representation of cultures in mainstream health care, Chan, Macdonald and Cohen (2009) suggested that we shift our focus from culture *in* medicine to the culture *of* medicine instead. When we make culture the principal lens, biomedicine emerges as just "one of many cultural approaches to health and illness" (Macdonald, Carnevale, & Razack, 2007, p. 468). This perspective allows health care providers to also critically examine the Eurocentric cultural knowledge base of biomedicine rather than trying to only understand the cultural 'other' in contrast to it

(Sakamoto, 2007). When this occurs, the culture of mainstream medicine no longer remains unnamed or unchallenged. This exercise may also serve to dismantle the implicit assumption that the patient's position of 'other' is more or less always one of disadvantage or deficit depending on how close or far away it is from the norm of mainstream medicine (Culley, 2006). As discussed earlier, this skewed perception was evident in the frequent negative reactions of the participants' physicians to their ideas to utilize culturally based strategies for care. This critical shift in perspective serves to dislodge biomedicine from its central location and makes room for other cultural viewpoints and ways of knowing.

Patient culture is much more fluid than we thought

We also need to reconsider our understanding of the cultures of patients. The fluid representation of cultural identity demonstrated by the participants does not fit with the fixed and essentialist factfile depiction of patient culture that is standard in mainstream medical settings. In their stories, the participants showed that they employed various cultural beliefs and practices at different times and situations to make meaning of their illnesses and/or to cope with them. For example, Theresa described how she drew variously on her Chinese, Canadian and nursing cultures to address different aspects and implications of her illness with different care professionals and family members. Based on other experiences, other scholars have also recommended that health care providers move beyond the static and homogeneous ways in which culture is theorized and applied to patients in medical practice (Chan et al., 2009; Dorazio-Migliore et al., 2005; Fuller, 2003; Laird, 1998).

Learning about what is important to you: Stay open and curious

Social workers and other health care professionals can disrupt this typically narrow understanding of patient culture by developing an attitude of openness and curiosity about cultural identities that goes beyond generic factfile descriptions of cultural groups. A way to generate this information is to invite patients into a dialogue that starts with the acknowledgement of not knowing about the patient's culture. The study participants suggested that health care providers ask patients broad questions about their lives that include inquiry about cultural influences that they view as pertinent to their health care.

For example, the question, “What do I need to know about you as a person to help me take the best care of you that I can?” that Chochinov (2007, p. 186) recommends in his approach to dignity-conserving care could be equally effective as a starting point for cross-cultural discussions. When we ask such a question, we create a space for people to describe their ‘otherness’ and an opportunity to enter their lifeworld. This approach encourages patients to tell stories about who they are and what is most important to them. Several participants stated that they would share information about their cultural beliefs and practices with health care providers if they expressed a sincere interest in learning about them. Social workers can then highlight the richness and fluidity of patients’ cultural identities during discussions in medical rounds and/or in their psychosocial assessments.

This type of inquiry positions patients readily at the forefront as the ‘experts’ of their own culture, while health care providers step back to a place of “seeking knowledge and trying to understand” what that encompasses (Dean, 2001, p. 624). As Doane and Varcoe (2006) point out, this approach to cross-cultural care reframes “difference as a place of connection” where practitioners and patients can form positive, responsive relationships (p. 19). Through this process, the voices of patients are endorsed with a “cultural legitimacy” regarding the goals of their care that is often absent in mainstream health care (Wiggins & Schwartz, 2005, p. 76).

These conversations do not need to exclude drawing on previous information that health care providers may have about a particular culture. Although the participants’ stories highlighted that such knowledge is tentative, and not applicable in the same way to all members of a particular group, it can offer an entry point to engage with and learn about new patients and families. Similarly, an idea put forward by minority participants in Gentlewarrior et al.’s (2008) study regarding culturally competent social work services was the suggestion that practitioners become familiar with cultural information pertinent to their clients. Bernard and Moriah (2007) also recommended that social workers develop some preliminary knowledge about the cultural groups they serve as part of their diversity training.

The challenge when doing this, however, is to avoid slipping into a presumption of competence that can lead once more to an appropriation of patient culture based on a reified template of cultural information. To do so would reinforce the status quo regarding the conceptualization of patient culture in mainstream health care. Ironically, the attempt to elicit cultural diversity can inadvertently move us further away from the provision of whole-person care. Kleinman and Benson (2006) pointed out how easily this can occur. They explained that the original purpose of the questions Kleinman developed to establish a patient's explanatory model about health and illness has often been derailed in this way. Kleinman's questions were intended to discern the personal meanings of an illness for an individual patient, but many practitioners interpreted the answers as representative of a wider set of fixed cultural beliefs. Consequently, what was intended to open up a conversation became a "conversation stopper" as health care providers slotted patients' answers into a master factfile. This has been observed in interactions between health care providers and Aboriginal patients as well (Elliott & de Leeuw, 2009).

When this occurs, the perspective related to the position of being "informed not-knowers", and the openness and curiosity associated with that viewpoint, is once more diminished (Laird, 1998). Gentlewarrior et al. (2008) remind us that we need to keep a "both/and" stance of "combining general information on cultural competence with information that is specific to the complex interaction of social identities that are unique to each person" (p.220). Again, this reflects the study participants' expressed desire in their stories to be recognized as unique individuals, who are culturally multi-faceted and versatile.

Learning about what is important to me: Be reflexive

This approach to cross-cultural care is not only about acknowledgement and inclusion of the beliefs and practices of culturally diverse patients. The experiences of the study participants highlighted the importance of a parallel process of reflexivity on the part of health care providers about their own cultural assumptions and biases. Laird (1998) stresses that it is vital "to make them as accessible as possible to ourselves and transparent to others" so they can be directly addressed (p. 30). For example, Fiona's

experience might have been very different if her oncologist had been able to articulate to her how truth-telling was an important imperative in conventional medical discourse that guided his interactions with her. This could have created an opportunity for Fiona to speak about how his commitment to this value negatively affected her care and well-being, which may have facilitated a discussion that led to a different outcome.

Hallenbeck (2001) and Hern et al. (1998) emphasized that it is especially important in HPC for health care providers to make the values and assumptions of Western medicine explicit to patients and their families, particularly as they apply to practices of truth-telling and informed consent.

The ability to be reflective about the culture of biomedicine may be difficult for mainstream health care professionals. As discussed above, Foucault suggested that dominant cultural beliefs and values are often not acknowledged or articulated because they are perceived as natural and common. However, the reconceptualization of biomedicine as an individual and distinct culture will uncover how such previously taken-for-granted beliefs and values are connected to it. When they are perceived as elements of a particular culture, health care providers may be more able to recognize them and reflect on how they influence their interactions with palliative patients who may have other cultural beliefs and values.

Similarly, an ongoing commitment to self-evaluation and critique is an essential component of Tervalon and Murray-Garcia's (1998) "cultural humility" approach to cross-cultural care. From this place of reflexivity emerges a recognition that cultural difference is not only about the cultural 'other', but also about the "the relationship between two perspectives" (Hunt, 2005, p. 136). For example, health care providers require an attitude of humility to acknowledge and address the power imbalances that can exist in health care relationships. When Frida's oncologist apologized to her for her paternalistic behaviour, she demonstrated this attitude and insight. By taking this step, a respectful space was created for Frida to safely offer her cultural perspectives and related expectations in future exchanges between them.

Yan and Wong (2005) described reflexivity as a dialogic process "in which both professional and client interactively negotiate, understand, and reflect on their cultures

with reference to their understanding of the problem presented by the client” (p. 186). The outcome of this activity is the co-construction of new meanings and resolutions derived from revealed cultural similarities and differences between them (Dean, 2001; Williams, 2006). Frida offers an example of this process when she talked to her oncologist about the importance of family relationships in her life. She shared this information because she did not want to start a potentially toxic chemotherapy that would prevent her from going on a long planned trip with her sister. At the same time, Frida’s doctor expressed her argument for the treatment based on her medical perspective and goals. In this exchange, they were able to stay open to each other viewpoints, and subsequently agree on an alternate plan that took both their perspectives into account.

The various stories of the participants showed that these processes of cultural recognition and reflexivity can help to promote positive end-of-life experiences for culturally diverse persons. They can facilitate exploration and risk-taking that expands health care practices into more imaginative directions. When this occurred for the participants, they experienced a sense of “cultural safety” that ensued from the experience of cultural respect and acknowledgement (Oliviere, 1999).

Points for Practice

I have described how we can reconsider the phenomenon of biomedicine by viewing it through the lens of culture. When we do so, biomedicine emerges as one cultural discourse alongside others of HPC and culturally diverse persons. From this perspective, the relevant aspects of various care approaches can be recognized and applied to provide whole-person care according to the unique viewpoints and needs of culturally diverse patients. In addition, the reconceptualization of patients’ cultures as fluid and evolving entities explains how individuals are able to draw on a range of cultural strategies to meet their changing needs over time and circumstance. I have identified various practice methods that social workers and other health care providers can use to facilitate a broader understanding of biomedical and patient cultures, which are summarized in Table 13.

Table 13. Ways to Re-Think and Re-Present Culture and Cross-Cultural Care

STRATEGY	ACTIONS
Promote new ideas about patient culture	<p>Challenge the notion that patients' cultures are static and unchanging.</p> <p>Highlight the fluidity of patients' cultural identities.</p> <p>Use opportunities such as discussions in medical rounds and/or psychosocial assessments to present these perspectives.</p>
Name the culture of medicine	<p>Position the culture of biomedicine alongside the cultures of HPC and patients.</p> <p>Articulate the beliefs and values of biomedical culture.</p> <p>Acknowledge the heterogeneity of biomedical culture.</p>
Actively explore the cultures of patients	<p>Be curious and open.</p> <p>Start from a place of not-knowing.</p> <p>Develop an attitude of cultural humility.</p> <p>Learn about, and draw on, preliminary information about patients' cultures as an entry point for inquiry and dialogue.</p> <p>Ask open-ended questions that elicit information from patients about what is most important to them regarding their care.</p>
Be reflexive	<p>Be transparent about medical, organizational, professional and personal beliefs, values and practices.</p> <p>Consider how they interact with each other and those of patients.</p> <p>Consider how they influence attitudes toward diverse knowledges of patients.</p> <p>Create opportunities for health care teams to collectively reflect on how these dynamics and interactions impact patient care.</p>

Opportunities for Future Research Directions

As I reflect on what I have learned about cross-cultural care in this study, I am also reminded of what we do not know and what we need to learn more about. New questions and possibilities have emerged as important topics for further exploration, which I will describe next. They fall along two lines of inquiry related to practice and effectiveness, which are reflected in other social work agendas for hospice palliative care as well (Kramer, Christ, Bern-Klug, & Francoeur, 2005).

Making cross-cultural care practical

Because I am a social work practitioner, I am especially interested in the practical implementation of whole-person care in everyday contexts. A central component to this approach to care is to ensure that patient perspectives are equally presented and considered in medical encounters with health care providers. A primary challenge to meeting this objective at the point of care is the potential time it may take to gather information about a patient's lifeworld and his or her individual beliefs and values. 'Thick description' entails interpretations of cultural meanings of health and illness at multiple levels. Even more time may be required when this information is solicited from family members who are involved in the patient's care. In hectic health care settings, particularly in acute care, practitioners from all disciplines may feel too busy and pressured to engage in such comprehensive assessments.

Although I have described some strategies in this study to facilitate culturally diverse patients to voice their views, other projects to identify additional rhetorical tools are required (Wiggins & Schwartz, 2005). Efforts need to be made to identify and address structural barriers that limit the time and opportunity for health care providers to elicit sufficient information about each patient's care needs and goals. Further exploration of the ways in which comprehensive assessments can be developed by an inter-professional team may identify ways in which existing resources can be used more effectively within fast-paced settings.

In addition, further development of interview methods that can generate a range of pertinent patient information in reliable and expedient ways is needed. For example, in

chapter seven, I identified various cultural dimensions that can be used to frame an interview guide that will elicit key information relevant to various aspects of whole-person care. Based on these dimensions, questions can be developed accordingly about patients' spiritual beliefs and practices, the non-medical activities they use to enhance their well-being, how they would like to participate in decision-making, and their concerns and goals for quality of life. These could be combined with the cultural constructs that Schim and Doorenbos (2010) described in their model of cultural congruence to expand the focus of inquiry. The use of quality-of-life questionnaires is also a helpful technique to forefront quality of life topics during medical consultations (Detmar & Aaronson, 1998). Future research projects wherein these lines of inquiry can be refined, piloted and evaluated in various care settings will help determine their utility and uptake by health care providers.

As I discussed in chapter one, I recognize that the process of gathering and expressing comprehensive patient information can be encumbered by language differences. All the participants in my study did speak English with only one person requiring periodic assistance from an interpreter. Future studies that include non-English speaking patients are needed to identify effective ways to forefront their experiences, ideas and expectations in medical encounters. For example, piloting comprehensive interview guides and inter-professional assessments as mentioned above with non-English speaking participants will help to determine the transferability of such approaches across cultural and linguistic groups.

I also think that the development of specific structural and individual strategies to promote effective partnerships between health care teams and patients and families are required. As suggested in this study, a realignment of power relations among health care disciplines through the de-centering of medicine is necessary to achieve whole-person care. This needs to extend to relations with patients and families as well. A critical review of current models of patient-centred care and inter-professional practice can serve as a starting point for these changes. For example, Opie (1997) has suggested that health care teams ought to be deliberately reflexive in their work to understand how professional discourses position patients, and how related power differentials can be practically redressed. She (1998) has put forward the idea that family meetings be reconfigured with

this awareness so that they become an active mode of empowerment for patients and families. Research that identifies additional ways to balance power differentials between health care providers and patients will bring a different meaning to collaborative teamwork among patients, families and professionals in cross-cultural care specifically, and health care generally.

Assessing effectiveness

Finally, further studies are needed to determine whether whole-person care makes a positive difference to health outcomes for culturally diverse patients. Generally, impact research in the area of cultural competency has been limited. From the start, models of cultural competency have been largely based on the evidence of limited clinical experiences rather than on any systematic empirical validation (Este, 2007). Although the “relationship between increases in cultural competence and reductions in health disparities seems intuitively plausible”, it has so far not been empirically demonstrated (Perloff et al., 2006, p. 848). Similarly, research regarding the effectiveness of patient-centred care, which presumably encompasses cultural competency, has been methodologically weak and inconclusive (Ontario Medical Association, 2010).

Conventional quantitative research approaches are challenged to answer this impact question adequately because concepts such as person-centred care and whole-person care are multi-faceted. At their core, they reflect relationships and interactions among patients, families and health care providers that do not correspond directly or consequently to measurable health outcomes that are meaningful or important to all parties. For example, behaviour changes by physicians may improve patients’ satisfaction regarding their experience of patient-centred care, but health outcomes may still be perceived as poor by health care providers (Epstein et al., 2005). Alternatively, patient-centred care may be linked to positive outcomes, but cost more than health care that is less patient-centred (Behhel, Myers, & Smith, 2000).

Therefore, this type of inquiry calls for the development of imaginative qualitative research studies that can show whether whole-person care makes a difference to the experience of HPC from the various standpoints of patients, families and health care providers. Of course, the question of whether whole-person care and patient-centredness

is intrinsically important, regardless of whether it impacts health outcomes positively, may need to be addressed first (Duggan, Geller, Cooper, & Beach, 2006; Ontario Medical Association, 2010).

Concluding Remarks

To feel cared for is our common desire

The activity of analysis draws to a close when conversations gradually diminish “into a series of more and more pauses, and finally to silence” (van Manen, 1997, p. 99). The silence is not indicative of an empty place, however. Instead it is a space fulfilled by meaningful understanding of a phenomenon. I have reached this place in this project.

The purpose of my research was to describe the lived experiences of health care for culturally diverse persons with life-limiting illnesses, to identify what they perceived as essential to excellent health care, and to understand how mainstream and minority cultural discourses influence the experience of care. Through the lens of culture, the participants emerged as unique and multi-faceted individuals with an array of needs and resources. I identified from their stories the importance of whole-person care to address their various physical, mental, emotional and spiritual concerns. Their experiences revealed that their cultural identities were fluid and versatile, which allowed them to draw strategically on a repertoire of mainstream and minority cultural discourses to meet their various needs throughout the course of their illnesses.

What arises for me as a final impression as I reflect on this study is an awareness of the participants’ common need and desire to feel cared-for and cared-about in ways that transcended their cultural diversity. This appeared to be the thematic thread that joined the requisites of whole-person care. This feeling transpired for all the participants when they were acknowledged as unique and whole individuals who were more than their illnesses, symptoms, or treatments. They felt cared-for when their opinions were sought and their ideas and approaches for treatment were welcomed, even when they were different from those of their care providers. This feeling resonated in their stories when they were treated with respect, compassion and dignity. These findings are consistent with other studies that also identified how important it is for patients to feel cared-for by

health care providers in all their interactions with them (Gourdji et al., 2009; Janssen & Macleod, 2010). I look back now at the experiences of Mr. Kim and his family, which I described in chapter one, and think how they would have been much more positive had we cared for him in these ways.

The extent to which health care providers can provide whole-person care to culturally diverse persons moves the focus of attention from perceived differences between them to what they share in common as human beings in need. This is the challenge and the opportunity for all professionals who work with persons living with life-limiting illness. The achievement of it constitutes the ethos of hospice palliative care.

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Appendices

Appendix 1: Introduction Letter to Third-Party Recruiters

THE UNIVERSITY OF BRITISH COLUMBIA



School of Social Work
Faculty of Arts
2080 West Mall
Vancouver, B.C. V6T 1Z2

Tel: (604) 822-2255
Fax: (604) 822-8656
Website: www.swfs.ubc.ca

Exploring the Influence of Culture in Health Care

November, 2008

Hello

As per our earlier conversation, I wanted to follow up with you regarding the study that I am conducting for my PhD dissertation, which has been funded by the Michael Smith Foundation for Health Research. The purpose of this study is to understand experiences of health care from the perspective of persons of diverse cultural backgrounds who have been diagnosed with a progressive life-limiting illness. As you know, cross-cultural interactions can be complex, and research has shown that unresolved cultural differences can result in poor or inappropriate outcomes in end of life care for minority populations. Therefore, the aim of this research project is to better understand the ways in which culture influences the experience of care for culturally diverse patients along the trajectory of terminal illness. I hope that the knowledge produced through this study can be used to inform health care practices and policy that will support relevant and appropriate palliative care for culturally diverse patients and their families.

My intention is to interview people of culturally diverse backgrounds who have a palliative diagnosis about their experiences of health care. I will be asking questions about their illness, their ideas about culture, and how culture has been relevant to their experiences of illness and health care. I plan to interview participants in meetings that may last from 30 to 90 minutes. With their

permission, a second interview of similar length may be requested in order to clarify or discuss some of what they said in the first interview. All meetings will take place at a time and location of their choice — which can include their home. The interviews will be audio-taped. I will arrange for a translator for those participants who find it easier to be interviewed in a language other than English.

I am wondering if you would help bring this study to the attention of individuals who might be interested in discussing their experiences of health care with me. This could be done either by posting or distributing the enclosed notice, or by obtaining permission for individuals to give their telephone number to me so that I could contact them directly and provide further information.

If you have more questions about this study, please don't hesitate to telephone me at xxx-xxx-xxxx or email me at xxx@xxx.ca. You are also welcome to contact my PhD supervisor, Dr. Deborah O'Connor, at xxx-xxx-xxxx or email her at xxx@xxx.ca for further information. Also, if at any point, you are interested in discussing the emerging findings, I'd be happy to meet with you and would welcome your feedback. Copies of any reports or publications will be available to you upon request as well.

Your help with this project would be very much appreciated! Please call if you have any questions or would like to know more about it.

Thanks again for your interest and support.

Sincerely,

Harvey Bosma MSW PhD (C)

Appendix 2: Study Information Flyers (English and Chinese)

THE UNIVERSITY OF BRITISH COLUMBIA



School of Social Work
Faculty of Arts
2080 West Mall
Vancouver, B.C. V6T 1Z2

Tel: (604) 822-2255
Fax: (604) 822-8656
Website: www.swfs.ubc.ca

Are you living with a serious progressive illness?

If so, I would be interested in talking to you about
participating in a study.

What is the study about?

The purpose of the study is to understand experiences of health care
from the perspective of people of diverse cultural backgrounds who have
been diagnosed with a serious progressive illness.

What would you need to do?

I would like to meet with you to discuss your health care experiences
at a time and location that is convenient for you.
The meeting will take no more than 90 minutes.
I will arrange a translator upon your request.

Why participate?

We hope that the findings of the study will help doctors, nurses and
other health care workers to provide appropriate health
care for people of diverse cultural backgrounds.

If you are interested in participating or would like to know
more about this study, please contact

Harvey Bosma MSW PhD (Candidate)
xxx-xxx-xxxx or xxx@xxx.ca

THE UNIVERSITY OF BRITISH COLUMBIA



School of Social Work
Faculty of Arts
2080 West Mall
Vancouver, B.C. V6T 1Z2

電話: (604) 822-2255
傳真: (604) 822-8656
網址: www.swfs.ubc.ca

你是否患有嚴重疾病?
如果有, 希望你能參加一個研究.

這個研究是關於甚麼的?
研究的目的, 是要了解不同文化背景而患有嚴重疾病的人士,
接受醫護服務的經驗.

你需要做些甚麼?
我想和你一個你方便的時間和地點會面,
討論你接受醫護服務的經驗.
會面時間不會超過 90 分鐘.
如果你提出要求, 我會替你安排翻譯員.

為甚麼要參與?
我們期望研究的結果可協助醫生、護士及其他醫護人員提供更適
切的醫護服務給不同文化背景的病患者.

如果你有興趣參與或想知道多一點這個研究詳情, 請聯絡

Harvey Bosma MSW PhD (博士班研究生)
電話 xxx-xxx-xxxx 或電郵 xxx@xxx.ca

Appendix 3: Participant Consent Form

THE UNIVERSITY OF BRITISH COLUMBIA



School of Social Work
Faculty of Arts
2080 West Mall
Vancouver, B.C. V6T 1Z2
Tel: (604) 822-2255
Fax: (604) 822-8656
Website: www.swfs.ubc.ca

Exploring the Influence of Culture in Health Care

Consent to Participate

Principal Investigator: Dr. Deborah O'Connor
School of Social Work
Telephone: xxx-xxx-xxxx

Co-Investigator: Harvey Bosma PhD (Candidate)
School of Social Work
Telephone: xxx-xxx-xxxx

The purpose of this study is to understand experiences of health care from the perspective of people of diverse cultural backgrounds who have been diagnosed with a serious progressive illness. This research is important because we know that culture often influences health care experiences, but we do not know in what ways this occurs. We hope that the findings will help doctors, nurses and other health care workers develop practices and policies that support appropriate health care for culturally diverse people and their families.

This study is being conducted as part of the requirements toward a PhD for Harvey Bosma. Funding for this study is provided by the Michael Smith Foundation for Health Research.

If you decide to participate in this study, you will meet with Harvey Bosma to discuss your experiences of health care. He will ask you questions about the illness you have, your ideas about culture, and how culture has been relevant to

your experiences of illness and health care. This meeting may last up to 90 minutes. If you are willing, another interview of similar length may be requested in order to clarify or discuss some of what you said in the first interview. All meetings will take place at a time and location of your choice — this could include your home. With your permission, the interviews will be audio-taped in the language of your choice and transcribed; a copy of the interview transcript will be given to you upon your request. We will also arrange for a translator to be available during the interviews if you request one.

Your participation in this study is voluntary. You have the right to refuse to answer any questions, to request that audio-recording be stopped at any time, and to withdraw any information you do not wish to have included in this study. You are also free to withdraw from the study at any time. Should you withdraw, the information you have provided up to the point of withdrawal will be used in the data analysis, unless you state that you wish to have it removed. Your decision to withdraw or not participate in this study will in no way jeopardize your involvement with any programs or services that you are or will be using.

The information you provide will be kept confidential unless you specify otherwise in writing. Consent forms, transcripts and audiotapes of all interviews will be kept in a locked cabinet in the secured offices of the Principal Investigator and/or Co-Investigator. Your name and any other identifying information will be removed from all transcripts; pseudonyms will be used to reference you. All electronic files will be kept on a password-protected computer in the secured offices of the Principal Investigator and the Co-Investigator. Access to these offices and files is strictly controlled and limited to the Principal and Co-Investigators.

We recognize that talking about this experience may be distressing to some people. You are not obliged to answer any questions that make you feel uncomfortable or that you do not wish to answer. We are prepared to stop the interview immediately upon your request. We are also prepared to help you locate appropriate support if participation in this study is unsettling for you, as well as provide a written list of support services to you.

While there are no direct benefits to you, some people find it beneficial to talk about their experiences of illness and the care that they have received for it. Some people also appreciate the opportunity to share information about their experiences that may help to improve health care for others.

We will report the findings of this study in Harvey Bosma's dissertation, journals, conference presentations and workshops. We recognize that there is the remote possibility that participants could be recognized by others given the small number of participants involved in this study. However, all efforts will be made to insure that you are not identified by others by changing or removing information that might otherwise readily identify you.

If you have any questions or desire further information about any aspect of this study, you are invited to contact Dr. Deborah O'Connor at xxx-xxx-xxxx or xxx@xxx.ca or Harvey Bosma at xxx-xxx-xxxx or xxx@xxx.ca. Furthermore, if you have any concerns about your treatment or rights as a research subject you may contact the Research Subject Information Line at the Office of Research Services at the University of British Columbia at 604-822-8598, or email to RSIL@ors.ubc.ca.

Thank you for considering involvement in this study. If you agree to participate, your signature is required below.

Sincerely,

Deborah O'Connor, PhD RSW

Harvey Bosma, PhD (Candidate) RSW

I understand that my participation in this study is entirely voluntary. I may choose not to participate or may withdraw from the study at any time.

My signature below indicates that (1) I consent to participate in this study, and (2) I have received a copy of this consent form for my own records.

Participant's Signature

Printed name

Date

I do/do not (please circle) give permission for the research investigators to use information that I am providing for future studies conducted by them related to this topic, assuming that the study is reviewed and approved through a university Ethics Review Committee.

Participant's Signature

Appendix 4: Semi-Structured Interview Guide

The interview guide includes a number of introductory questions, follow-up questions and probing questions (Kvale, 1996). Introductory questions were generally open-ended for the purpose of yielding spontaneous and rich description. Follow-up questions and probing questions were asked to pursue topics and encourage further elaboration about them. I included some specific demographic questions at the end of the interview, if this information hadn't already been provided otherwise when answering other questions. During the interview, I moved flexibly among the various questions according to the type and depth of information provided by the participants.

The following offers a sample of the types of questions I asked in the interviews:

Can you tell me about your health and illness — starting anywhere you'd like in that story?

Can you tell me what it has been like to receive health care for your illness?

- How has information about your illness been shared with you? With your family?
 - How much/what kind of information have you wanted to know about your illness? About your prognosis?
- How do you make decisions about goals of care? About which treatments to take?
 - How does your family (friends) participate in making decisions?
 - How is your family involved in your care?

Aside from the conventional medical treatment that you've had, are there other things you do to care for yourself, to treat the illness?

- How did you learn about these ways? Where do they come from?
- Do you discuss these with your doctor? Nurse? Other health care professionals?

Can you describe your interactions (relationships) with Health Care Professionals (HCPs), for example, doctors, nurses, social workers, others?

- Can you tell me about a positive interaction with a HCP? What made it positive?
- Can you tell me of a time when you had a difficult/upsetting interaction with a HCP? Can you describe what happened? How was this dealt with?
- Aside from your interactions with medical doctors, have you had interactions with other HCP (for example, nurses, social workers, PT, OT, etc.)? Can you tell me about those?

What is important to you in health care? How would you describe good health care?

- Can you provide an example of good health care? Of when it's working well?
- Can you provide an example of when it isn't working well? When you're frustrated by it? When you're feeling at odds with it?

How would you describe yourself culturally? What comes to mind?

- What does being _____ (for example, Chinese) mean to you? Can you describe what being _____ is to you?
- Are there ways of doing things in your everyday life that you would describe as being cultural?
- How does your culture and/or being _____ influence your experience of health care?
 - Can you give an example?

What would you want a HCP to know about you? About your culture?

Can you tell me whether HCPs have talked to you about what is important to you in your health care?

- Can you tell me more about this?
- Can you describe how HCPs have taken these things into account when providing care to you?

Is there anything else that you would like to add?

Demographic Information

Gender:

Age:

Marital Status:

Family:

Education:

Birthplace:

Length of time in Canada:

First language:

Diagnosis and date: