ASSESSING QUALITY OF LIFE AND QUALITY OF CARE FOR PALLIATIVE PATIENTS IN A RURAL SETTING USING A MIXED METHOD APPROACH

by

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Abstract

This study explores how individuals living with a life limiting illness experienced and understood their quality of life and quality of care. Currently, few studies have explored the perspectives of palliative patients. The purpose of this study is to provide an in-depth analysis of the experiences of palliative patients and their understanding of quality of life (QoL) and quality of care (QoC) within the context of the Shuswap region of British Columbia (B.C.). This study highlights challenges and strengths of rural palliative care with the goal of informing future policies, programming and services in the rural Shuswap and more broadly. A mixed method approach was used for this study; participants were interviewed twice using a semi-structured interview, completing the McGill Quality of Life Tool prior to the second interview. Interpretive description and descriptive statistics were used for data analysis. The findings of the study indicate that there is a highly inter-connected relationship between the quality of life (QoL) and quality of care (QoC) for the Shuswap rural palliative patients. The findings also indicate that overall the palliative patients living in the rural Shuswap are pleased with their QoL and QoC; however, all participants expressed concerns regarding the coordination of their health care services. Many participants attended multiple health care appointments per week and would like to see their appointments more coordinated. In addition, all of the participants shared their strong desire to remain as independent as possible. Therefore, this study’s findings suggest that care needs to be more coordinated from a patient centred perspective which could result in a higher QoL for patients.
Preface

This thesis was approved by the University of British Columbia Behavioural Research Ethics Board and the Interior Health Research Ethics Board (H13-01480).
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Dedication

This thesis is dedicated to rural palliative clients who courageously teach us what really matters in life.
Chapter 1 Introduction

Quality of Life and Quality of Care for Palliative Patients in the Rural Setting

In Canada, concerns associated with palliative care are on the rise, despite the fact that we live in a death denying society where death is often seen as a medical failure rather than a natural progression of the human lifespan. The increase in palliative care concern is related to the fact that our population is aging, and individuals are living longer with chronic and life limiting illnesses (Crooks & Schuurman, 2008; Kelley, Williams, Demiglio, & Mettam, 2011). Canadian Senator Sharon Carstairs (2010) illustrated the priority of this issue in Canada when she called for “federal leadership, financial support and coordination of a national strategy to address palliative care” (p.47). In addition, in March 2013, the British Columbian (B.C.) Government released a new provincial action plan to improve end-of-life care “with the goal to improve the way health care providers meet the needs of people coping with end of life, including their families and caregivers” (p. 4). While these frameworks and action plans feature many positive aspirations including better health outcomes, improved care, and reduced health care costs, the concerns are that these services and programs are often implemented in urban centres with little to no impact in rural communities (Wilson, Thomas, Burns, Hewitt, Asei, Waree & Roberston, 2012). Kelley (2007) specifically points out that in Canada, as well as in Australia and England, it has been well documented that people who live “in rural and remote areas have less access to palliative care services than people in urban areas” (p. 143). In addition, the Canadian Institute for Health Information has suggested that rural individuals are generally less healthy than their urban counterparts. Rural health is likely influenced by lower income, decreased access to health care, and fewer specialized health care services (Wilson et al., 2012).
The need for the effective delivery of palliative care services is becoming increasingly urgent as we rapidly approach a demographic shift where globally people over the age of 65 are outnumbering children under the age of five (World Health Organization, 2012) – a first in human history. The health care field has become increasingly interested in how to best serve the palliative population. For the purposes of this study palliative care will be defined as “an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (Economist Intelligence Unit, 2010, p. 5).

The Shuswap region is located in the Southern Interior region of British Columbia. The geographical area is 30,180 square kilometers (Colombia Shuswap Regional District (CSRD), 2007) with a population of 50,512 (2011 Canadian census). Approximately 30,630 residents (61% of the population) are located in four municipalities. An additional 18,760 residents (37%) live in unincorporated areas, and the remaining 760 residents (2%) are on First Nation Reserves (CSRD Report, 2001). The largest municipality within the Shuswap is Salmon Arm, where the majority of health care services are located. In rural Shuswap palliative care has been identified as an urgent need as the community has called for an action plan to improve palliative care services (Interior Health, 2013). Like the rest of the country, the Shuswap has a large aging population; in 2011, 24% of the Salmon Arm population was 65 years of age and over compared to a national percentage of 14.8% (Statistics Canada, 2011). Hence, the need for palliative care services in this region is evident.

Currently, the Shuswap palliative care is provided by a local generalist healthcare team rather than by a palliative care specialist team; this is a common occurrence in rural communities (Kelley, et al., 2011). Currently, the Shuswap has limited home care services, a 40 bed acute
care hospital, and three designated end-of-life beds that are located in a long term care facility. The end-of-life beds do not include guaranteed registered nursing (RN) coverage; therefore, palliative patients need to be stable to be able to access these beds. Most of the time licensed practical nurses (LPN) are looking after these patients. In addition, certain pain management methods cannot be used in the end-of-life beds because it requires RN coverage as some pain management methods are outside of the LPN’s scope of practice.

In 2011, the Shuswap communities formed a working group called the Shuswap North Okanagan Palliative Working Group (SNOPWG). SNOPWG has been advocating for an increase in palliative care services with the goal to improve the quality of life (QoL) and quality of care (QoC) for the patients and their caregivers. Their goal is to enhance and build on existing community services and infrastructure (Interior Health, 2013).

For the purpose of this study rural will be referred to as Beale’s rural definition which “refers to individuals living outside metropolitan regions with urban centres of 50,000 or more population” (Du Plessis et al., 2001, p. 6). Geographically, patients living within the boundaries of the Shuswap are isolated from the tertiary care sites that provide a higher level of medical intervention, for example, radiation, cardiac services, and dialysis. In addition, people living within the Shuswap region do not have access to specialized multidisciplinary care teams; often the availability of services is limited and this trend is unlikely to change in the near future.

Many Shuswap residents are aware of the need for improved palliative care services in the area. In November 2012, SNOPWG held a community forum to further build on the themes that emerged from a recent community palliative care survey of 147 individuals, consisting predominantly of health care providers (Interior Health, 2013). The findings from both the survey and the forum were then generated into a report designed to guide future programs and
funding for the Shuswap community. However, with the focus of this group on improving QoL and QoC, there are some concerns that the concepts may not be fully understood from rural palliative patients’ perspectives. For example, it is known that the QoL of rural individuals is affected by the ability to access care within their own community (Pesut, Robinson, & Bottorff, 2011). However, limited healthcare services, commuting to larger centres, economics, rural values, weather conditions, and other socioeconomic factors force rural patients to make tough choices about whether to stay in their own community, to commute for health care services, or even to relocate for care (Kelley, 2007; Goodridge & Duggleby 2010; Robinson, Pesut, Bottorff, Mowry, Broughton, & Fyles 2009). These hard choices need to be explored to gain a better perspective of how QoC and QoL impact rural patients.

While this type of research has not occurred in the Shuswap, similar research studies have explored palliative care in other rural communities. In 2011, Pesut, Bottorff, and Robinson published an article called, Being known, being available, and being mutual. In the article, the authors unpack their research findings from a study that took place in four rural communities in Western Canada. While studies like this are valuable, the majority of the research that has taken place to date has been from the perspectives of the caregiver and/or care providers. It is important to also capture the unique perspectives of palliative patients. Robinson et al. (2009) also suggest that “we know very little about the patient and family perspective regarding palliative care in rural and remote settings” (p. 256). In addition, this research often takes place retrospectively. Hence, this study will focus directly on the perspective of rural palliative patients, thus adding important insight into rural palliative care.

Purpose

The goal of palliative care is to improve QoL and QoC for palliative patients and their families, but there is concern that these concepts are not fully understood from the rural
perspective. Kelley (2007) points out that research for “rural palliative care is limited in comparison to other palliative care topics” (p. 145). Therefore, this type of research is paramount in gaining a better perspective of what constitutes QoL and QoC for rural individuals.

The purpose of this study is to provide an in-depth analysis of the experiences of palliative patients and their understanding of quality of life (QoL) and quality of care (QoC) within the context of the Shuswap region of British Columbia (B.C.). This study will highlight challenges, problems, and strengths with the goal of informing future policies, programming and services in the rural Shuswap and more broadly.

**Research Questions and Objectives**

This study will explore the ways in which palliative patients understand and experience the relationship between QoL and QoC in the context of their rural life. To answer this question three objectives have been formed.

i) To develop a deeper understanding of QoL and QoC from the perspective of a rural palliative patient;

ii) To better understand the usefulness of the McGill QoL measure in a rural setting; and,

iii) To compare and contrast the qualitative and quantitative findings of patient QoL and QoC to discern areas of agreement and disparity.

**Defining Quality of Life and Quality of Care**

This study uses Cohen, Leis, Kuhl, Charbonneau, Ritvo, and Ashbury’s (2006) definition of quality of life (QoL). According to these authors QoL is defined as “subjective wellbeing, reflecting differences or gaps between hopes and expectations and current experiences” (p. 755). Quality of care (QoC) is defined as a high standard of health care characterised by being safe, effective, patient-centred, timely, efficient and equitable (Goodridge & Duggleby, 2010). The MQOL tool was utilized in this study and the objective was to measure palliative patient’s quality of life. The tool takes into consideration five specific domains: physical symptoms,
physical wellbeing, psychological domain, existential domain and supports domain (Cohen, 1995). Klugman and Dalinis (2008) address ten principles about QoC in their book “Ethical Issues in Rural Health Care”. The 10 principles that they have suggested include:

1. Care based on continuous healing relationships
2. Customization based on patients’ needs and values
3. The patient as the source of control
4. Shared knowledge and the free flow of information
5. Evidence-based decision making.
6. Safety as a system property
7. The need for transparency
8. Anticipation of needs
9. Continuous decrease in waste
10. Cooperation among clinicians

(List from Klugman & Dalinis, 2008, p. 120)

It is important to consider QoL and QoC in this study because at the end-of-life the significance of these two specific concepts is often heightened due to the nature of the circumstances. For example, a palliative patient may choose to forgo radiation treatment for pain management because it is not available in their community and subsequently live with unnecessary pain which will likely impact their QoL. QoL considerations inform many aspects of public policy and QoC considerations are the cornerstone of health care policy. Therefore, it is only through a sophisticated understanding of QoL and QoC and their interrelationships within a particular demographic (i.e. rural communities) that we can develop effective health care policies to serve the needs of the demographic in question.

This chapter has described the background to the thesis. Chapter two contains a summary of the literature. Chapter three will describe the method used to conduct this study. Chapter four presents the major themes that were constructed from the data collected. Chapter 5 provides an overview of how this study’s findings contribute a new perspective on patient-centred care for rural palliative patients.
Chapter 2 Literature Review

What is known about palliative care in rural areas, in particular quality of life and quality of care?

The literature review for this thesis is a summary and not an inclusive account of all current literature. This is intended to provide a brief summary of current palliative care research with a focus on QoL and QoC trends in rural palliative care. It also includes a review of selected government frameworks developed for palliative care within Canada.

Canadian Palliative Care in the Global Context

How does Canada rank in palliative care on a global scale? According to the Economist Intelligence Unit report released in 2010, Canada ranks ninth place out of 40 countries. The Economist Intelligence Unit score was based on four factors: end-of-life health care environment, availability of end-of-life care, cost of end-of-life, and end-of-life quality. In the end-of-life quality section Canada ranked fifth place. The report suggests that the Canadian Government has recently shown an increased interest in improving the national standards for palliative care. However, Canada placed 27th for the cost of end-of-life. In fact, Dumont, Jacobs, Fassbender, Anderson, Turcotte, and Harel (2010) found that Canadian families often pay 25% of their palliative care costs which is why the overall ranking fell to ninth place.

Over the last few years, the Canadian government has released several documents regarding the state of palliative care in Canada (e.g., Carstairs 2010; Ministry of Health British Columbia, 2013; Ministry of Health British Columbia, 2006, 2013). In one such report, Senator Carstairs (2010) clearly outlined that Canadians should expect to receive equitable access to palliative care based on patient needs wherever they live in Canada (p.3). This is particularly important given estimates, based on population growth statistics, that the number of deaths occurring annually in Canada will nearly double to almost 480,000 annually by year 2056.
Similarly, Kelley et al. (2011) argue that there will be “an increased demand for palliative care, due to an aging population, and with more individuals living longer with chronic and terminal illnesses” (p. 2).

While the need for palliative care is currently increasing, the Worldwide Palliative Care Alliance suggests that while more than 100 million people would benefit from hospice and palliative care annually, less than 8% of those use it (Economist Intelligence Unit, 2010, p.5). Complicating matters, “many individuals are never recognized as actively dying and so fail to receive many of the benefits associated with palliative care” (Pesut, McLeod, Hole, & Dalhuisen, 2012, p.1). All of these points demonstrate that palliative care is on the rise and service providers, policy makers, and researchers need to attend to all aspects of palliative care, including the unique needs of the rural populations.

**Rural Palliative Care Population Trends**

When determining the importance of rural palliative care, it is important to take into consideration the rural population trends. Crooks and Schuurman (2008) note that the “number of people relocating to rural areas upon retirement and the process of aging-in-place in such communities are amplifying the need for palliative care in these settings” (p.139). In addition, it is estimated that 20% of North Americans live in rural areas with a higher concentration in Canada (Wilson, Justice, Sheps, Thomas, Reid, & Leibovici, 2006). As stated previously, given the unique contexts of rural palliative care, researchers, policy developers and service providers need to be aware of population trends. In addition, these stakeholders need to be aware of what people living in rural areas expect with regards to their QoL and QoC.

Rural Canadians often do not have access to high quality palliative care options, despite the fact that the rural population is aging (Goodridge & Duggleby, 2010; Kelley, Sellick, & Linkewich, 2003). The Canadian Hospice Palliative Care Association (CHPCA) has
acknowledged that palliative care services are severely limited for non-urban populations in this country, a situation similar to many other countries (Quality End-of-Life Care Coalition of Canada, 2010). Rural communities often do not have interdisciplinary teams with advanced palliative care training. In addition, common challenges faced by rural communities include: recruitment and retention of qualified staff, lack of awareness of available services, inability to afford services, unmet informational needs of patients and caregivers, lack of knowledge about symptom management, and lack of funding and resources (Robinson, Pesut, & Bottorff, 2010).

Despite the fact that public preference for home deaths has been highly reported, the challenges faced by rural communities result in fewer home deaths due to a lack of availability of home care services (Wilson, Truman, Thomas, Fainsinger, Kovacs-Burns, Froggatt, & Justice, 2009). As a result, there are an increased number of admissions into acute care settings and long term care facilities in rural areas when many of these patients would be better served at home. Another issue is the distance that rural palliative patients are often required to travel for health care services (Kelley et al., 2003; Kelley et al., 2011). The burden placed on rural palliative care patients and their families in relation to the need to travel out of town for health care services has been well documented (e.g., Lockie, Bottorf, Robinson, & Pesut, 2010). This additional burden must be taken into account when considering health care services in rural communities.

Despite the numerous challenges faced by rural residents, the rural population often has a strong attachment to place, not just geographically but also socially. Castleden, Crooks, Schuurman and Hanlon (2010) conceptualize the importance of ‘place’ as follows:

The ways in which people give meaning to places, engage in place-making activities, understanding their place in social hierarchies, develop a sense of place, and create emotional attachments to places in reference to its social nature. (p.265)
While living rurally has its drawbacks, it is apparent that many rural residents are willing to forgo some aspects of health care because of the benefits that rural living can provide. Pesut, Hooper, Sawatzky, Robinson, Bottoroff, and Dalhuisen (2013) pointed out that in rural areas there is a “greater need for cooperation across sectors because of limited resources” (p.5). Greater cooperation often translates into community involvement, family involvement, volunteerism, church involvement, and overall community collaboration. Collaboration and sense of community are significant factors in overcoming large service barriers. McKee, Kelley, Guirguis-Younger, MacLean and Nadin (2010) suggested that rural hospice volunteers often fill in the formal service gap that rural communities face. When evaluating these rural trends, Kelly (2003) suggests that an ethical approach to health care in rural communities must take into consideration the experiences of the people within the community, the political environment, social dynamics, and the economics of the community. Therefore, each rural community has its own strengths and weakness and their individual characteristics must be taken into consideration. Robinson et al. (2010) suggest that “palliative care in rural communities needs to be based upon a thorough understanding of the nature and strengths of these communities” (p.79). Another common trend that is well documented in rural communities is the dual relationships that health care providers have. Hughes, Ingleton, Noble, and Clark (2004) report that “health care providers may be friends and neighbours, as well as care professionals” (p. 44). This unique dual-role often leads to a sense of community and overall relational connectedness within communities that is unique to the rural population and can contribute to the overall QoL and QoC for palliative clients.

When comparing the health of urban residents to rural residents, “[in] Canada, rural people are typically less healthy than their urban counterparts” (Wilson et al., 2012). The general health status of rural population is linked to multiple factors, including: older population,
higher rates of poverty, and less formal education (Hughes, et al., 2004). However, one important factor to consider is the pervading attitude of rural people toward the natural life cycle. For example, Hughes et al. (2004) suggest that “rural dwellers tend to view health as the ability to work, and are likely to be self-reliant in outlook” (p. 44). The desire for self-reliance and unique definition of health helps to explain why rural residents may respond differently when faced with a terminal illness and why quality of life may be defined somewhat differently than for their urban counterparts.

**Measuring Quality of Life Using the McGill Quality of Life Tool**

Not surprisingly, Cohen and many other researchers (e.g., Axelsson & Sjordon 1999; McMillian & Mahon, 1994; Mystadikou, 2004; Steinhauser, Bosworth, Clipp, McNeill, Christakis, Parker, & Tulsly, 2002) have created many different QoL measurement tools specifically for the palliative care population. Jordhoy, Ringdal, Helbostrad, Oldervoll, Loge, and Kaasa (2007) conducted a literature review and found that there are 39 QoL measures specifically designed for the palliative population. Of the 39 tools designed to measure QoL for palliative patients; 19 are multidimensional, one of which was the McGill Quality of Life Questionnaire (MQOL), which is the questionnaire that is utilized for this study (see appendix A for a copy of the MQOL). The MQOL tool was selected for this study because it addresses psychological and existential issues that some of the other tools do not address. Interestingly, the MQOL tool has been validated in a variety of settings: Montreal, Quebec City, Saskatoon, Toronto, and Vancouver (Cohen, Mount, Bruera, Provost, Rowe, & Tong, 1997) all of which are urban settings. The MQOL tool has also been used in several countries: e.g., Israel (Kyeong et al., 2006) and Korea (Bantur & Resnisky, 2005). While the McGill tool has been utilized in many different places, it has not been validated in a rural setting. Therefore, in this study I will begin to explore the usefulness of the MQOL tool by comparing the results obtained through its
administration with data obtained through semi-structured interviews. When evaluating the QoL of palliative patients in a rural context, it is important to also consider QoC. Evaluating QoL exclusively would not explain the struggle that many individuals face in a palliative situation. Baldwin and Woodhouse (2011) suggest that good quality of care can translate into a good death for both the patient and the family. QoC also translates into the everyday interaction that individuals have with health care professionals which can have a profound impact of the QoL for individuals.

The Importance of QoL and QoC in the Study

The nature of QoL and QoC are subjective and philosophically unique to each individual. As noted earlier, this study uses Cohen’s et al.’s (1997) definition for QoL and Goodridge’s and Duggleby’s (2010) for QoC. These definitions are not inclusive of all perspectives; however, these definitions are meant to serve as a reference point and to provide context for this study.

There are multiple studies that have explored palliative care in a rural context. Robinson, et al. (2009) completed a comprehensive rural palliative care literature review and found several trends. They noted several barriers to providing high quality care: geographical distance, lack of resources, lack of relationship boundaries, and inadequate role preparation. Of the 24 studies reviewed, Robinson et al. found that “only six studies assessed the rural patient perspectives” (Robinson et al 2009, p. 254). However, none have specifically focused on how patients experiences and understand their QoL or QoC.

The location of a patient’s death is often significant for the patient and their family. At present, approximately 60% of B.C. residents die in the hospital setting despite the fact that only 10% of deaths are unexpected and sudden (Ministry of Health, 2006; Wilson et al., 2009). Interestingly, “a growing number of studies report there is a preference among dying persons for home-based care” (Wilson et al., 2009, p. 1753). Despite the high number of hospital deaths,
this is already a decline from the 1980s when approximately 80% of deaths were in the hospital setting. The numbers are reflective of the trend that individuals want to stay home for as long as possible. Place of death is an important factor and indicator of QoL for many individuals, in particular rural patients (Wilson et al., 2009; Robinson et al., 2009). Jordhoy et al. (2007) echoes this, suggesting “that the aim of quality of life for palliative care clients should be improvement and preservation of a normal life for as long as possible” (p.674).

The number one priority in the 2013 British Columbian End-of-Life Action Plan is to “[r]edesign health service to deliver timely coordinated end-of-life care” (Ministry of Health, p. 13). As part of the priority, one of the four actions is to focus on the QoL for individuals nearing their end-of-life. The 2013 Action Plan also includes a framework for end-of-life care that includes principles to be followed to ensure equitable high quality palliative care service for British Columbians. Clearly, the need for improved palliative care services and infrastructure is being recognized throughout many levels of government in Canada. While, these principles serve as a framework, Crooks and Schuurman (2008) point out that there is a unique nature to palliative care provision in rural communities (p. 139). Robinson, et al. (2009) also highlight that palliative care in rural communities needs to be based upon a thorough understanding of the nature and strengths of the communities. Kelley (2007) suggests that the research on “rural palliative care is limited compared to other palliative care areas” (p.145). My research aims to address an understudied area in the research: the experiences of rural palliative patients. In addition, if we do not understand the priorities of palliative patients, then how can we practice a patient-centered approach? A patient-centered approach is defined as being respectful of individual patient preferences, needs, and values, which helps guide clinical decisions (Institute of Medicine, 2001).
Chapter 3 Design and Methods

Mixed Method Research Design

This study was conducted using a mixed method approach for data collection and analysis which was comprised of both qualitative and quantitative data. This method was selected for this study as it helps provide a deeper understanding of the research objectives and enriches the results in a way that could not be accomplished by just collecting one type of data (Hanson, Creswell, Clark, Petska, & Creswell, 2005). Hanson et al. (2005) point out that a mixed method approach “allows [researchers] to test theoretical models and to modify them based on participant feedback” (p. 226). Similarly, Sandelowski (2000) suggests that a mixed method design “is a dynamic option for expanding the scope and improving the analytic power of studies” (p. 254). The mixed method approach was an ideal method to addressing the research question of this particular study.

Two specific semi-structured interviews were conducted with each participant; the first interview focused on QoL and the second interview focused on QoC. For this study a total of seven participants were interviewed. All were interviewed twice with the exception of the last participant, who was only able to participate in the first QoL interview due to a decline in his health. The MQOL tool was completed by participants at the beginning of the second interview. The data collected from the interviews was then used to “collaborate, refute, or augment findings for the instrument” (Hanson et al., 2005, p. 229). When designing a mixed method research approach, it is important to determine if both qualitative and quantitative data will have an equal distribution or if one is going to take priority. For the purpose of this study, unequal priority was placed on the qualitative and quantitative data. The qualitative data from the semi-structured interviews was given priority and the quantitative data from the MQOL tool was given less
priority. This is also referred to as a concurrent nested method (Hanson et al., 2005). The yellow highlighted areas in Figure 1 below outlines the procedural route used for data collection.

```
<table>
<thead>
<tr>
<th>Concurrent Implementation</th>
<th>Sequential Implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equal</td>
<td>QUAN</td>
</tr>
<tr>
<td>Unequal Priority</td>
<td>QUAL</td>
</tr>
<tr>
<td>(QUAN + QUAL)</td>
<td></td>
</tr>
</tbody>
</table>

Data Collection Procedures

Concurrent Implementation

Equal                   Unequal
Priority                Priority
(QUAN + QUAL)

Sequential Implementation

QUAN                   QUAL
Priority                Priority
(QUAL + qual)

Figure 1 Model of Mixed Method Data Collection. Adapted from "Mixed Method Research Designs in Counseling Psychology," by Hanson, et al., 2005, p. 227. Adapted with permission from author.

Criteria for Selection

The participants in this study were all geographically located within the Shuswap (See appendix B for the geographical boundaries). Participants all had a medical diagnosis with a life-threatening condition or illness and had a life expectancy of up to one year. To determine that the participants met these criteria, they were registered in the B.C. Palliative Program, which is a physician driven process. Finally, participants had to be over the age of 19 years and sufficiently cognitively healthy to participate. This was determined by how well the participant
understood the consent process. All participants were assumed competent because no concerns about cognitive capacity manifested during the consent process or the subsequent interview. All of the study participants spoke English, however, if a non-English speaking individual wanted to participate then an interpreter would have been hired. See appendix M for interpreter confidentiality agreement.

**Sampling Considerations**

The intention was to interview five to ten participants. For this study seven participants were interviewed. A convenience sampling method was used to reach this sample size. Convenience sampling refers to a process whereby participants are selected based on the accessibility of participants who meet the inclusion criteria (Thorne, 2008). This method was selected for several seasons: the Shuswap palliative population is generally small, usually between 15-30 individuals at one time (Personal communication with Reene Roberge, May, 16 2013). In addition, the timeframe for this study was less than one year; therefore it was essential to gather the data in a timely manner.

At the time of the study, I was employed in the Shuswap Community as an acute care social worker, which meant that I was also an insider within this community. This factor needed to be considered when recruiting and interviewing participants as it could have potentially placed limitations on the research study. Nevertheless, Foster, McAllister, and O’Brien (2005) suggest that being an insider also has multiple benefits such as prior knowledge about the structure and culture of the community participant trust, and an understanding of the jargon used in the field. Because I live and work in a rural community, I am often required to navigate this dual relationship of being both a community member and a profession in the community. For example, it was not uncommon for me to be professionally involved in someone’s life and then see them in an exercise class or at the local church the following day. This dual relationship can
pose some risks such as mentioned by Pesut et al. (2011): e.g., “loss of privacy, and anonymity” (p. 5). Privacy and confidentiality were essential to this research study as participants were engaging in in-depth interviews about their perceptions of the quality of their care. Therefore, it was important to build trusting relationships with participants; this is one of the reasons that I chose to conduct two interviews one on QoL and one of QoC. The issue of privacy and confidentiality came up twice during this research study. One of the participants was a community member who also happened to be a member of a church that I had attended several years prior to conducting the study. While I had not seen this individual for the last two years, he was eager to participate in the study and expressed a preference to be interviewed by someone whom he was familiar with. A prior relationship with another participant presented a more significant challenge. One week prior to the interview, a member of his extended family had a baby apprehended at the hospital and I had been involved with this case. I was not aware that this participant was related to that family until I arrived for the interview and recognized one of the family members. While this did not appear to affect the participant, it caused some discomfort for me during the first interview. For this research study the consent forms explicitly stated that the information provided by the participants would be confidential and that each participant’s identity would remain confidential. The consent form was signed prior to the first interview and I verbally reminded participants about this agreement prior to the second interview.

**Selection Process**

The recruitment of participants started in the fall of 2013 once the University of British Columbia Okanagan Ethics Board and Interior Health Authority Ethics Board approved the study. As mentioned previously, I am an insider in the community and, therefore, did not
directly recruit participants to the study to avoid role conflict. Recruitment took place in the following ways:

i) The Salmon Arm Home and Community Care Nursing (CCN) agreed to send letters to all of their current palliative care clients. In addition, the case managers of clients spoke to their clients about the study if they felt the participant might be interested. See Appendix C for the letter sent out by the CCN.

ii) In October, I spoke at the Salmon Arm Medical Staff meeting about the study. This is a meeting attended by physicians with hospital privileges. They were given information about the study, flyers, and Consent to Contact Forms.

iii) The Shuswap Hospice Society was also informed about the study at one of their monthly staff meetings.

iv) To generate community awareness, posters about the study were strategically placed in locations such as the community laboratory, patient waiting areas, and physician offices. See Appendix D for a sample poster.

v) Alternately, participants were also able to complete the Consent to Contact form through which potential participants could request that I contact them. See Appendix E for the Consent to Contact Form.

vi) The chemotherapy department at the Shuswap Lake General hospital was informed about the study and they provided information about the study to appropriate clients in the clinic.

All potential participants were invited to contact Merel Voth (Co-Investigator/Researcher). If a potential participant contacted me and indicated that he/she was interested in
the study, I would then explain the purpose of the consent process and answer any questions about the research. Individuals who signed the Consent to Contact Form were informed that I would contact them within five business days to see if they were still interested. If they remained interested in participating, a consent form was emailed or mailed to them. Prior to proceeding with the research interviews, informed consent had to be obtained. Participants had the consent form available to them at least three days prior to the first interview. Participants were given a $20 honorarium for their participation even if they withdrew after signing the consent forms. All material used for recruitment and consent purposes was prepared using plain language.

The Participants

A total of seven participants were interviewed for this study, four males and three females who ranged in age from 54-84 years of age. Though the demographic information sheet did not collect cultural or ethnic background it is important to note that all study participants were Caucasians. All of the participants had some form of cancer, one of the participants also had progressive multiple sclerosis (MS). The time of official diagnosis of the illnesses ranged from five years to five months prior to participation in the study. Twenty two years was the mean time that participants had lived in the Shuswap. (See Table 1)
Table 1 Demographic Characteristics of Participants

<table>
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<tr>
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<table>
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<tbody>
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<tr>
<td>13 or more</td>
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<tr>
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<thead>
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</tr>
<tr>
<td>Married</td>
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</tr>
<tr>
<td>Widowed</td>
<td>3</td>
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<tr>
<td>10-20</td>
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<tr>
<td>30-40</td>
<td>0</td>
</tr>
<tr>
<td>40-50</td>
<td>2</td>
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<td>Question not completed</td>
<td>1</td>
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</tbody>
</table>

<table>
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<tr>
<th>Number of Years in Contact with the Health Care System in the Shuswap</th>
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</tr>
<tr>
<td>Question not completed</td>
<td>2</td>
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Data-gathering Methods

The data was collected directly from palliative participants through a semi-structured interview (appendix G), the MQOL measurement tool (appendix A), and a demographic form (appendix L). The participants interviewed were considered vulnerable due to their declining health. Schulmann-Green, McCorkle, and Bradley (2009) recommend that researchers interviewing seriously ill patients should follow some basic principles when conducting their interviews. For the purposes of this study, the interview technique used was derived from Schulmann-Green et al.’s “Researcher’s 12 Techniques for Conducting Quality Interviews with Seriously Ill Individuals about End of Life” (see Appendix H for a copy of the 12 principles). Each participant was interviewed twice over the course of six weeks. It was important to conduct two interviews for several reasons:

1. Many palliative patients have multiple barriers to participation due to fatigue and pain; therefore, shorter interviews are more beneficial.
2. Multiple interviews allow for relationship building between the interviewer and the participant.

Each interview was 30-60 minutes in length. The semi-structured interviews included a narrative account and the use of interpretive analysis to gain a rich description of the participants’ perspectives on QoL and QoC.

In addition to the interview, MQOL, and the demographic data, I also used a field journal. This journal was used for several reasons: it allowed for the documentation of non-verbal information, it acted as a backup in the event of failed recording, and it facilitated the documentation of interviewer ideas and insights which could be helpful for subsequent interviews and analysis. The non-verbal information collected included my personal impressions of how the participant interacted with me and circumstances relevant to the interview. For example, one participant had her husband’s ashes on the coffee table when I was interviewing her. Another participant insisted that I watch her favorite television program with her before we
started the interview. In addition, the field notes also included some personal responses and experiences that I observed throughout the interview process. Being reflective about the interviews was important for my own wellbeing. Journaling is a self-care strategy that I find helpful for processing difficult situations.

**The Instrument: The McGill Quality of Life Questionnaire**

The McGill Quality of Life Questionnaire (MQOL) tool was designed by Cohen, Mount, Bruera, Provost, Rowe, & Tong, in 1995 and revised in 1997. The tool was designed specifically for palliative patients and consists of 16 items. The design of the MQOL tool was “derived from informal patient interviews, a literature review and existing instruments” (Cohen et al., 1997, p. 6). Stewart & Welch (2004) suggests that “instead of asking about a long list of symptoms, respondents are asked to list the three symptoms that are the most problematic and then to rate those three symptoms for severity” making this tool more user friendly (MQOL Section, para. 3). The MQOL scale uses a range that allows participants to respond on a scale of 0-10 (Cohen et al., 1997). In addition, the MQOL has a qualitative component which focuses on the overall QoL of the participants and asks participants to list/describe factors that contribute to their QoL and factors that worsen their QoL. The strength of this instrument is that it balances physical and non-physical symptoms, which is uncommon in most palliative QoL scales. Pesut et al. (2013) suggest, “[An] essential part of rural palliative care improvement is having validated measurements and systematic data collection” (p. 12). Hence, one of the study’s objectives was to determine if the participants’ qualitative data aligns with and/or contradicts the MQOL data.

**Data Analysis**

An important aspect of data analysis involves data management which allows for tracking, organizing, and sorting to ensuring that the data will be accessible and useful.
throughout the study. This allows for a meaningful and accurate account of the analytical process (Thorne, 2008). Concurrent nesting was used throughout this study: this refers to the process in which the qualitative and quantitative data are not given equal priority in the data analysis phase (Hanson et al., 2005). In this study the qualitative data was given more priority because the data collected during the semi-structured interviews provided more detail; however the quantitative data did provide a unique perspective on the topic. (See figure 2. for the concurrent nested method that was used for this study.)

Figure 2. Concurrent Nested Method. Adapted from Hanson et al., 2005 with permission.

**Quantitative data.** Descriptive statistics were used to describe the quantitative data gathered for this study through the MQOL tool. The aim of descriptive statistics was to provide a summary of the sample (Mark, 1996). First, I used Cohen’s scoring sheet to score the MQOL questionnaire (Appendix I *MQOL Scoring Sheet*); then the information from the scoring sheets was entered into an excel spread sheet. The descriptive statistics were generated for each of the question domains: physical well-being, physical symptoms, psychological, existential, support, as well as the overall score of the QoL.

**Qualitative data.** The management of the qualitative data involved a number of phases. First, I listened to the audiotapes from the interviews and then they were transcribed by a hired
transcriptionist. Once I received the transcriptions I checked them against the audio file for accuracy. This two-step process ensured that I was familiar with the data. The transcripts were then imported into the NVivo10 computer software program. This program was chosen because it is highly recommended by experienced researchers in the field. For each of the interviews, I wrote a one or two page summary of the interviews in my field journal.

Thorne’s interpretive description principles were used to analyze the data. This method explicitly locates itself within a philosophical tradition of social constructionism where there are multiple ways of viewing and truth telling (Thorne, 2008). Interpretive description was chosen for this research study because it provides a context in which clinical phenomena can be studied. Interpretive description “provides us with a solid and defensible basis upon which to judge whether a particular piece of qualitative output is worthy of our serious attention” (Thorne, 2008, p. 35).

Inductive reasoning and constant comparative analysis are used in interpretive description. Inductive reasoning makes broad generalizations from specific observations. Thorne (2008) suggests that qualitative description “will be open and exploratory, in contrast to the more narrow and focused description that would be sought using quantitative techniques” (p.48). Using inductive reasoning provides several benefits: a good quality description of a complex phenomenon which increases intellectual honesty, a general awareness of phenomena, and an “empirical basis from which new research questions can be generated” (Thorne, 2008, p. 48). In addition to inductive reasoning, a constant comparative analysis was used. Constant comparative analysis is an “approach where you compare every piece of data with all other that may be similar or different from it in order to theorize all possible relations among data” (Thorne, 2008, p. 151). For example, when participants shared their desire to remain
independent, each participant described how they went about staying independent from a slightly different perspective yet they were all describing the same QoL indicator.

Thorne’s interpretive description method is heavily influenced by the work of Sandelowski, Anderson, and Morse (2008). Thorne suggests that when working with data it is important to conceptualize the data. Therefore, she suggests using Morse and Richards’ (2012) four stages of making meaning of the data. The first phase is comprehension of the data; this occurs when there is a desire to learn everything about the subject matter while suspending judgement and without drawing conclusions (Morse et al., 2012). The next phase is synthesizing: the process where “various instances or events to describe typical or composite patterns within the data” (Morse et al., 2012). During the synthesis phase the researcher decontextualizes the processes in order to form common features within the data. This phase included “fracturing the data - taking it apart and examining those discrete parts for the similarities and differences they reveal” (Thorne, 2008, p. 143). The preliminary coding was conducted by myself as well as the thesis advisory committee. I worked with the thesis advisory committee to develop a coding framework which was used by the researcher to code the transcripts of the interviews in NVivo10.

Synthesizing and Comparing the Qualitative and Quantitative Results. The third phase is theorizing. During this phase the researcher develops an explanation about the phenomena (Thorne, 2008). The objective of this process is to determine how the qualitative and quantitative results compare and contrast. Klassis (2012) refers to this process as “meta-inference (that) may identify contradictory as well as confirmatory elements of the evidence, and leads to a new understanding of the phenomena under study” (p. 378). Qualitative data and quantitative data from the study were evaluated to determine if there were correlations and/or discrepancies between the two data sets. The objective was to compare the qualitative accounts
of the quality of life to the overall single item rating scale from the MQOL. This was completed by evaluating and exploring discrepancies between the interview data and the MQOL data.

Finally, the aim of my study was to develop informed ideas about the research objectives, as outlined below:

i) To develop a deeper understanding of QoL and QoC from a rural palliative patient’s perspective.

ii) To better understand the usefulness of the McGill QoL measure in a rural setting.

iii) To compare and contrast the qualitative and quantitative findings of patient QoL and QoC to discern areas of agreement and disparity.

The final phase of the cognitive process was recontextualization. Recontextualization refers to the process in which the researcher “articulates that which has been synthesised into a form that is applicable to other settings and contexts” (Thorne, 2008, p. 166). For this particular study, this step was completed by writing a formal report about the findings. These findings will then be presented back to the Shuswap Community and the academic community. (see the knowledge translation plan on page 35.)

Reliability and Validity

It is important to note that determining validity does not depend on replicable outcomes; instead, the focus is on multiple ways of knowing and understanding reality (Sandelowski, 1993). Given that this study used a mixed method approach, the arguments for validity and reliability are situated within different paradigms. Therefore, this paper first addresses the validity and reliability of the MQOL tool, and then addresses the validity and reliability of the semi-structured interview.

Reliability and validity of the quantitative McGill Quality of life tool. It is important to determine the validity and reliability of the MQOL tool to ensure that the tool is measuring that
which was intended to be measured. Cohen et al. (1997) echo this perspective (1997), suggesting that, “Any instrument designed to measure a subjective construct, such as quality of life, must provide evidence that it has validity, that is, that it is measuring what is intended to measure” (p. 5). The MQOL tool has been compared to the single-item scale measuring overall quality of life (SIS) as well as to the self-administered version of the Spitzer Quality of Life Index (SA-QLI) (Cohen et al., 1997). This comparison study took place in eight palliative care services, in four cities across Canada with the MQOL predicting the QoL of patients better than the SIS and SA-QLI. The MQOL has “demonstrated acceptable internal consistency and reliability” (Cohen et al., 1997, p. 3).

The MQOL tool represents four different domains: existential, support, physical, and psychological (Cohen et al., 1997). These different domains are broken into six different subscales and a number of questions are attached to each subscale, as shown below in Table 2. Chonbach’s Alpha was calculated to determine internal consistency (Cohen, 1997).
Table 2 MQOL Subcategories and Internal Reliability. (Cohen et al., 1997.)

<table>
<thead>
<tr>
<th>Scale/sub-scale</th>
<th># of Items</th>
<th>Cronbach’s Alpha</th>
</tr>
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<tbody>
<tr>
<td>Psychological symptoms</td>
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</tr>
<tr>
<td>Physical symptoms</td>
<td>3</td>
<td>0.62</td>
</tr>
<tr>
<td>Physical well-being</td>
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<td>n/a</td>
</tr>
<tr>
<td>Existential well-being</td>
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<td>0.79</td>
</tr>
<tr>
<td>Support</td>
<td>2</td>
<td>0.74</td>
</tr>
<tr>
<td>Total scale</td>
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<td>0.38</td>
</tr>
</tbody>
</table>

The MQOL has been designed to be “general in nature in order to maintain brevity and to assure applicability to all patients” (Stewart, 2004). Cohen’s instrument has been validated in several different populations but it has not been validated in a rural population. In this research study I explored its usefulness for the rural population.

**Quality considerations for the qualitative data.** Honouring participants’ stories is important, but we must also consider the quality of this type of data (Thorne, 2008). Sandelowski (2004) suggests that “statistically significant finding are not necessarily clinically useful, and qualitative findings are said to show the tears that statistical accounts wipe off” (p.1373). Interpretive description was utilized for this particular research study because it provides a way in which the thick descriptive accounts of palliative patients can be heard, observed, recorded, and understood in a new way. The goal was to “find ways to apprehend and re-present these different
representations to achieve the “‘fuller knowing that advances knowledge and influences practice” (Sandelowski, 1993, p.3). Based on this understanding, Sandelowski draws on Guba and Lincoln’s work which describes four factors to test the quality of the study. The four factors include:

i) truth telling,
ii) applicability,
iii) consistency, and
iv) neutrality.

The first factor is truth telling which, through a quantitative lens, would be tested through internal validity; however, Sandelowski (1986) suggests that for qualitative research this is referred to as credibility. Credibility and truth telling “generally [reside] in the discovery of human phenomena or experience as they are lived and perceived by subjects, rather than in the verification of a priori conceptions of those experiences” (p. 30).

The second task is applicability, which, from a quantitative perspective, refers to external validity; from the qualitative perspective, this task is more concerned with “fittingness”. Sandelowski (1986) suggests that “a study meets the criterion of fittingness when its findings can fit into the context outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experience” (1986, p. 32). Although this is a small study, it is not unreasonable to expect that other rural palliative patients might resonate with the findings.

The third task is consistency. From a quantitative perspective this refers to reliability, however from a qualitative perspective, this refers to auditability. Auditability is when another researcher can follow the decision trail of the study and the researcher is able to come to a comparable conclusion (Sandelowski, 1986). For this study auditability was determined through
close collaboration with the thesis committee. The methods section provides details of how this study was carried out and the decisions that were made.

The fourth factor that contributes to determining this study’s rigor is neutrality. From a quantitative perspective, this refers to objectivity and from a qualitative perspective, it refers to confirmability. Sandelowski (1986) states that confirmability is “achieved when auditability, truth value and applicability are established” (p. 33): the goal is to reduce the distance between the researcher and the participant and to “eliminate the artificial lines between subjective and objective reality” (Sandelowski, 1986, p. 34). In order to achieve neutrality, I used a field journal after each interview and again when I reviewed the audiotapes of the interviews. In addition, several of the transcripts were read, reviewed, and coded by the thesis committee and myself. Because I am an insider in the community, it was at times tempting to draw conclusions prematurely about what participants said during the interviews; however, a commitment to neutrality (to the best of my ability) allowed me to suspend clinical judgement and ensure conformability of the research findings.

**Ethical Considerations**

Informed consent was obtained by all of the participants prior to the first interview. The consent forms were either emailed or mailed directly to the participants. Participants had at least three days to review the consent forms prior to making a decision about their participation in the study. At each subsequent interaction with the participant, the researcher checked in with the participant to ensure the consent was ongoing. This approach is particularly useful when there are multiple researcher-participant interactions (Dean & McClement, 2002 p. 378). Participants had the option to withdraw from the research without explanation, and they had the right to request that all their data be eliminated from the study.
For this study the interviews were digitally recorded. When the digital recorder was not in use it was stored in a locked briefcase or locked in a filing cabinet. Once the interview was completed, the information was transcribed by a hired transcriptionist (See appendix J for transcriptionist confidentiality agreement). The transcribed information was then stored on a password protected computer. The hardcopies of the completed MQOL measures were scanned and stored as PDF files on the computer. Hardcopies were then stored in a locked filing cabinet in Dr. Rachelle Hole’s office and will be kept for five years.

Inherently, palliative patients are considered a vulnerable population (Dean & McClement, 2002; Randall & Downie, 2006). End-of-life interviews often include “sensitive subject matter, heightened emotions, and increase the risk for discomfort to both the interviewer and the participants” (Schulman et al., 2010, p. 90). Despite the obvious vulnerability of this population, doing this research had several direct and indirect benefits to the participants. Participant benefits included being able to tell their own story. For some participants, this experience might have been provided with similar benefits as narrative based therapy (Noble & Jones, 2005).

Nevertheless, it was essential for me to be aware of the vulnerability of the participants. For the purposes of this research, I referred to the twelve techniques developed by Schulman-Green et al. (2009) as a guide throughout the interviews with the participants. In addition to Schulman-Green et al.’s. guide, this research was closely supervised by the thesis committee. The committee consisted of Dr. Barbara Pesut, Canada Research Chair with extensive experience in palliative care research; Dr. Rachelle Hole, a social work faculty member with expertise in research with vulnerable populations, and Dr. Brian Rasmussen, a social work faculty member with extensive clinical skills working one-on-one with clients.
Role Conflict

As mentioned before, I am an insider in the Shuswap community; this insider status could have potentially caused some ethical concerns. A patient’s decision regarding participation in the study might have been influenced by the fact that they already know me. Mitchell and Irvine (2008) point out that researchers have a “researcher footprint”. This is something I needed to be mindful of: in particular, the emotional well-being of the participants. I developed a post card of community resources about palliative care that was given to all of the study participants (see Appendix K for a copy of the postcard). In addition, if a participant required emotional support or personal care (e.g. pain management) then I would have referred them to the palliative care coordinator in the community for follow-up, as stated in the consent forms. Another ethical consideration that needed to be addressed was the dual roles that I hold as the acute care social worker and researcher. If a participant became an inpatient at the Shuswap Lake General Hospital while they were involved in the study and happened to be referred to my caseload, then the co-researcher (Dr. Rachelle Hole, Principal Investigator) would have taken over the subsequent interviews, to reduce role conflict. While this did not happen, several potential participants became my clients at the hospital during the recruitment process and were therefore not included in this research study.

Knowledge Translation

The goal is to disseminate the research finding in some of the relevant journals: Palliative Medicine Journal, Rural and Remote Health, and Journal of Palliative Care. The dissemination of this study is important because it will be a way in which palliative patients are given a voice. In addition to these academic arenas the research findings could also be presented at the Canadian Hospice Palliative Care Conference, the Rural and Remote Health Care Research Conference, and Social Work Conferences.
Knowledge mobilization in the Shuswap will also be an essential part of this knowledge translation plan. The research findings will be disseminated in several different ways. It is important to give the research findings back to the Shuswap community, in particular the palliative care programming stakeholders. The intention is to provide a formal presentation of the research findings to the medical staff at the Shuswap Lake General Hospital as well as the community integration team. A copy of the findings will also be sent to the financial stakeholders outside of the Shuswap community that allocate program funding. Finally, I intend to present this information at the Shuswap Hospice Annual General Meeting in 2015.
Chapter 4 Findings

This chapter will present an interpretive description of how palliative participants have experienced their quality of life and quality of care in the rural Shuswap. This chapter has been divided into two sections: Quality of Life and Quality of Care. This chapter also includes a brief section on stigma experienced by the participants, which directly affected their QoL and QoC. Lastly, the chapter will conclude with a section on QoL and QoC intersection and the findings from the MQOL tool.

Section 1, Quality of Life

The four subcategories in QoL, section 1 include cognitive self-management, decisions, lifestyle identity, and rural living. Each section will explain how the particular topics relate to the overall QoL of participants.

Cognitive self-management. The notion of cognitive self-management refers to actions and beliefs that the study participants hold on a conscious level about how to live with a life-limiting illness from an emotional perspective. As one participant suggested, “The mind controls the whole body.” This statement suggests the importance of cognitive self-management. The concept is broader than an illness narrative because it takes into consideration the actions and behaviours in which participants engage to manage their illnesses and maintain their QoL. This concept of cognitive self-management was embedded in both the QoL and QoC interviews by all of the study participants.

Cognitive self-management also refers to how participants in the study spoke about their terminal illnesses and, particularly, how they related to their impending death and their current QoL. One participant said, “Well, you see, my cancer is classified as terminal. But that doesn’t necessarily mean I am going to die tomorrow.” This belief was echoed by many of the
participants in the study and perhaps allowed them to continue to have a high QoL. All of the
data were medically classified as palliative yet the degree to which participants related to
this diagnosis varied.

The majority of the participants did not refer to their illness by name but instead used the
word “it”. Referring to “it” appeared to be a tool that allowed participants to depersonalize and
distance themselves from the illness. “It” was also less intrusive, yet many of the participants
were experiencing major life interruptions due to their illnesses that likely impacted their QoL.
When participants spoke about their palliative journey and their imminent death, they often
spoke in metaphors, as in the chart below.

**Table 3 Metaphors used by study participants**

<table>
<thead>
<tr>
<th>Metaphor</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Crystal ball</td>
<td>Referring to the fact that no one really knows how long we will live.</td>
</tr>
<tr>
<td>Vegetable state</td>
<td>A complete loss of independence, lack of purpose and meaning in life.</td>
</tr>
<tr>
<td>Expiry date</td>
<td>The actual day that death occurs, a cold medical term</td>
</tr>
<tr>
<td>The man upstairs</td>
<td>Likely referring to God, and his divine timing.</td>
</tr>
<tr>
<td>Getting a life sentence</td>
<td>Feeling imprisoned in one’s own body.</td>
</tr>
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</table>

Several participants mentioned that their own situation could be a lot worse and that they
were grateful for their good fortune despite their current illness. This is evident from some of
the comments made by participants. Several participants spoke about how good they had it and
compared themselves to others with similar illnesses. One participant commented, “I feel sorry
for most other people out there because they have so many problems and I have really nothing,
you know.” Another participant suggested, “I’m lucky.” Many participants spoke of experiences
of deaths in their own families when symptoms were not well managed; they had seen how their
family members suffered. Having this particular attitude and perspective appeared to help some
of the participants see their own life situation in a positive light. It also appeared that
participants who held this perspective were able to maintain their QoL.

Gratitude was another self-management strategy about which some participants spoke. Some participants were grateful for a lack of chemotherapy side-effects; others were grateful for the support that their family and friends provided. It appeared that gratitude allowed participants to see that there were good things around them and happening to them. For some participants, gratitude required them to focus on things that were being done on their behalf, such as assistance with meals and being driven to appointments, to maintain or improve their QoL. It was also identified that some participants had a fundamental life orientation of gratitude, which allowed them to truly be thankful for their lives regardless of their circumstances. They were able to see that life is a gift instead of a burden. These participants were often able to maintain a positive mindset because of this gratitude orientation.

A positive mindset appeared to be the most influential factor for self-management for this group of participants. When participants described their experiences of staying positive, several echoed what one participant said, “I try not to think about my illness.” Another participant suggested,

Well, it’s positive thinking. You know, if you are going to dwell on it all the time well, it’s not very positive. And that’s one of the things they tell you which is important -- positive thinking. So, I basically don’t think about it at all.

Despite the knowledge of the benefits associated with positive thinking, another participant explained, “It’s always on your mind. You go to bed with it on your mind; you wake up with it on your mind.” Participants described their ability to manage their emotions, but they also explained their struggles with this concept. One participant commented, “I’m doomed anyways.” It is evident that the participant’s ability to cognitively manage their emotions varied
amongst this participant group, yet all were aware of how important it is to have a good mindset and how it directly impacted their QoL.

**Decisions made by participants.** For this study group, decisions made by participants were comprised of three key themes: the process of making decisions, personal decisions, and health care decisions. All three types of decisions are related to participant QoL. The process of making decisions varied from one participant to the next; however, all seven participants had made significant life decisions within the last six months that impacted their QoL. For two participants, this included moving to a higher level of care. Several other participants had made significant decisions regarding their health care, finances, lifestyle choices, and personal care decisions. A number of participants in the study suggested their preferred method of making decisions was to “take it day by day,” and as one participant explained, “Wait and see [what happens next]”. Interestingly, another participant explained that she makes decisions based on necessity: “I haven’t panicked yet.” One participant felt that making decisions was often a “scary” process because the outcome is so unclear. Another participant explained how important it is to obtain information prior to making a decision. Yet another participant explained that making decisions was a spiritual process: “I pray about it”. As is evident from the comments, the process by which participants made decisions varied and was often impacted by health status. Many participants just preferred to wait and see, and therefore take it day by day. It appeared that making decisions in the moment allowed them to stay focused on the present instead of worrying about the future. Planning for the future still appeared to be of some importance; however, given their diagnoses, long term planning was not an option. Hence, the participants who learned to adjust to this reality appeared to have some mastery in this particular area. In fact, they actually appeared to be more joyful in the moment and perhaps even enjoyed a higher QoL compared to those who struggled to adjust.
Personal and medical decisions were often linked to QoL for participants, as was evident for two of the participants who had recently moved into a different housing situation based on their declining health. One participant explained how he enjoyed living in supportive housing because he and his partner no longer needed to worry about cooking, cleaning, and laundry, which gave them more energy for other activities. Other participants intentionally preserved their energy. For example, one participant limited her activities and hired someone to help her with yard work. Similarly, another participant had made it a priority to participate in social and physical activities, and he had therefore made a conscious decision to avoid attending medical appointments on those days. Despite having a strong desire to be independent, the participants made decisions that would allow them to let go of tasks that were previously associated with independence. Letting go of these tasks ultimately preserved their energy so that they could participate in “life-giving” activities, which very likely contributed to their QoL. Four of the seven participants discussed their desire to travel; however, three of them made the decision to not travel based on their current medical condition. One participant explained, “I definitely can’t go across the line south because my insurance, they won’t cover nothing. And before I had the cancer it was $886 a month for medical insurance”. Another participant explained that he would like to go to Alberta to see his daughter for Christmas but was not planning on visiting. He shared:

I was hoping I would have peace to go for Christmas this year, but I don’t think that’s there. So I think I will be here for Christmas. Last Christmas was the first time our daughter ever had Christmas without us. She’s 34.

Another participant with severe nausea, vomiting, and diarrhea explained, “You don’t know how it’s [the body] going to react. [My physician] puts me on new medication all the time, so I stay home, just sit, and wait for the time to come.” He also explained that his way of
life had changed in many ways and that now “a good life is that I’m not in the bathroom all day long with this chemo.” Participants also shared that their personal decisions were often impacted directly by their medical status, which was often ambiguous: “I don’t plan much ahead anymore because at this moment I honestly don’t know what to plan.” For these participants, travelling had been a way of life prior to their illness. Many family members lived out of town, and not being able to go and visit was very difficult for the participants. For many of them, they were starting to see that their illness was starting to become limiting. What seemed so simple before was becoming more complex. Participants were starting to see the limitations their disease was imposing on them, and this was a difficult adjustment for many of the participants.

During the interviews, when participants were asked about decisions, two of the participants made specific comments regarding their wish to die at home. One of the participants explained,

I love it here…can’t see myself living in assisted living, not at all. No, it would drive me crazy. I have friends that have been in them and yes, some of them are quite nice. Some not so great. And you got this dinky little four walls with a dinky little TV because that’s all the space you have.

Another participant explained that his wish was to die at home but that he would choose to go into care if his care needs could no longer be met at home. He also explained that he could not expect his wife to become his full-time care provider because he felt that would impose on her QoL. Many participants also needed to make big medical decisions. These types of decisions will be covered in the QoC section.

**Lifestyle Identity.** The notion of lifestyle identity refers to how participants are able to live “as normal”, to have a purpose, and to maintain their personal identities with their terminal illness. All of the study participants spoke about independence, and the importance of
maintaining independence in relation to their QoL. Independence was defined in different ways. For several of the men in the study, independence was focused on their ability to continue to complete tasks commonly associated with masculinity, such as shovelling the driveway, fixing things in the house, and, for one participant, helping chop wood. For other participants, independence was focused on maintaining the ability to look after themselves. One participant noted, “I can still do a lot considering I have myeloma. I can still handle a lot on my own. I can still dress myself. I can still eat good. I go out on my own.” Another participant said,

I do everything myself. I mean, my meals, my personal hygiene, my shower, everything. I’ve lived alone for a lot of years so I am used to that…. People get their knickers in a knot because I stay alone at night, well, I’ve done that for many years.

All of the study participants had an incredibly strong desire to remain independent for as long as possible. Maintaining their independence was likely related to their self-identity; as long as individuals were able to maintain their self-identity, they appeared to be in control of their lives. In a sense, they were still bigger than their illnesses. Many of the activities that participants identified were also part of the rural culture. For example, participants described activities such as chopping wood and getting ready for winter.

Participants spoke a lot about normalcy during the interviews. For many participants, normalcy referred to daily activities that they enjoyed, which helped them maintain a QoL. Lifestyle identity included conscious processes like staying connected to the local community and on-going communication with family and friends. One participant explained how “keeping connected” was imperative for him as it allowed him to change his focus away from his disease. For some participants, this meant staying connected with family and friends. This was evident from one participant’s comment:
Well my ability to interact with people, get out and visit them and enjoy time with them. Yeah, it’s quite a boost, a really big boost. People spend a little time with me and they say you are looking better.

Another participant said, “People come over to visit for, say, an hour, have a cup of tea or something. That’s fine. I love that.” For other participants, it was important to continue to curl and golf, as mentioned by this participant: “I’ve been out and about and had a few drinks, and I’m going curling this afternoon, curling tomorrow, you know. So we are pretty active.” Being active and going out to have a drink is something this participant had always done, and he was grateful to continue to do so. This participant also speculated that without these activities, his QoL would decrease significantly. Curling might not be unique to the rural population; however, in rural communities curling tends to be popular amongst all age groups. It is a social activity that unites many people over the cold winter months.

A number of the participants explained that their illness had not been too problematic because they were not experiencing pain and were able to continue to participate in activities that they had always enjoyed, allowing them to maintain their QoL. One participant described, “It really hasn’t stopped us at all from doing anything. We still dance a lot.” It appears that remaining active in social functions and community groups provided the study participants with a sense of purpose, and at times, it provided a sense of normalcy.

The concept of normal lifestyle stressors and choices also came up during the interviews. For example, body image and body weight came up for three of the seven participant interviews. One participant noted, “We [his wife and he] just decided that we are putting on too much weight.” As a result, he had recently decided to start using his indoor bike. Another participant noted that she was trying to eat more because she had felt that she had lost too much weight: “You can tell by my clothes that my pants just hang on me. My friends say, ‘You don’t have a
bum anymore.’ I say, ‘Yeah, I know. But hopefully that will come back.” Another participant spoke about how he was adjusting to his ostomy. Another concept of normal lifestyle preferences came up when two participants talked about weather. One participant asked the interviewer if she could make it warmer. Similarly, another participant spoke about the poor weather and how it challenged his ability to go out and smoke.

The two women in the study both spoke about gardening, something they had previously enjoyed. One of them said, “I had a garden last spring, a little garden. And I have lots of pots and baskets around on my deck and around my house and I like to do that.” These activities gave participants a sense of purpose and maintained a previous interest that brought them a sense of joy. Rural residents often have a strong connection to the land and have large vegetable gardens. One of the participants shared that she had to downsize her garden when she moved from the farm into town, and she found it difficult to adjust to.

Participants also spoke about how their QoL remained the same: “It really hasn’t changed. It’s just that I can’t do as much.” This perspective was echoed by many of the participants in the study that despite their life-limiting prognosis and sometimes troubling symptoms, they maintained that their QoL was still good.

Lifestyle identity also refers to how the participants were interacting with the subject of death. None of the participants shared that they were afraid of death itself, yet they expressed some fear of the dying process. One participant shared, “As long as I don’t suffer too much before I go.” Suffering was associated with a poor QoL, and that it would not be worth living if it meant living with intolerable level of suffering. Some participants described intolerable suffering as being completely dependent on others. For others it meant being bedridden, while others shared their fear of being in a vegetative state. Many participants shared that they were unsure of the dying process and feared the physical suffering that might be involved with dying.
Several participants shared their dying wishes in some unique ways. One participant said, “Well, if it comes to that point that I am going to suffer like that, then I might as well just get a bottle of 151 proof and drink it and that will end it for me because I don’t drink.” This participant also shared that he did not want to become like his uncle in “diapers”; he was fearful that he would become completely dependent on others and he could not handle the thought of having to endure such a dying process. This participant did not directly say that he could not tolerate a poor QoL; however, based on his comments, it appears that he would only be willing to endure a certain amount of suffering and at some point he would want to take matters into his own hands. Another participant talked about her spouse’s death: “He laid down and went to sleep.” She hoped the same could happen for her. She shared that her mother had willed herself to die after she had a stroke and it took her two months to die. Based on this participant’s comments, she wanted to maintain her QoL until she died, which was the case for her husband, but not for her mother who died a slow and painful death.

Several participants, interacting with the subject of death, shared that they tried hard not to think about their illness and their impending death. One participant was planning on taking a break from his chemo and medical appointments. This meant that he would be able to think less about being “palliative.” Another participant explained, “Probably the toughest day we’ve had through the whole thing was the day the palliative care nurse came. She sat here for two hours talking about death. That’s all she talked about. Goodness.” One participant felt that a miracle was within God’s power, whereas another participant said, “Well the man up above, he’s not worrying about me, I’m sure. You know what I mean? It ain’t gonna be a miracle.” Many of the participants wanted some control of their illness, but as one participant said, “I actually can’t do much about it, you know.” Interestingly, one participant said, “I’m 84 years old and so I am getting to the end of my life-span statistically anyway.” Each participant spoke about the dying
process in a different way, and each had his or her own reasons for believing how death might occur. The time and place of death was unknown for all of the participants; however, each one of them knew that their death was approaching. The way in which they chose to interact with their impending death appeared to be linked to their lifestyle identity. For some of the participants this meant that they had particular wishes, this included the participants that had a greater desire for control and independence. While others preferred to wait and see what they would need at the end of their life.

**Rural Living.** The participants interviewed for this study lived in several different communities in the Shuswap: Salmon Arm, Sorrento, Eagle Bay, and Enderby. Participants in general shared experiences that reflected the benefits of living in a small community and how it contributed to a good QoL. Most of the participants had been living in a small community for the majority of their lives and held the belief that living in a rural community was one the most important factors to their overall QoL. The choice to live in a small community was often conscious: “It is my choice to live here; I like the quietness here.” Similarly, another participant said, “I have always lived in smaller places. I don’t like big cities.” Several of the themes that emerged from the data under the concept of rural living include small town experiences, transportation, and health care services. Each of these concepts will be explored in more detail below.

The small town experience refers to beliefs, ideas, and values participants held about what it means to live in a small rural community. One participant said, “Bigger is not always better, eh? Maybe the smaller hospitals have better care. I don’t know.” Some of the participants believed that the health care in their small community would be better because they had an established relationship with their care providers. One participant believed that the “quality of care might be better in the rural community than if I were back in Calgary.” Another
participant shared that the small town experience for him meant that his cancer treatment was a “community affair” and that he felt supported by his local community. Another participant said, “It’s a smaller place. People are friendlier. Things are handier. They are not big time?” This belief was echoed by many of the other participants. The small town experience also refers to being “known” in the community. For many of the participants, this meant being seen by neighbours, friends, family, and caregivers in public places such as a grocery store. Overall, the participants felt that living in the rural Shuswap provided them with an informal network of support that would not be available to them in a larger centre. This informal support ranged from neighbours helping out to relationships with health care providers who provided personalized care. Participants were grateful for the support they received and for how their illnesses were a community affair. Being a part of this type of community provides a sense of belonging that often positively contributes to the overall QoL of any individual, regardless of their health status and age. Despite the advantages of rural living, there are also disadvantages. One participant explained that he struggled to find housing: “When we are looking for a place to rent a lot of people when they find out that I got terminal cancer they are sort of -- Oh, they don’t want to rent out to you. They figure -- they don’t want to admit it but they figure cancer, well, that’s contagious.” ‘Being known’ and living in a small community clearly has its disadvantages when you are in a position like this gentleman. In addition, there is stigma and superstition about people dying in a rental suite; once people find out, they do not want to rent the suite.

Other themes that emerged from the data regarding rural living include privacy and community support. One participant explained how he loved the privacy and quiet of his rural lifestyle, and how he could not imagine living in an apartment in town. Living rurally can provide a deep sense of privacy yet at the same time foster a true sense of community. As one participant explained, “I have wonderful neighbours and friends around me that are always
keeping tabs on me so I never feel abandoned or alone -- never.” Though none of the participants outwardly said that living rurally improved their QoL, based on the comments, it was implied that living rurally increased their overall QoL because they were a part of a community which cared about their wellbeing.

For the most part, participants were pleased with the medical services they were receiving in their own communities and were eager to point out the benefits of their health care services. One participant shared that he had a conversation with his community care nurse about some local stuff and he felt that “from a conversation point of view, you know you could have some kind of a conversation that was meaningful, at least friendly and all that kind of stuff.” Participants could relate to their caregivers about something other than just their illnesses.

Many of the participants were extremely grateful for the level of services available to them in their own communities. In addition, participants appeared to have low expectations of community care nursing. One participant was told he could not have any home care nursing care because he lived too far out of town and they were short staffed. He responded by saying, “It don’t bother me.” Another participant said, “I was pleasantly surprised to learn how much care is available.” Many participants held the belief that they had chosen to live rurally; therefore, they did not expect the health care system to be responsible for their personal health care needs in their own homes.

Section 2, Quality of Care

QoC includes five subcategories: relationships with care providers, time and efficiency, communication, traveling for care, and care provider competency. Each will be described in detail below in relation to QoC.

Relationship with Care Providers. Relationship with care providers refers to how participants characterized their relationships with their health care providers and how this
impacted their QoC and their QoL. The majority of the participants identified their primary care physician as their care provider, though one participant mentioned her pharmacist, and two others mentioned the nurses at the chemo clinic. The participants described their relationships with their primary care physicians as an essential component to the QoC and QoL.

In general, it appeared that the participants believed their physicians held the greatest amount of medical knowledge about their diseases. For example, one participant stated, “Well, I take it that he knows what he is telling me. He’s telling me what’s good for my own health and I accept that.” Similarly, another participant noted, “My doctor is pretty good. She’s pretty good. She knows me. She knows me more than I know myself.” Another participant said, “He’s number one as far as I’m concerned.” Participants also acknowledged that physicians deal with life and death every day; therefore, they are the experts in the field. One participant simply said, “They deal with it every day --- They know those that are gonna survive and those that are gonna die.” Overall, the participants in the study appeared to have a great deal of confidence in their primary care physicians and believed that their physicians directly influenced their QoC and QoL.

A personable relationship with health care providers was likely the biggest factor in the level of satisfaction of participants with their health care. For one participant, this meant being able to call his doctor by his first name: “I always call him doctor, you know. I’ve been brought up that way. I was in the military, you referred to doctors as doctors you know and he said, ‘No, no, no, no, no.’ He gave me his first name. He said, ‘You can call me by my name.’” Another participant explained that when her regular doctor was on vacation, she would wait for him to return “because it wasn’t that serious but I’d have rather talked to him because he knew the problems.” Participants were extremely grateful when their care was personalized. They also felt that the personal connection to their physicians resulted in good QoC.
Participants also spoke about times when they had a health care crisis and how relationships manifested. One participant described how he was quickly admitted to the hospital during such a time. He was particularly grateful when his own family physician came in during his lunch break to check up on him. Another participant shared his experience of falling and severely injuring his face:

I was not feeling good when I went in there that day. I walked in. You could just see the look on his [physician’s] face. He says, ‘What’s happened to you?’ And he’s genuinely concerned about me. Immediately you could tell.

This physician quickly got this participant admitted to hospital. This participant later shared that he was disappointed with the lack of response from community care because he had been managing well prior to the hospital admission. He felt that the community care providers assumed he would manage just fine once he was discharged from the hospital. Another participant said, “When I had the problem with the feeding tube, he took his lunch hour off and came to the hospital with me.” Participants were extremely grateful for times when professionals did whatever it took to meet their care needs, and participants described this as excellent QoC.

Three participants described a time they felt their relationships with their health care providers was problematic. One participant’s family physician was often unavailable; therefore, she often saw one of his temporary replacement physicians. She felt that this fragmented her QoC. She ended up switching physicians because she wanted a more accessible physician. Another participant shared,

But I think sometimes you should get a second opinion. Because sometimes when the doctor’s familiar with you, he’ll just say, ‘well, okay, you work hard. Okay, you got aches and pains. Just take it a little easier. Don’t do anything.’ But sometimes aches and
pains are something.

For this participant, getting a second opinion allowed him to be more secure about his prognosis and treatment options.

Several other items stood out from the data: availability of health care services, for example, not requiring a pre-booked appointment if something was urgent. Participants appreciated this patient-centred approach and found that it contributed to the overall QoC. Another helpful hint was “being able to talk to them [healthcare providers]. And get help if I need it.” One participant explained how she appreciated how her pharmacist “took the time to explain about the medication for the myeloma and what it would do to me. [She took] half an hour talking to me.” Taking the time to explain procedures, treatments, and medications was important to many of the participants. They not only wanted things to be explained, but they wanted explanations that were understandable.

Differing values also appeared to come up in the interviews, in particular, pertaining to medical marijuana. Medical marijuana came up with two of the seven participants. Both participants were using marijuana, yet neither was able to access medical marijuana through their primary care physician. One participant thought that it was illegal and therefore did not ask his physician. The other participant asked his physician and was told that he would make a good candidate for it, but the physician did not have a license to prescribe it. He ended up getting marijuana from his regular supplier; however, it was unlikely that his care provider was aware of this.

**Time and Efficiency.** All of the participants in the study willingly and actively took part in their required health care treatment but felt that at times “their time” was seen as insignificant or irrelevant. Yet for most participants, time is what they valued most at this stage in their lives. And for them, good QoC would take this into consideration when scheduling diagnostic,
treatment, and follow-up appointments. One participant said, “They don’t realize that you actually have a life also. Everything is done on their times, like, when I cancelled because he doesn’t work Mondays and Tuesdays and I golf Thursday, Wednesday and Friday. So why do I have to give up my golf every time?” His comment illustrates that patients want their time to be honoured and that coordinating care with their daily lives is an essential component of good QoC. Another participant shared her frustration: “Those stupid doctor appointments. I have to take up the doctor’s time just to write out a simple prescription.” This participant was in her 80s, and she had to go in to see her physician monthly because some of her pain medication was a controlled substance, and she was told she would have to renew her prescription monthly. She felt it was a waste of her time but also of her physician’s time.

Having a chemotherapy clinic in Salmon Arm was helpful to some participants because it meant they would not need to travel out of town to get the required treatment. Many took note of the fact that they could get their blood work done at the chemotherapy clinic the day before treatment rather than going to the community lab. Here is one participant’s experience:

You get these appointments you know. I think it’s just fabulous they do the blood work at 8 o’clock in the morning at the hospital because it’s all over with. If you go up the hill to the clinic you can sit in the clinic. I went with my daughter once. I had a doctor’s requisition to go there. It had to be done there. But we’ve driven by a few times- that place was loaded to the hilt and finally she [daughter] says we’ll go early in the morning. So she grabbed a couple of folding chairs, put them in the vehicle, and we were there by 7 in the morning. It doesn’t open till 7:30. We put the chairs out in the sidewalk and we sat there. I was number three- there was already two ahead of me at seven in the morning. But I didn’t get service till 20 after 8- almost an hour later. So when they do the stuff in oncology, they say be there for 8. You go into the hospital at
8 o’clock and depending upon how busy the emergency is, the lab technician shows up, and does it all.

Another participant shared, “When we first started I think I had a medical appointment every god damned day just about. I actually turned down a couple and said I’m tired. I need a day off, you know.” This patient received a $40 charge for a missed appointment. This, unfortunately, caused some friction in the patient - doctor relationship. Not only was the patient upset about the charge, but he also felt that his doctor did not value his time. Another participant shared that his daughter worked in the medical field and that she had been a strong advocate for him. He felt that he was started on chemotherapy more quickly than the average patient because his daughter knew how to advocate for him.

Another factor that influences timing is direct admissions to the hospital. Two participants had recently been directly admitted to the hospital without having to go through the emergency department. This represented excellent QoC to both participants.

Unfortunately, poor timing and inefficiency within the health care system were much more prevalent for many of the participants. Many participants shared their frustration with the lack of coordinated and timely care they had experienced. Below is a list of the issues noted by the participants based on their experiences.
Table 4: Perceived issues as per participants’ experiences within the health care system

<table>
<thead>
<tr>
<th>Perceived Issue:</th>
<th>Participant’s experience:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Waiting on a specialist</td>
<td>“I think that’s a whole problem with the health service is waiting for a specialist opinion”</td>
</tr>
<tr>
<td>Time wasted</td>
<td>“I don’t know why there is a shortage. There’s always about a dozen of them (nurses) up there. Because I go everyday into that place to get my blood work done.”</td>
</tr>
<tr>
<td>Travelling</td>
<td>Participant travelled over three hundred kilometers for a five-minute appointment that he felt could have been done over the phone.</td>
</tr>
<tr>
<td>Scheduling</td>
<td>“Well, I think a couple of things: like, they got to change their booking system. They know they can’t get things done.”</td>
</tr>
<tr>
<td>Wrong specialist/diagnosis</td>
<td>“To be honest, my care has not been bad at all. Sometimes it just takes longer than it should and that’s all. That’s not a problem there. But I -- I haven’t -- this is one of the better ones I’ve had with all the problems -- I’ve had other problems with the health system and all that and, like, I have a bi-fem surgery here, that they put garden hoses in bypassing the artery down past the Y. But the problem there was they kept sending me to a back specialist and it was nothing to do with the back. So it took over two years to send me.”</td>
</tr>
<tr>
<td>Wait times at appointment</td>
<td>“Well, yeah, and I think it’s just something to do with that and I think because they’ve booked their times too much. There’s no sense getting there on time. You never get in on time, like, an hour later or so.”</td>
</tr>
<tr>
<td>Waiting on blood work</td>
<td>It’s long time, you know, especially when you couldn’t drink -- have anything to at midnight.</td>
</tr>
<tr>
<td>Response time was too slow to make a difference</td>
<td>Two participants shared that home care nursing would be able to respond to their immediate needs, and that their friends and family were much more helpful.</td>
</tr>
</tbody>
</table>

**Travelling for Care.** Travelling was relevant to all of the participants. Many participants received the majority of their medical care in Salmon Arm; however, some participants also had to travel to the Cancer Centre in Kelowna for specialist, and or diagnostic appointments. Travelling was also required to see family for many of the participants. Several other participants shared that their transportation was a relatively minor issue, as one participant shared, “It is a relatively short drive to get to whatever you need,” clearly noting the difference between rural and remote living. All study participants lived within 35 minutes of a hospital and within three hours of a tertiary care centre. Another participant shared that she had been relieved she did not have to travel to Vancouver as some other patients sometimes do. In addition, several of the participants shared that travelling throughout their own community was very easy.
because there were no traffic jams, they knew the layout of the community, and some of the health care services were within close proximity – even in the same building.

Some participants expressed frustration with traveling. One participant shared that parking was a major problem for his wife, so she ended up dropping him off and missing an appointment she wanted to attend with her husband. This was a big deal for this participant because even though he was the patient, his wife was just as much a part of his illness treatment. She was the one who looked after all of his care needs when the doctors were not around. The unwillingness of the doctor to postpone the appointment to await the wife made this participant and his wife feel excluded from some of the most important health care conversations.

Similarly, another participant shared, “There was no place for you to drive in and park for instance. Obviously if you’re coming in from Salmon Arm, you’re in a vehicle, it has to park somewhere.” In one interview, a participant shared his frustration with the lack of knowledge at the larger centres about travel times. He did not mind travelling but felt that the health care professionals had no clue that he had travelled three hours to get to an appointment that took five minutes and, from his perspective, could have been done over the phone. The financial hardship of travelling only came up in one of the interviews. In general, participants did not mind travelling but felt parking and wait times for out of town patients needed to be better managed.

**Communication.** Communication is an essential component to QoC and also QoL for the participants in the study. There were several examples of excellent communication in this study and examples of how this type of communication was perceived by the participants. There were also examples of communication breakdowns and how that compromised some of the health care of the participants. This section explores examples of the ways in which communication with health care providers was perceived by the participants.
Overall, participants were pleased with the ways in which their health care providers communicated with them. The majority of the participants greatly appreciated being informed about their care. One participant shared that when he was in the hospital, his physician would “come right in and talk to me and explain what the surgeon was gonna do and wanted to do and I mean there was just, I was knowledgeable as you could be about anything.” Another participant shared that she appreciated “being able to talk to them and get help if you need it.” Some of the participants shared that just knowing that help is available is sometimes enough. Another participant appreciated that her pharmacist “took the time to explain, you know, with the medication for the myeloma that -- what it would do to me and I’m sure, you know, half an hour talking to me set him back with other things.” Taking the time to communicate was highly valued by several participants and contributed to their QoC.

Unfortunately, participants also shared stories where it appeared that there was a communication breakdown. One of the participants described the QoC he received at hospital when he was very ill. He explained, “I was sick. I was throwing up. I was in the shakes.” The nurse inquired if he was an alcoholic. The participant was offended because he was not an alcoholic. Later that evening, the participant was discharged and the nurse told him, “I don’t understand what’s wrong with you.” Shortly after the hospital visit the participant was diagnosed with a terminal cancer. The participant explained, “They didn’t even give me nothing. I came home and I just kept treating myself because there was no help there at all. So I didn’t go back and I won’t go back.” The QoC was so poor in this participant’s opinion that he said he would never go back because he felt that they saw him as an alcoholic rather than a “legitimate” patient. Another participant shared that he was upset by the lack of communication about a prostate exam that was conducted in front of his wife. “He [the physician] never told her he was gonna do a physical exam on me right there in front of her. Never said a thing.”
participant was troubled by the fact that his wife was present for the physical exam without his prior knowledge that this would be taking place. This participant felt humiliated by the physician, and the participant felt that this should have been communicated first. Another participant described getting his diagnosis from a specialist:

Well I think the initial diagnosis given to me was done maybe not recognizing that when you first go to somebody and tell ‘em you have cancer, and then they put a date on your expiry, that sets off alarms and my family was not invited in [participant tears up]. C*** was there, J*** was there. They were not invited to come and to hear it or share, ask questions until I was walking out and he says oh did you wanna bring your family up or something?’ Like it was a complete after thought. And by then, I wasn’t interested in talking to anybody. And I thought of course it’s hit them pretty hard.

Communication styles and ways of breaking “bad new” was noted by several participants in the study. For two of the participants, getting a terminal diagnosis was a complete shock. One participant said he thought he was going in for a checkup and then received the terminal diagnosis. These two participants did not outwardly say that they needed some preparation, but it would appear that some prior conversation about their condition might have been beneficial.

Another participant had recently received around-the-clock nursing care in her home when she was discharged from the hospital. She explained, “They were all nice people. I’ve got nothing to say about the people. You know, they’ll sit and chat, chat, chat. That’s very tiring.” This participant cancelled the services within a week because she felt that she did not require twenty-four hour nursing care; however, she also commented that she simply felt it was impeding her ability to get the rest she needed in order to regain some of her strength.

**Privacy when communicating with patients.** In Salmon Arm the chemotherapy clinic is located in a very small physical space. There are three chemotherapy chairs in one room, a small
workstation for two nurses and a clerk, and one small office space for physicians to meet with patients. Several participants in the study had received services in the chemotherapy department in Salmon Arm. One participant shared, “The oncology clinic had no place for me to answer the questionnaire that was private. It was busy yesterday. And there was no place to go.” He also said, “So, if you’re looking at the quality of care, those conversations should be able to be done with some degree of privacy.” In addition to privacy, two of the participants have mild hearing impairments, which would make it difficult for them to hear in a crowded space such as the chemotherapy clinic.

The use of language also came up during the interviews. Here is how one participant described her good care:

I’ve been fortunate with the doctors that I’ve got. You know, they’ve given me the time when I’ve gone to talk to them or they’ve had to talk to me. They’ve been good about it and explained in English, not in big words that I didn’t understand. I’ve been fortunate that way too. That’s one problem I’ve found when I had the other doctor. I would have to say, excuse me, explain it. I don’t understand those Latin words you are using.

This participant also shared that “some of them, I feel they are using too many medical words that the average person or a senior doesn’t understand.”

**Competency of care providers.** Participants made comments about the competency of their health care providers in several different ways. Some participants talked about their symptom management; others spoke of the clinical care they had received and how that impacted their QoC; others spoke of the medical decisions they had made based on recommendation of the health care providers. The perceived competency was often based on an experience which in some cases had very little to do with competency and perhaps more to do with people management skills and approach to providing health care.
Clinical Care. Overall, the care that participants received was characterized as good QoC. However, competency of care was questioned by several participants. In particular, lack of training, resources, and time gave participants the perception that their QoC and safety might be at risk. For example one participant explained, “I didn’t know if they were actually doing it right sometimes.” He said that he was receiving chemotherapy through a slightly different administrative route – a “bottle” – and he was unsure if the nurses were doing it right. Several different nurses did the procedure differently; therefore, he was questioning the competency of the care providers. Another comment from a participant was “I think part of it is sometimes they are a little under trained. And they are too busy.” Another participant commented, “It’s nothing to do with, like, these are nice people. That’s no problem. It’s just sometimes they are just overwhelmed.”

Symptom management was also discussed by participants. All of the participants had symptoms either from their disease and or their treatment. Two of the participants shared that they were using “unorthodox” treatment. One participant was using marijuana oil to help his migraines and the other participant was smoking marijuana to help ease his mind and increase his appetite. The participant shared, “I can usually tell when my migraine is starting. So as soon as I feel anything like that I just take some of that and within five minutes it relaxes me.” This particular participant shared that he preferred using marijuana oil instead of pain medication because it had less side effects for him. The participant did not request medical marijuana from his care providers. It appeared that he thought that marijuana was illegal because he made two comments: “I think it’s silly it’s not being used.” He also jokingly asked me not to report him. The other participant requested medical marijuana from his primary care physician and she told him that she did not have a license to prescribe it to him. He explained to her that it was very effective for him, and that it would improve his symptom management. Unfortunately, this
participant’s request was declined and, from his perspective, this directly affected his QoL and QoC. Several participants exposed their most troubling symptoms, some of which were not being addressed through medical treatment. One woman explained that her most troublesome symptom was her loss of hearing, while two others explained that their most troublesome symptoms were the lack of appetite. Similarly, one participant shared that she had difficulty sleeping, but that she had not been given a sleeping medication because her physician told her that she was already on so many medications. Interestingly, participants did not question their QoC despite the lack of symptom management. Instead, many echoed the comment, “I cope,” and many just endured their symptoms daily and tried to remedy them as best they could themselves. One participant shared that her lack of appetite was related to her loss of taste; unfortunately, not only did she lose her appetite but she also shared that it affected her social life:

I don’t really go out for dinner or anything because I can’t taste what they are serving. Although I was invited out for Christmas dinner and I must say I enjoyed it. It wasn’t quite as tasteful as it should be (laughs) but it wasn’t bad. I enjoyed it. It was a lovely meal.

Medical decisions for this participant group were primarily focused on life-prolonging treatments. Six of the seven participants had the options to take chemotherapy, radiation and surgery. However, the decision process was slightly different for each participant, as is evident from comments such as the following:

The biggest one [decision] I’ve had to make was going on chemo. That was the one that was the toughest to make ‘cuz I’ve always said I’d never go on chemo, but I felt that I got to a point that the options that the doctors had for me were being severely limited so if I had continued with no chemo, then the options left for them would’ve been pain management whenever it came up and that would be it.
A number of the participants commented on how their physicians had influenced their decision to take treatment. Participants appeared to be influenced by their physicians in two ways: they saw their physicians as the experts in their health conditions, and participants believed that their physicians would positively influence their health. For example, one participant commented:

I made choices -- well, the doctor actually made them for me. He says either you take it or you ain’t going to be here --- If you say, no, you’re only going to go sooner. You got a chance if we do the surgery and give you chemo.

Similarly, another participant shared, “I figure they know better than -- more about it than me.” And, another participant said, “Well, I take it that he knows what he is telling me. He’s telling me what’s good for my own health and I accept that.” Many of the participants appeared to have confidence in their physicians’ abilities to direct their plan of care with regards to treatment. This appeared to aid them in the decision making process.

**Intersections: Quality of Life and Quality of Care in Relation to the MQOL**

Interview findings suggest different themes that are important to each participant. Upon reviewing and coding the data, it appeared that each participant had an overarching theme for both QoL and QoC, and these themes were closely related. In other words, the primary topic of discussion related to quality of life was also a primary driver of how they evaluated the quality of their care. The vignettes below illustrate the overarching theme for each participant and how his or her QoL intersects with QoC. In addition, each participant’s overall QoL rating is listed with a brief summary of the highlights from their MQOL scale. (Names have been changed to protect the confidentiality of the participants.)

**Participant 1: Jake.** Jake rated his overall QoL at a 9. He defined his QoL by his independence; he especially enjoyed helping people out, going out for coffee with the guys, and
being able to be in the comfort of his own home. He defined QoC as having a meaningful connection with his care providers. For example, he enjoyed being able to call his physician by his first name; this made him feel their relationship was more personal. He also explained that his QoC improved when he was able to get his blood work coordinated at the chemotherapy clinic; this significantly reduced wait times for him. Jack completed the MQOL, and he did not report any troublesome symptoms. However, in the interview, he indicated several symptoms such as weakness and fatigue. He also did not report any sadness or depression but during our interviews he was very teary eyed.

**Participant 2: Bill.** Bill rated his overall QoL at 5. He described a good QoL as having independence, which for him was becoming more limited. He lost a lot of his previous independence even though he was still living at home. He could no longer do the things he previously enjoyed. His physical health made him more dependent on medication, and he always needed to be close to a washroom because of his chronic diarrhea. He felt that his QoL decreased significantly because he loved to travel and he lost that sense of freedom and adventure that he previously had. For Bill, QoC was characterized by communication with his health care providers. On a few occasions he lacked QoC due to communication errors. However, he also explained that when the communication was optimal, his care improved significantly. On the MQOL scale, Bill listed several troublesome symptoms, but he failed to mention two significant symptoms: weight loss and fatigue. These two symptoms directly impacted his QoL daily. He went to bed at 6 PM every night, and he was worried about his continued weight loss.

**Participant 3: John.** John’s overall QoL score was 7. His overarching theme is best described as independence. He loved to be involved in his community curling club in the winter, and in the summer he is often out playing golf. Being able to participate in these physical
activities provided a sense of normalcy for John, and it was also his social outlet. He lived alone; therefore, being able to get out and see friends was very important to his QoL. John did not mind travelling to get his health care needs met; however, he was very frustrated by the lack of efficient care available to him. He often made multiple trips due to a lack of coordinated care. John’s QoL would improve if the health care system took into consideration the value of his time. The MQOL tool appeared to correlate with many of the same findings as the interview. However, the interviews provided much richer data; in particular, it provided context for his answers regarding the importance of patient-centred care that takes into consideration the patient’s life outside of his or her illness.

**Participant 4: David.** David rated his overall QoL at 5. He enjoyed life and suggested the single most important thing to his QoL was normalcy. His QoC did not meet his needs. He requested medical marijuana, which he never received through the medical system; however, he had his own supplier. David was not offered any life prolonging treatment and died several weeks after he was interviewed. For the MQOL tool he listed swelling as one of his physical symptoms in the questionnaire; this really restricted his mobility. Appetite was also listed as a physical symptom and was mentioned several times in both interviews. Interestingly, lack of mobility and pain were not listed in the MQOL. Pain was mentioned in the interviews and mobility appeared to be a huge barrier for him. He listed a 7 for control over his life. During the interviews, he gave the impression that things were under his control. He had also felt supported and rated that at an 8. Interestingly, his care team seemed to provide him with the bare minimal supports.

**Participant 5: Rose.** Rose rated her overall QoL at a 7. She prided herself on her independence and self-management. Rose felt strongly that if she kept in good spirits, she could “beat” this disease. She characterized her QoL by being able to live independently, drive, and
look after her own personal care needs. For Rose, time and efficiency were significant factors to her QoC. She felt that it was a waste of her time and her physician’s time to meet constantly renew medications that she has been on for years. Rose’s QoL and QoC are connected. She had a limited amount of energy and felt that if her care was more coordinated and patient-centred, it would take less of her energy. Rose did not fully disclose all of her physical symptoms on the MQOL, nor did she state how her QoC was affecting her QoL when completing the MQOL. She disclosed both of these items in great detail during the interview. Rose did not complain, and using the MQOL tool did not fully capture the issues related to her care needs. During the interviews, it was apparent that her physical symptoms had not subsided, but that she had just learned to live with them.

**Participant 6: Linda.** Linda rated her overall QoL at a 9. Independence and privacy were very important to her overall QoL. She described that being able to live alone in the comfort of her home was extremely important. Her QoC was characterized by doing whatever it takes to stay at home, regardless of the cost. At one point she had private care givers with her 24 hours a day, seven days a week. However, she promptly fired them when she felt well enough to manage on her own again. She felt that it was too intrusive having someone in her home all the time. For the MQOL tool, Linda listed tiredness and lack of taste under her troublesome symptoms. However, during the interview she also discussed general weakness and weight loss. While these symptoms are related the way in which the Linda described her symptoms during the interview provided for a more contextual response which was helpful in understanding how this affected her QoL. This participant did not mention shortness of breath during the interview or MQOL, but she had home oxygen. She did not report any depression, worry, or sadness. Yet, during the interview the theme of death and dying came up a lot. She did not appear to be depressed or sad about this but she did seem to have some worries about how this might all
transpire for her.

**Participant 7: Markus.** Markus was the only participant in the QoL interview whom, by the time we had scheduled the second interview, had been moved to an end-of-life bed in the community. He declined participating in the QoC interview. However, his input from the first interview was very valuable and insightful. Markus described his overall QoL at a 7. He had recently moved to a new assisted living facility with his partner, and they were enjoying their new life there. He no longer had to worry about completing tasks around the house because all of those things were now taken care of for him. Being able to keep a daily schedule filled with social activities and obligations gave him a sense of purpose and normalcy, which was very important to his QoL.
Table 5. Descriptive statistics of the components of the McGill Quality of Life Questionnaire.

<table>
<thead>
<tr>
<th>Question</th>
<th>Mean/10</th>
<th>Median</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall quality of life</td>
<td>7</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Physical symptom 1</td>
<td>3.2</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Physical symptom 2</td>
<td>3.2</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Physical symptom 3</td>
<td>0.8</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td><strong>Domain #1 Physical Symptoms</strong></td>
<td><strong>7.6</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical well-being</td>
<td>8</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td><strong>Domain #2 Physical Well-being</strong></td>
<td><strong>8</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>0.8</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Nervous of worried</td>
<td>0.8</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Sadness</td>
<td>0.7</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Fear of future</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td><strong>Domain #3 Psychological</strong></td>
<td><strong>9.16</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Existence is meaningful</td>
<td>6.5</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Achieved goals</td>
<td>6.7</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>Life is worthwhile</td>
<td>8.7</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Control of life</td>
<td>7</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>Like self (feel good about self)</td>
<td>8.8</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Every day is a gift/burden</td>
<td>8.3</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td><strong>Domain #4 Existential</strong></td>
<td><strong>7.7</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>World is caring</td>
<td>7.2</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>Feel supported</td>
<td>3</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td><strong>Domain #5 Support</strong></td>
<td><strong>7.91</strong></td>
<td>9</td>
<td>3</td>
</tr>
</tbody>
</table>
Summary

To summarize, this process uncovered several different themes in terms of the ways in which participants perceived their QoL and QoC. It also suggested that QoL and QoC are closely connected and often intersect. The intersection of these two topics needs to be taken into consideration when evaluating QoL. Overall, participants under-reported their troublesome symptoms on the MQOL tool, which directly affected their QoL and QoC. The major findings in this study suggest that participants wanted to be as independent as possible for as long as possible, and they wanted their care to be timely and efficient. The findings of this study suggest that a greater need for collaboration within the health care system is necessary if improvements are to be made to the overall QoC and QoL of patients. In addition, the findings of this study suggest that there is a particular culture of care specific to the rural population. For example, it was particularly important for participants to receive care from care providers they trusted and with whom they had built a meaningful relationship. In the culture of this care, meaningful communication with health care providers and members of the community was also important to the participants because it gave them a sense of normalcy. It also meant that they were not facing their palliative journey alone and that this was largely a community affair.
Chapter 5 Discussion

In this chapter I will discuss the main findings of this mixed method interpretive descriptive research study. It begins with an introduction to the study’s objectives followed by a summary of the main findings and how the findings relate to the existing palliative care literature. Following is a section dedicated to the limitations of this study. The chapter will also include implications for future research and implications for palliative care in rural communities.

Quality of Life from the Perspective of the Palliative Patient

The majority of palliative research is based on the perspective of primary caregivers and health care professionals. While these perspectives are valuable, they do not describe the lived experience of patients themselves (Robinson et al., 2009; Ryan, 2005). This research study focuses solely on the experiences and stories of palliative patients. One objective of the study was to gain a deeper understanding of how rural palliative patients described their QoL and QoC, and what contributes to an overall good QoL at end of life. Over the last few years, the Canadian Government has released several documents outlining the goals and strategies on how to improve the state of palliative care in Canada (e.g., Carstairs, 2010; Ministry of Health BC, 2013 and 2006). The primary objective of many current palliative care initiatives is to provide patient-centred care. To gain a deeper understanding of good QoL and QoC from the perspective of the patient, it is important to inquire about their unique experiences. One goal of the study was to gain insight into the patient perspective. Based on the literature review, no study has focused specifically on QoL and QoC of rural palliative patients.

Summary of Findings

For this study, qualitative semi-structured interviews and the quantitative MQOL tool were used to examine the relationship between QoL and QoC from the perspective of palliative
patients living in the rural Shuswap region of British Columbia. A total of seven participants were interviewed twice, with the exception of the last participant, who was interviewed once. Each participant described their QoL and QoC slightly differently, yet several major themes were constructed from the data gathered and analyzed. The findings will be discussed in relation to the research questions and also in relation to the existing palliative care literature.

**The Importance of Independence.** In this study, a major theme that emerged from the data was a strong desire for independence among the participants. The literature suggests that this is characteristically part of rural culture. It has been reported that rural dwellers differ from their urban counterparts in several ways. Hughes, at et. suggested that some of these differences include “difficulties of travel, the lack of professional supportive resources locally, and the importance of self-help and self-reliance” (2004, p. 46). Similarly, Nelson (2010) noted that rural dwellers are different ethically and culturally from their urban counterparts. Specifically, he suggested, “personal and shared cultural values, such as self-reliance, self-care and a strong work ethic affect how residents perceive their illness” (p. 53). This study also strongly supports the importance of self-reliance as a contributing factor to QoL, which was sought out by all of the participants. In this study, self-reliance was referred to as independence, and one of the ways in which participants spoke about their QoL was in reference to the ability to stay independent. For most participants, this meant being able to live in their own homes without the assistance of home care nursing, and being able to participate in their usual recreational and social activities. The desire to remain independent as long as possible is not unique to the rural culture; however, the way in which rural palliative patients perceive independence may be distinctly different from the way in which it is perceived by urban palliative patients. For example, people living in rural areas are faced with “fewer service providers, geographical isolation, transportation problems, limited funding, lack of service availability, cultural diversity, and a relative concentration of
older people” (Kelley, et al., 2003). These challenges were reflected throughout this study. However, Nelson also noted that many “rural residents tend to look to families and friends first and these informal support systems are usually reciprocal, implicitly based on the understanding that the recipient of help now will later be repaid in kind” (p. 53, 2010). Therefore, formal support services are often used to complement the efforts of family and friends. Interestingly, only one of the participants in this study was using publicly funded formal support during this study. Another participant shared that his situation “isn’t bad enough yet.” This created a unique culture of care because participants could count on their community to help them in a time of need.

The participants in this study had relatively few choices when it came to their end of life care. Participants living more than thirty minutes out of town could either pay for private home care services or receive two to three one-hour visits from the local home and community care nursing office. Castleden et al. (2010) found that rural participants were often willing to pay out of pocket if they wanted to die in “physically and socially aesthetically pleasing places” (p. 289). My study confirms these findings; however, there may be a slightly different motive for participants to pay out of pocket. Among the participants of this study there was a willingness to incur expenses to remain independent, for as long as participants could remain in their homes, they could retain some sense of normalcy. The desire to die in aesthetically pleasing places was important for these participants, but the normalcy that home provided was a higher priority. However, with the lack of publicly funded formal home support services in rural areas, this option is often limited. Nevertheless, Wilson et al. (2006) found that “home deaths were more common in rural or semirural areas than in urban areas” (p. 175). These findings were attributed to the rural residents having more informal support compared to their urban counterparts. In my
research, several participants were hoping to have a home death supported by their family, friends, and private home care services.

Overall, rural palliative patients in this study considered their independence to be the most predominant factor influencing their overall QoL and QoC. The value placed on independence is relevant to rural palliative patients and urban patients alike; however, to rural dwellers, the meaning and lived experience of independence is often different. Often people living in rural communities have grown accustomed to inventing innovative ways of making things work due to that lack of availability of health infrastructure. For example, McKee, et al. (2010) described that “[in] many of the small, isolated, under resourced communities in our region, palliative care services have not been fully developed, and volunteers are leading the way by advocating, organizing and mobilizing supports” (p. 109). Volunteers, family and friends play a significant role in helping rural palliative clients remain independent. In addition, these community members belong to an informal care that tends to be more person-centered, which is what participants in this study indicated as an important aspect of QoL and QoC.

Living and Dying in a Rural Community

Participants in this study made a conscious choice to live in a rural community; some had only ever lived in a rural community, while others moved to the Shuswap to enjoy their retirement years. This finding is consistent with Crooks and Shuurman’s (2008) research finding that suggested that the demographic trend is “relocation to rural areas upon retirement” (p.139). Most participants in the present study were keen to point out the benefits of living in a small community: a sense of community, quietness, and the convenience of having everything close together. One participant, who relocated from Calgary several years ago, pointed out that his QoC was better in the Shuswap because geographically he was now much closer to the hospital and his doctor.
Having a sense of community and belonging was an important factor for participants. One participant pointed out that his cancer journey was really a “community affair.” Another participant was keen to point out that he loved his privacy; he lived in a house that overlooked the lake, and there was not another house in sight. The rural lifestyle offers many perks that are simply harder to obtain in the city. Many participants outlined the benefits of living in a rural community, especially in relation to their QoC and QoL. However, this was not always the case. One participant discussed the stigma of living in a small town with a life limiting disease. He felt that in some situations he was treated as if his illness were contagious. Pesut et al. (2011) found that “being known and knowing others within the community provided benefits that often countered deficits in resources” (p. 4). However, from my participant’s perspective, being known was problematic because of the stigma attached to his illness and the stigma attached to having a person die in a rental apartment. While studies like Wilson et al. (2012) look at rural and urban differences at end-of-life care, the stigma of living and dying in a rural community warrants further investigation as the literature on this specific topic is limited.

**The Culture of rural palliative care.** Another primary objective of this study was to develop a deeper understanding of how palliative patients described their QoC, and how their QoC affected their QoL. When Goodridge and Duggleby (2010) completed a study that helped inform a framework for assessing rural palliative care, they suggested, “high quality of health care is characterized as care that addresses the objectives of being safe, effective, patient-centred, timely, efficient and equitable” (p.142). While all of these quality indicators were mentioned by the study participants, this research study draws special attention to three particular areas: communication and coordination; relationships with care providers; and time and efficiency within the health care system.
Communication and Coordination. When Goodridge and Duggleby (2010) refer to communication, they are referring primarily to inter-professional communication. However, in this study, participants spoke about communication that exists between themselves and their care providers. Ryan (2005) suggested, “Caring communication delivered sincerely and with a confirmation of the humanity of a patient renders a sense of security and is an essential component to the meaningful care of patients facing death” (p.1101). In the present study, patients emphasized the importance of meaningful conversation with their primary care provider(s). Participants explained that compassionate communication with health care providers was essential to their QoC but also to their QoL. This is likely due to the fact that participants felt less alone in their illnesses when they had a meaningful relationship with their care providers. In the rural Shuswap, patients often see the same care provider throughout their palliative journey, which often fosters a supportive relationship but also a continuum of care.

Family physician practices tend to be small; therefore, patients get to know the clinic staff. Duggleby, Penz, Goodridge, Leipert, Berry, Keall, and Justice (2010) found that their participants valued individuality and community. Their findings are consistent with this study’s findings, which also suggest that individual communication improved the QoC, but for many of the participants, knowing the supportive role of care providers also impacted their QoL. This study illuminated once again the importance of this personalized communication and how important it is to the QoC of the patient. Significantly, patients desire meaningful communication during their care but also a personal connection to their care provider, highlighting the importance of the relationship that patients have with their care providers.

Relationships with Care Providers. In this study, participants were keen to point out the benefits of living in a rural community. They enjoyed the relationships formed with their primary care providers and their regular chemotherapy nurses, creating a culture of care that is
likely unique to rural communities. Robinson, Pesut, & Bottorff (2010) highlighted several barriers to providing palliative care in a rural community, such as a lack of resources, recruitment and retention of qualified staff, lack of awareness of available services, inability to afford services, unmet informational needs of patients and caregivers, lack of knowledge about symptom management, and lack of funding and resources. While all of these issues are relevant to the Shuswap, this study’s participants mentioned very little about these issues. Perhaps individuals living in rural communities do not expect the same level of services as urban dwellers. However, they do expect a relationship with their care providers that allows for some level of personal connection. Goodridge and Duggleby (2010) referred to this as patient-centeredness: it “involves providing care that is respectful of, and responsive to, an individual patient’s preferences, needs and values; it also involves insuring that patient values guide all clinical decisions” (p. 146). While Goodridge and Duggleby provided a good summary of patient-centred care, participants in this study appeared to have higher expectations of the level of service that qualified as patient-centred care. Participants in this study were even willing to sacrifice QoC to preserve the personal connection with their care-providers. For example, one participant explained that he would rather see his regular family doctor who was “nice and personable” than see some specialist out of town who did not really know anything about him. Another participant explained that it was a waste of his time going to see an out of town specialist for a five minute appointment. Lockie, et al. (2010) interviewed family caregivers about commuting for palliative care and suggested, “Although commuting was costly, it had significant benefits for patients in terms of supportive relationships and quality of life” (p.4). This is likely due to the relationships that these study participants formed with care providers at the Cancer Centre(s). While this perspective is held by some patients, if the appointment does not take into consideration the amount of effort required to travel to these out of town
appointments, they can also be perceived by patients as inefficient, according to the participants in this study. This leads to patients being dissatisfied with their care because their time is not considered by the health care team to be valuable.

Overall, participants saw that their relationships with their care providers were essential to their QoC but also to their QoL. Nelson (2010) pointed out that rural health care providers commonly participate in multiple and overlapping relationships within their community (p. 53). This was also the case for some of the care providers and their relationships with several of the participants in the study. Participants generally found these overlapping relationships to be helpful and felt that their care providers would tend to them in the same way they would a family member or a friend. Gessert and Calkins (2001) suggested that “rural care providers are more likely to have a primary care practice, to care for multiple members of the same family, to visit patients in their homes, and to provide continuity of care.” (p. 22). While participants in the study did not use the language ‘continuity of care’ when they described their care experiences, this theme came up several times and, for some of the participants, this theme appeared to be an expectation. While patients find these dual relationships and continuity of care helpful, they are, from the care provider’s perspective, at times challenging to navigate as patients do not always understand their professional boundaries (Robinson et al., 2009). However, these distinct relationships are likely a product of the rural culture in which individuals must look after each other because there is a lack of formal social infrastructure.

**Time and Efficiency within the Health Care System.** This research study highlights a new perspective on QoC and QoL. In particular, this study highlights the ways in which QoC and QoL relate to time and efficiency within the health care system. In this study, participants explained that they want care that does not just focus on efficiencies within the system but also efficiencies that take into consideration how care can be more coordinated and relevant to their
overall QoC and QoL. When Goodridge and Duggleby (2010) referred to efficiency and timeliness, they suggested that care should not be delayed due to a lack of resources, lack of available care providers, and lack of services. However, as mentioned previously, when palliative patients discuss time and efficiency, they are talking about their own time and resources. Participants shared examples of ways in which their care was often fragmented – not with their care providers – but within the health care system. For example, one day participants would need to go in for a computed tomography (CT) scan, while the next day they needed to go in for blood work, and then the following day they would need to go in for a consultation with a specialist, then later they would have to go into their primary care physician for a medication prescription, and sometimes they would then be referred for palliative chemotherapy or radiation. Depending on the preference of the patient, it could be a much more efficient use of their time to schedule these appointments in succession on a single day. One participant shared that he did not mind attending medical appointments as long as they did not interfere with his scheduled social activities. This particular participant shared that his QoL depended on him being able to get out and socialize with his friends, and that he would place more priority on getting out with friends than going to a medical appointment. He wanted his schedule to be taken into some consideration when appointment bookings were made. Despite the fact that participants were pleased with their care, they felt that their illnesses had become their full-time jobs, and that there was a lack of consideration when it came to scheduling appointments. This could lead to a sense of frustration that impacted the QoC but more so the QoL because the little energy participants had left was required to attend various medical appointments. If care was better coordinated, participants speculated that both their QoC and their QoL would improve because they would have more time and energy to participate in life giving activities.
The Use of the McGill Quality of Life Questionnaire in the Rural Population

Participants in the study completed the full MQOL questionnaire at the beginning of the second interview. The MQOL scale was chosen for this research project because it is a validated and acceptable tool to measure QoL for palliative patients (Cohen, Mount, Strobel and Bui, 1995), but it has not been validated with a rural population. Therefore, one of the purposes of this study was to begin to explore the usefulness of the MQOL in a rural population. In this study, participants were keen to take part in the interview; however, the majority of the participants under-reported their troublesome symptoms on the MQOL tool. Hence, there was some disparity between the questionnaire and the semi-structured interviews. In previous research, Ferral and Coyle (2001) reported that palliative participants were grateful for the interviews and questionnaires because it was a way in which participants’ needs could be communicated. Otherwise, they might not have openly discussed their concerns. In this study, participants were also grateful for the interviews; however, the results of this study would be quite different if only the MQOL tool was used. For the rural population, the use of one single measurement tool would not provide the critical information about how to improve the QoC and QoL for palliative patients due to their tendency to prefer direct communication over paperwork. The interviews provided a much richer and deeper explanation of the perceptions of palliative patient as well as their experiences and needs. Because the study was relatively small in size, this research cannot be used to validate usefulness of the MQOL tool in this rural population; however, this research does suggest that this hypothesis warrants further investigation as the tool might not meet all of the needs for the rural population. Bentur and Resnisky (2005) completed a validation screen for the MQOL tool in the Israel hospice setting and highlighted the importance of having a tool that is specific to the population group and the culture. Furthermore, they suggested, “language and cultural communication patterns may also have a crucial effect on
how an individual assesses ‘quality of life’” (p. 538). For example, in this study, participants did not report symptoms on the tool for which there appeared to be no medical solution; however, during the interview participants shared how they had just learned to cope with these problematic symptoms. The MQOL tool itself was not problematic; participants preferred to engage in a meaningful conversation about their QoL and QoC rather than to simply record their symptoms. Nevertheless, Cohen, Mount, Bruera, Provost, Rowe and Tong (1997) suggested that “if palliative caregivers wish to evaluate the full impact of their care, they must measure changes in quality of life (p.5). Therefore, it would appear that the use of a semi-structured interview would provide us with the information that is needed to improve the state of rural palliative care.

**Study Limitations**

Knowledge acquired from the perspective of palliative patients is limited, yet this perspective is essential to gain a better understanding of what palliative patients require to improve their QoL and QoC (Ryan, 2005). The majority of the palliative care research that currently exists focuses on the perspectives of caregivers and health care professionals. The intention of this study is to focus on gaining knowledge directly from the patients. The study is not intended to be generalizable because of its small sample size, but it is intended to provide a perspective that has not yet been explored. Arguably, the findings provide a lens from which to explore the experiences of other rural palliative patients pertaining to QoL and QoC. Nevertheless, the sample size of this study was small and the strength of the study could have improved if the sample size was bigger and if purposive sampling could have been utilized. In addition, the Shuswap is a small region located within the interior of British Columbia and the region is quite wealthy which likely influenced the findings in this study.

The findings of this study assist with understanding the ways in which QoL and QoC are interconnected for seven palliative patients in the Shuswap. The findings illuminate the
importance of meaningful conversation, the importance of connectedness between a palliative patient and their health care team, and the desire for care within the health care system to be more coordinated. While this study highlights some important aspects of QoL and QoC for rural palliative patients, the perspectives of seven individuals do not provide a full scope of experiences. Similarly, many of the study participants were receiving health care services within the same geographical region.

**Study Implications**

Thorne (2008) suggested, “All research ends with a consideration of what the next logical steps might be if we are to advance knowledge” (p.206). In keeping with Thorne’s suggestion, this study’s findings provide some important information about strategies to improve the QoL and QoC for palliative patients in a rural setting. The study also provides some unique ideas about future research inquiries.

**Implications for service delivery in the Shuswap.** The findings of this study provide a better understanding of the ways in which QoL and QoC are experienced by palliative patients living in the Shuswap. The findings emphasize providing care that takes into consideration the importance of coordinated care that is time efficient for the patient. In addition, participants share a unique perspective about the importance of the “continuum of care” while health care professionals are inclined to believe that rural communities require more specialist services. Perhaps what needs to be taken into consideration is advancing the knowledge of local care providers. Arora, Kalishman, Dion, Som et al. (2011) partnered with an urban academic medical-centre and rural primary care providers to provide complete disease management. The outcomes for patients were positive because they received patient-centered care in their own community with their regular care provider, thus ensuring a continuum of care. This is a model that could be considered for primary care physicians but also for other allied health professionals.
in the Shuswap. The QoL findings also suggest that patients want to be as independent as possible in their activities of daily living. Service delivery, such as home care services, must be structured in a way that promotes and supports sustained patient independence. Providing services that help keep an individual at home as long as possible provides a better QoL as well as a greater sense of normalcy for the individual. Overall, participants in this study were pleased with the QoC and QoL that they were experiencing in the Shuswap. The participants attributed their QoC and QoL to several factors, including (but not limited to): a sense of community, meaningful conversation, personal relationships with care providers, and a sense of community connectedness.

**Implications for future palliative care research.** The study’s findings suggest that the next logical steps to take, with regards to advancing knowledge about palliative care from the perspective of the patient, would be to investigate what patient-centered care means for this population. The health care system aims to provide patient-centered care; however, this study illustrates that health care professionals and palliative patients have different ideas of the critical elements that constitute patient-centered care. For example, participants in this study highlighted the importance of improving the coordination of the care, thus eliminating wasted time and energy required to attend medical appointments while health care professionals may overlook this and other aspects of QoL since their focus tends to be on QoC. Overall, there are a limited number of studies on the perspectives of palliative patients. More research is required to develop a broader understanding of the unique perspective of palliative care patients and their needs in relation to improved QoL and QoC.

In addition, future research with regards to stigma that is experienced by palliative patients in rural communities needs more exploration. We need to know how this affects their ability to access care, and how this ultimately effects their QoL. Lastly, the use of the MQOL
tool within the rural population needs more exploration. Participants under-reported significant QoL issues that were revealed during in-depth interviews. Why they failed to report those on the MQOL remains to be determined.

**Conclusion**

This study provides a unique perspective of the ways in which QoL and QoC are interconnected for palliative patients living in the rural Shuswap. The findings of the study indicate that there are indeed connections between these two concepts. The findings from seven study participants suggest that QoL was often characterized by sustained independence, which allowed participants to have some level of normalcy in their final journey. From the perspective of these participants, QoC was characterized by the delivery of care within their community and the delivery of care in a manner that respected their time. The most prominent research contribution is that participants shared a new perspective on the importance of coordinated and timely care. Participants wanted their medical appointments to be more coordinated in order to allow them to shift their focus from managing their health to living their lives. Ultimately, participants did not want their illnesses to become a full-time job. Participants shared that their QoL would likely increase if the health care system considered the value of the time and energy that a patient invests in managing their health. In order to do this, health care professionals must consider the bigger picture of the connection between QoL and QoC when developing a health care strategy for a patient. Rural palliative patients require a health care strategy that aligns with their need for independence within their community-based lifestyle in order for them to maintain an acceptable QoL in the final stages of their life.
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Retrieved from: http://www.who.int/world-health-day/2012/toolkit/background
/en/index.html
# McGill Quality of Life Questionnaire

**STUDY IDENTIFICATION #:_____ DATE: _____**

**Instructions**

The questions in this questionnaire begin with a statement followed by two opposite answers. Numbers extend from one extreme answer to its opposite. Please circle the number between 0 and 10 which is most true for you. There are no right or wrong answers. Completely honest answers will be most helpful.

**EXAMPLE:**

I am hungry:

<table>
<thead>
<tr>
<th>not at all</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>extremely</th>
</tr>
</thead>
</table>

- If you are not even a little bit hungry, you would circle 0.
- If you are a little hungry (you just finished a meal but still have room for dessert), you might circle a 1, 2, or 3.
- If you are feeling moderately hungry (because mealtime is approaching), you might circle a 4, 5, or 6.
- If you are very hungry (because you haven’t eaten all day), you might circle a 7, 8, or 9.
- If you are extremely hungry, you would circle 10.

**BEGIN HERE:**

IT IS VERY IMPORTANT THAT YOU ANSWER ALL QUESTIONS FOR HOW YOU HAVE BEEN FEELING JUST IN THE PAST TWO (2) DAYS.

**PART A**

Considering all parts of my life - physical, emotional, social, spiritual, and financial - over the past two (2) days the quality of my life has been:

<table>
<thead>
<tr>
<th>very bad</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>excellent</th>
</tr>
</thead>
</table>

*Please continue on the next page...*
PART B: Physical Symptoms or Physical Problems

(1) For the questions in Part "B", please list the PHYSICAL SYMPTOMS OR PROBLEMS which have been the biggest problem for you over the past two (2) days. (Some examples are: pain, tiredness, weakness, nausea, vomiting, constipation, diarrhea, trouble sleeping, shorness of breath, lack of appetite, sweating, immobility. Feel free to refer to others if necessary).

(2) Circle the number which best shows how big a problem each one has been for you OVER THE PAST TWO (2) DAYS.

(3) If, over the past two (2) days, you had NO physical symptoms or problems, or only one or two, answer for each of the ones you have had and write "none" for the extra questions in Part B, then continue with Part C.

1. Over the past two (2) days, one troublesome symptom has been: ________________________. (write symptom)

   no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous problem

2. Over the past two (2) days, another troublesome symptom has been: ________________________. (write symptom)

   no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous problem

3. Over the past two (2) days, a third troublesome symptom has been: ________________________. (write symptom)

   no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous problem

Please continue on the next page...

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4. Over the past two (2) days I have felt:

physically

terrible

5. Over the past two (2) days, I have been depressed:

not at all

12345678910 extremely

6. Over the past two (2) days, I have been nervous or worried:

not at all

12345678910 extremely

7. Over the past two (2) days, how much of the time did you feel sad?

never

12345678910 always

8. Over the past two (2) days, when I thought of the future, I was:

not afraid

12345678910 terrified

9. Over the past two (2) days, my life has been:

utterly meaningless and without purpose

12345678910 very purposeful and meaningful

10. Over the past two (2) days, when I thought about my whole life, I felt that in achieving life goals I have:

made no progress whatsoever

12345678910 progressed to complete fulfillment

Please continue on the next page...
11. Over the past two (2) days, when I thought about my life, I felt that my life to this point has been:

| completely worthless | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | very worthwhile |

12. Over the past two (2) days, I have felt that I have:

| no control over my life | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | complete control over my life |

13. Over the past two (2) days, I felt good about myself as a person.

| completely disagree | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | completely agree |

14. To me, the past two (2) days were:

| a burden | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | a gift |

15. Over the past two (2) days, the world has been:

| an impersonal unfeeling place | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | caring and responsive to my needs |

16. Over the past two (2) days, I have felt supported:

| not at all | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | completely |

Please continue on the next page...
PART D

Please list or describe the things which had the greatest effect on your quality of life in the past two (2) days. Please tell us whether each thing you list made your quality of life better or worse during this time. If you need more space, please continue on the back of this page.

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Thank you very much for your help.

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Appendix B: Shuswap Geographic Boundaries

Geographic Boundaries of the Shuswap, British Columbia.

The red region of the map is the Shuswap.

The Columbia-Shuswap Regional District is a regional district in the Canadian province of British Columbia, located in the Southern Interior region on the Trans-Canada Highway between Vancouver and Calgary, Alberta. The regional district borders the Province of Alberta across the Rocky Mountains. Columbia-Shuswap regional district comprises the regions known as the Shuswap Country, which focuses around Shuswap Lake and lies to the north of the Okanagan region, and the northern part of the Columbia Country, namely the "Big Bend" of the valley of the Columbia River from the Town of Golden to the historic City of Revelstoke, British Columbia. (Revelstoke is sometimes referred to as being in the North Kootenay, Golden is usually thought of as being part of the East Kootenay sub-region, the Columbia Valley). The Canada 2006 Census population was 50,141, spread over a land area of 28,929 square kms. and a water area of over 2,000 square km's. The regional district's offices are in Salmon Arm, near the southwest corner of the regional district.

Appendix C: Recruitment Flyer

Title of Study: Assessing Quality of Life and Quality of Care for Palliative Patients in a Rural Setting Using a Mixed Method Approach.

INFORMATION LETTER

Invitation to Take Part

We are doing a study to learn more about how palliative patients living in the Shuswap experience and understand their quality of life and quality of care. We are inviting you to participate in this study because you are currently a client in the B.C. Palliative Care Benefits Program. This research is being conducted by researchers at the University of British Columbia. We think that your experiences will help us learn about more about how to improve the care of future patients. Your participation is voluntary, and you can leave the project at any time.

How will the project work?

We will be asking people about their experiences and understanding of quality of life and quality of care. There will be two interviews with the palliative client and the researcher. The interviews will be digitally recorded. Each interview will take 30-60 minutes each and will include a short questionnaire. The interviews will be conducted in a private and comfortable location. For example, the interview can be conducted in your home if you choose, or in a private place (e.g., office). Individuals who agree and want to have an interview with one of the researchers are called participants. Participants will receive a $20 honorarium as a thank you for their contribution.

What if there are some things you want to say but want them to be private?

We will make sure that only people on the interviewing team will be able to identify what you said. No one will be allowed to use your name when repeating what you said. Your name will not be on any tapes or reports. Your name will only be on your consent form and a demographic information sheet that will help us record contact information. All of the information collected at the interviews will be kept in a locked office and locked filing cabinet at UBC Okanagan.

What if you don’t want to participate; or if you start and then decided you don’t want to continue?
That is okay. If you change your mind, that’s okay. We don’t want anyone to do anything that makes them uncomfortable. We want this project to be a good experience from start to finish, so if you decide halfway through to stop, that’s OK.

Sometimes when people start talking about things that have happened, it can be hard. We hope this won’t happen, but if it does, you can choose to not answer a question or to stop the interview. If you require any support or counseling, you will be given a list of resources of community services available to you. If you need further help finding someone to talk to, a member of the research team will be available to help you.

**What happens to the material after?**

Answers to the interview questions will be digitally recorded. The research findings will be used by Merel Voth to complete her master’s thesis in social work. In addition, a report will be shared with UBC and Interior Health. We will also write articles to go into a journal or magazine, and we will present the information at a conference (e.g. The Canadian Palliative Annual Conference). Your name will NOT be included in any reports or presentations.

**What if I have any questions?**

If you have any questions or concerns about anything to do with the project you can ask Merel Voth (250-307-3421; merelvoth@alumni.ubc.ca) or Dr. Rachelle Hole (250-807-8741; rachelle.hole@ubc.ca).

**What’s next?**

This sheet is meant to tell you basic information about the project. After you’ve had a chance to think about it, and ask any questions you want, you can let us know if you want to help us out. If you do – great! If you don’t – that’s fine too.

If you want to take part, please contact Merel Voth at 250-307-3421. Alternately, you can fill out the consent to contact forms and return it to your community care nurse, and someone from the research team will contact you.

Sincerely,

Merel Voth,
Student Researcher
250-307-3421
Appendix D: Recruitment Poster

Are you living with a life limiting illness?

We want to hear about your experiences living in the Shuswap, in particular how your illness has affected your quality of life and how it has affected your health care.

Eligibility Criteria:
Must be 19 years of age or older, live in the Shuswap region, and living with a palliative diagnosis.

What is required: 2 interviews that will take place at your preferred location.
For your participation you will receive a $20 honorarium.

If you are interested please contact graduate student researcher Merel Voth at 250-307-3421 or merel.voth@alumia.ubc.ca or principal investigator Dr. Rochelle Hole at 250-807-8741
Appendix E: Consent to Contact

Title of Study: Assessing Quality of Life and Quality of Care for Palliative Patients in a Rural Setting Using a Mixed Method Approach.

I am interested in learning more about this research study. By signing this form I consent (give permission to) Merel Voth(graduate student) to contact me by phone to answer questions about the study and talk about participating in the study.

________________________________________
(Name)

________________________________________
(Phone Number)
Title of Study: Assessing Quality of Life and Quality of Care for Palliative Patients in a Rural Setting Using a Mixed Method Approach

Principal Investigator:  Dr. Rachelle Hole, Associate Professor of Social Work  
UBC Okanagan School of Social Work, 3333 University Way, Kelowna, BC, V1V 1V7  
250.807.8741

Co-Investigator:  Dr. Barbara Pesut, Associate Professor of Nursing...

Co-Investigator/Graduate Student:  Merel Voth, RSW, BSW  
Master of Social Work Student  
UBC Okanagan School of Social Work, 3333 University Way, Kelowna, BC, V1V 1V7  
250.307.3421  
merel.voth@alumni.ubc.ca

For the purposes of this consent form, the language has been adapted in consideration of participants' different literacy levels.

Purpose of this research:

This research is being conducted by a graduate student (Merel Voth) at The University of British Columbia Okanagan. The goal is to learn about the quality of life and quality of care for palliative patients in the rural setting of the Shuswap.

In the rural Shuswap, palliative care has been identified as an urgent need, and the community has called for an action plan to improve palliative care. We want to hear about your experiences.

You are being asked to participate because you are currently a palliative care client, on the BC Palliative Care Program, and you are an adult over 19 years of age. We think your experiences are important and will help us understand more
about palliative care experiences and the positive and/or negative aspects of your current experience of quality of life and quality of care.

Taking part is voluntary. You can leave the study at any time without any questions; this will not have any consequences with regards to your health care.

What you are being asked to do for this research:

We will be asking about your experiences, which will be audio recorded. You can request for the audio recorder to be turned off at anytime during the interview. The two interviews will take about 30 minutes to 60 minutes each and will be conducted in a private and comfortable location. For example, the interview can be in your home or office, if you choose. Individuals agreeing to have an interview with one of the researchers are called participants. Participants will be asked to complete a short survey about their quality of life and will also be asked a few questions. In addition, we will also be asking you some demographical information: for example, age and gender. The two interviews will take place within one to three weeks of each other. At the first interview meeting, you will be given a $20 honorarium for participating.

What will happen to the study results?

The results of this study will be reported in a graduate thesis which is a public document that will be available on the internet. A journal article(s) might also be published in an academic journal(s). Some of the researchers’ findings might also be presented at relevant professional conferences. Lastly, this information will be given back to the Shuswap Community through a written report and presentation.

Potential risks:

Sometimes it can be hard for people to talk about their experiences. We hope this won’t happen, but if it does, you can chose to not answer a question or ask to stop the interview and research. If you would like, we will find someone (like a counselor or a support person) for you to talk to privately. You will also be given a postcard with information about community resources. If you chose to withdraw from the study at any point for any reason, it will not have any consequences with regards to your health care.

Potential benefits:

Your opinions and thoughts about your palliative care experiences are important because this research study will provide health care providers with more information about what you believe is important. This information will help the Shuswap community make decisions about how to improve palliative care.
services in this area. In addition, this project will help others who are also palliative.

Therefore, being involved in this research will allow for your perspectives to inform the findings of this research which will shape the standards and safeguards, policies and practices guiding the current palliative care services.

**Storage of Information:**
All original data will be kept for a minimum of five years following the publication of this research study. The material will be stored in a locked filing cabinet in the Principal Investigator's office. Following the five year period, all hard copies of data and participants' information (e.g., consent forms) will be destroyed through confidential shredding at UBCO. Any secondary use of the data collected for this research is subject to ethical review and approval by a Research Ethics Board.

**Confidentiality:**
Privacy is important. Your name will not be on any tapes or reports. All information from the interviews will be kept in a locked office. The only people who will have access to this material are members of the research team.

Once we have gone through all the material we will be writing a formal document. The report will be shared with UBC Okanagan; however, the names of people who took part will NOT be shared. The identity of participants will be kept private. We will also write articles to go into a journal or magazine and present the findings at a conference or meeting.

It is very important to protect your privacy, but there may be circumstances when the researcher must share information with others. If the researcher finds out during the interviews that a vulnerable person is being neglected or abused, this would need to be reported to the authorities that help vulnerable adults. Also, if the researcher learns about criminal activities that put a vulnerable person at risk, this might also need to be shared with the authorities. Every effort will be made to protect your privacy and the only exception to this rule is when keeping that privacy means that someone will be harmed or is at serious risk of being harmed.

**The use of an interpreter:**
For participants that require an interpreter, the interpreter must sign a confidentially agreement prior to starting the interview.
Choosing to stop your participation:

Your participation in this study is entirely voluntary. You may refuse to participate or withdraw from the study at any time. If you decide you want to stop at any point, that is fine. If you choose not to participate or if you choose to stop, this will not affect the services and supports you receive. If you withdraw from the study, you will still receive your $20 honorarium. If you withdraw from the study you can request that your information be eliminated from the study.

Contact for information about the study:

If you have any questions or concerns about the project, you can ask Merel Voth (250-307-3421; merel.voth@alumni.ubc.ca) or Dr. Rachelle Hole (250-807-8741; rachelle.hole@ubc.ca).

Contact for concerns about the rights of research subjects:

If you have any complaints about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 1-877-822-8598, or the UBC Okanagan Research Services Office at 250-807-8832. Or, you may contact the Chair of the Interior Health Research Ethics Board at 250-870-4602 or by email at researchethics@interiorhealth.ca

Consent:

Your signature means that you are consenting to taking part in this study. Your signature also means that you have a copy of this consent form.

_________________________  __________________  _____________
Name of Person                         Signature                  Date
Appendix G: Interview Guide

Interview Guide for: Palliative Care Study in the Shuswap.

I. Review:
   o Review and complete consent form and give one copy to the participant

II. Introduction:
   o Explain the study purpose and digital recording (reiterate confidentiality of the interview)
   o Ask participants to not to use names of persons during the interview. Names will not be entered into the written transcripts or data analysis.
   o Reiterate that we can stop the interview at any time, and that they can skip questions.
   o Review the general research objectives with participants in lay language. (E.G. Gain an understanding of what they find valuable about their rural lifestyle.)

III: Potential Questions and Probes for Interview 1 and 2:

   Interview #1: Focus is Quality of Life (QoL) of Participants

   What were you considering when you rated your overall QoL scale today?
   o What did you consider when you rated your QoL at xx?
   o What were you thinking about when you provided that the number on the scale?

   What does QoL mean to you today in perspective of your life today?
   o What does a good life mean to you?
   o What does quality of life mean to you?

   What are the things that are most important to you today?
   o What is one thing you really enjoy doing at the moment?

   What do you think about most?
   o What do you worry about the most at the moment?
   o What are some things you really miss at the moment?

   How has your understanding of a “good life” influenced how you have made your decisions?
   o What informs your decisions?
   o Who helps you make decisions?

   Have you done any planning for your future needs in the context of this illness?
   o What have those plans included?

   How has your quality of life improved?
   o Are there certain things that have improved for you
   o What has contributed to the improvement(s)
How has your quality of life decreased?

- What has contributed to these changes?

As a researcher looking at how people describe their quality of life, what do you think is particularly important for us to know?

**Interview #2: Focuses on the Quality of Care (QoC) of Participants**

Can you tell me who is involved in your care? And what sorts of things they are helping you with?

- How have you experienced the care?
- What healthcare interventions have been helpful to you?
- How have your symptoms been reduced, or increased as a result of your care?

In your opinion, what are the greatest strengths of your care team here in the Shuswap?

- What has been most helpful?
- What makes it helpful?

In your opinion what are the biggest barriers to good quality care in the Shuswap?

- What has been most challenging to receiving good care?
- What have you found difficult in your community?
- What are some care services you would like to see in your community?

In your experience, can you remember a time when you felt that your care was excellent?

- What made it excellent?

In your experience, can you remember a time when your care was particularly problematic?

- What made it problematic for you?

Last time we talked about what is important to have a good life overall. Have you had to make challenging decisions in relation to what is most important in your life. Can you tell me about those decisions?

- How has the quality of your personal care affected your lifestyle?
- Can you tell me about those decisions?
- What have they been?
- Has your desired quality of life influenced those decisions and if so how?
- How has your understanding of a “good life” influenced how you have made your decisions?

How is the quality of your care impacting your quality of life?

As researchers looking at quality of life and quality of care, what do you think is particularly important for us to know?

- Is there anything else that would like to let us?
Appendix H: 12 Principles of Interviewing a Critically Ill Patient

Twelve Techniques for Conducting Qualitative Interviews with Seriously Ill Individuals about End-of-Life Issues.

Technique #1: Find a recruiter who knows that participant pool.
Technique #2: Take adequate time with obtaining informed consent
Technique #3: Foster a sense of trust and safety from the outset of the interview
Technique #4: Develop a sense of the participants
Technique #5: Meet the participant where he or she is.
Technique #6: Start with safer ground and peel back the layers
Technique #7: Go slowly
Technique #8: Go where the participant goes
Technique #9: Redirect the participant appropriately
Technique #10: End in a way that allows the participant to reflect and regroup
Technique #11: Wear only your interview hat
Technique #12: Interviewer reflection.

Schulman-Green D., McCorkle R., and Bradley E. (2009) Tailing Traditional Interviewing Techniques for Qualitative Research with Seriously Ill Patients About the End-of-Life. Omega 60(1) p. 89-102
Appendix I: McGill Quality of Life Scoring Criteria

McGill

Palliative Care McGill

McGILL QUALITY OF LIFE QUESTIONNAIRE SCORING

PART ‘A’

Part ‘A’ is a Single-Item Scale (MQOL-SIS) measuring overall quality of life. It is not included in the MQOL scores but is used for purposes of comparison to the MQOL scores.

POSSIBLE SCORES

All MQOL items, MQOL submeasure scores, and MQOL Total Score have a possible range from ‘0’ to ‘10’. In order for ‘0’ to always indicate the worst situation and ‘10’ the best situation, the following items must have the scores transposed prior to calculating the subscale and Total scores or data analysis.

Prior to calculating MQOL scores or data analysis, transpose the scores for Items 1, 2, 3, 5, 6, 7, and 8 by subtracting the raw score from 10 for each subject.

MQOL SUB-MEASURES

There are 5 MQOL submeasures: Physical Symptoms; Physical Well-being; Psychological; Existential; and Support. They are scored as follows.

- **Physical Symptoms.** This is a three-item scale. The score is the mean of the scores for Items 1, 2, and 3 (transposed).
- **Physical Well-being.** This is a single-item measure. The score is the score for Item 4.
- **Psychological.** This is a four-item scale. The score is the mean of the scores for Items 5, 6, 7, and 8 (all four transposed).
- **Existential.** This is a six-item scale. The score is the mean of the scores for Items 9, 10, 11, 12, 13, and 14.
- **Support.** This is a two-item scale. The score is the mean of the scores for Items 15 and 16.

MQOL Total Score

The MQOL Total score is the mean of the 5 submeasure scores.
The McGill Quality of Life Questionnaire (MQOL) was developed by Dr. Robin Cohen and Dr. Balfour Mount of the Division of Palliative Care, Dept. of Oncology, McGill University because existing quality of life questionnaires were not appropriate or valid for use with the terminally ill. An instrument is needed that is valid when used in the setting of any type of terminal illness, from the time of diagnosis to death. MQOL is intended to meet this need. MQOL has been designed to measure subjective well-being, that is, the patient’s experienced quality of life. It may be used in conjunction with other outcome measures when additional health-related outcome variables are of concern. MQOL comprises five sub-measures relating to: Physical Symptoms; Physical Well-being; Psychological Well-being; Existential Well-being; and Support. MQOL scores reflect subjective well-being in each domain but do not identify the contributing variables. Central goals in MQOL design included brevity and generalizability.

NEW VERSION

We are presently testing a revised version of MQOL called “Quality of Life in Life-Threatening Illness – Patient Version (QOLLTI-P)”. However, we do not yet know if it is in fact an improvement on MQOL, and therefore are not distributing it at this time.

ORIGIN OF ITEMS

Initial MQOL questions were chosen based on a literature review, clinical experience, and the results obtained from a preliminary longitudinal study of quality of life in patients receiving palliative care (n=50). This study used established instruments: the Functional Living Index - Cancer (FLIC) (Schipper et al, Journal of Clinical Oncology, 1984), Purpose-in-Life Questionnaire (PIL) (Crumbaugh and Maholick, Journal of Clinical Psychology, 1968), and Edmonton Symptom Assessment System (Bruera et al, Journal of Palliative Care, 1991), supplemented by additional questions of our own where required for conceptual completeness. MQOL development by us to date has included the following studies: a pilot study involving palliative care patients (n=40)(Cohen et al, Palliative Medicine, 1995); a multi-center study, also featuring palliative care subjects (n=150)(Cohen et al, Palliative Medicine, 1997); a study of people with cancer at all phases of the disease trajectory (n=247)(Cohen et al, Cancer, 1996); a study of people living with HIV/AIDS (n=107)(Cohen et al, AIDS, 1996); a study of responsiveness and test-retest reliability (Cohen and Mount, Cancer, 2000); and a study of changes in quality of life during the first week of admission to palliative care units (Cohen et al. Palliative Medicine, 2001). These studies have enabled a series of evolutionary MQOL modifications to enhance acceptability, validity, and reliability.

MQOL includes questions based on those in existing instruments: the FLIC (MQOL items 7 and 8), PIL (MQOL items 9-12), and the Missoula-Vitas Quality of Life Index (items 13-15). Please ensure that those with whom you discuss the MQOL are made aware of the origin of these questions.

IF YOU WANT TO USE MQOL

You are free to use MQOL. We ask only that you return to us the completed User and Information Registration Form (attached) and acknowledge the source of MQOL in any publications or professional activities where it is used. If you use MQOL, we would be...
appreciate any MQOL data you could make available to us to help us learn more about the properties of MQOL. Any feedback you might have about MQOL would be gratefully received.

FAMILY CAREGIVER QUALITY OF LIFE

We have recently developed a measure of the quality of life of the family caregivers of palliative care patients (QOLLI-F: Quality of Life in Life-Threatening Illness – Family Caregiver Version)(Palliative Medicine 2006; 20: 755-767). Please contact me if you would like further information about QOLLI-F.

Sincerely,

S. Robin Cohen, Ph.D.
Assistant Professor and Research Director
Jewish General Hospital
McGill University, Departments of Oncology and Medicine
email: robin.cohen@mcgill.ca
Appendix J: Transcriptionist Confidentiality Contract

TRANSCRIPTIONIST CONFIDENTIALITY AGREEMENT

The parties to this Agreement agree that all information whether in the form of data, or reports regardless of how communicated, recorded, or received by the research transcriptionist while employed on the graduate research project: “Quality of Life and Quality of Care for Palliative Patients in a Rural Setting” by the Principal Investigator, Merel Voth is confidential and proprietary and will be kept as such.

The research transcriptionist shall use all the project information in confidence solely for the purposes of graduate thesis research at the UBC Okanagan School of Social Work and shall not -

(a) Make any other use of the information except as expressly first authorized by the Principal Investigator in writing; nor

(b) Disclose or permit or cause to be disclosed the information to any person except as are necessary to properly report on the transcription done and only then under terms of confidentiality of the same or stricter effect as these.

Signature: __________________________________________________________

Printed Name: ______________________________________________________

Date: __________________________________________________________________

The University of British Columbia Okanagan, 3333 University Way, Kelowna B.C.

Masters of Social Work
Appendix K: Postcard Support

Supports and Resources Available to You in the Shuswap

- Shuswap Hospice Society (250)-833-7099
- The Relaxation Group for Cancer patients and their caregivers (Contact: Nina (volunteer) 250-833-0347)
  - BC Cancer Society (Salmon Arm Office) (250)-833-4334
  - BC Cancer Agency (Salmon Arm) (250)-833-3636 ext. 3636 (chemo department)
    - Mental Health (250)-833-4100
    - Afterhours Crisis Line (888) 353-2273
    - Community Care Nursing (250) 832-6643
- Shuswap Lake General Hospital (250) 833-3600
Appendix L: Demographic Information Sheet

Demographic Information of Participants for the Palliative Care Study in the Shuswap

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<th>Participant ID</th>
<th>Gender</th>
<th>Age</th>
<th>Years living in rural community</th>
<th>Date of 1st diagnosis</th>
<th>Length of contact with the health care system</th>
<th>Martial Status</th>
<th>Education</th>
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Appendix M: Interpreter Confidentiality Contract

INTERPRETER CONFIDENTIALITY AGREEMENT

The parties to this Agreement agree that all information whether in the form of personal communication, data collection, or reports regardless of how communicated, recorded, or received by the research interpreter while employed by the graduate research project “Quality of Life and Quality of Care for Palliative Patients in a Rural Setting” by the Principal Investigator (PI) Dr. Rachelle Hole is confidential and proprietary and will be kept as such.

The research interpreter shall use all the project information in confidence solely for the purposes of graduate thesis research at the UBC Okanagan School of Social Work and shall not -

(a) Make any other use of the information except as expressly first authorized by the Principal Investigator in writing.

(b) The interpreter will not have any prior connects to the participant being interviewed (e.g. family, friends, and or colleague)

The interpreter agrees to abide to their professional code of ethics, in particular the confidentiality agreement.