THE LIVED EXPERIENCE OF BEREAVED CAREGIVERS:
CARING FOR LOVED ONES AT END OF LIFE IN RURAL ONTARIO HOME SETTINGS

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Abstract

The purpose of this study was to explore the lived experience of bereaved caregivers who cared for their loved ones at end of life in rural Ontario home settings. van Manen's hermeneutic phenomenology research method was utilized to guide this study and to gain a rich understanding of the lived experience through participants' interviews. This study's sample consisted of eight participants from rural locations in the Eastern and Waterloo-Wellington counties of Ontario, Canada. Five themes were uncovered: (1) Facing a Terminal Prognosis and Deciding to be a Caregiver; (2) Being in it for the Long Haul; (3) Drawing on Sustaining Reservoirs; (4) Haunting Concerns and Comforting Memories; (5) Reflecting on an Invaluable Journey.

Key Words: palliative, end of life, terminal, rural, remote, caregiver, bereavement, phenomenology, qualitative, lived experience

Dedication

This thesis is dedicated to the courageous rural palliative caregivers who volunteered to participate in this study and to their loved ones who live on in the stories that were shared.

Acknowledgements

After an immense amount of self-reflection, I was reminded of why I started this journey in the first place. I came to realize it has a lot to do with everyone in my life that I owe thanks to during this transformative life experience.

Mom and Nanny- Through losing each of you, I have become more aware of the important things in life and to be more appreciative of each day given to me. In helping care for each of you at home during the final stages of your life I gained an irreplaceable experience that has shaped me into a better palliative care nurse and human being; to both of you, I thank you for your ongoing love and guidance.

> Love as powerful as your mother's for you leaves its own mark. Not a scar, no visible sign…to have been loved so deeply, even though the person who loved us is gone, will give us some protection forever. (Rowling, 1997, p. 216)

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Chapter One: Coming to the Study

I was a native rural dweller for the first 26 years of my life and lived in a small town of less than 1000 people. I grew up knowing the bounty the land and animals could provide to sustain our human existence and was constantly reminded of the natural beauty that surrounded us in the unspoiled lands. I attended the local elementary school and high school and I went to school with the same people from kindergarten until twelve grade. In the rural setting everyone knows one another in some shape or form whether it is being family, friends, neighbours, classmates, team mates, or coworkers. After graduating high school I went to the local college in the closest city to attend a collaborative baccalaureate nursing program partnered with an Ontario University. During my baccalaureate schooling I also continued to attend school with people I knew from high school and my community. After graduating I became a rural visiting nurse specializing in palliative care. For the next several years I cared for members of my community that I either knew directly or indirectly from having grown up in the same community as them. Practicing as a rural visiting nurse I feel that my nurse-client relationships were on a different level than the relationships I currently have with clients who are based in urban settings. The difference is that I often felt more accountable for my actions in rural settings. My clients were not strangers to me like I experience in an urban setting now and I knew I would be held answerable to their loved ones when I encountered them in the community.

Over the course of the four years I spent working as a rural visiting nurse I observed the hardships faced by the caregiver(s) caring for their loved ones dying at home. It often felt like we were barely able to scrounge up the resources needed to support the caregiver(s) in helping keep their loved ones at home for end of life (EOL). At times the stress and anguish was written all over the caregivers’ faces. This professional experience sparked my interest in studying the lived experience of caregivers in rural home settings. This interest was intensified in 2013/2014 when I became the caregiver for both my grandmother and mother who both lived their EOL in our rural town. It was only during this period of my life that I was truly exposed to the reality of rural caregiving of loved ones at EOL from the perspective of a caregiver. Although as a nurse I had some previous professional knowledge of the struggles that caregivers faced, my insight into the severity and at times unremitting nature of the challenges faced by caregivers, was superficial. It was only through my own experience as a caregiver that I was enabled to see how much of what clients and their caregivers experience remained hidden and behind the scenes to nurses and professional staff. I lived and breathed the hardships that came from the lack of services and coordination at times and I also experienced some of the most beautiful memories that I hold onto in my times of grief. While the latter experiences were some of the hardest times of my life I still feel blessed and thankful to have been a part of those sacred journeys with my loved ones.

I have since left my rural setting and live and practice as a palliative care visit nurse in an urban setting. Transitioning to living and practicing nursing in an urban setting has opened my eyes to a different way of life that seems stark and less warm or intimate than life in rural settings. Reflecting on my current practice with caregivers who live in urban settings, and juxtaposing these thoughts with the experiences of the participants for this study who live in rural settings has stimulated deeper thought. In particular I have been challenged to consider how meaning comes to be constituted in webs of relationships influenced by geography (proximity and distance) and how such considerations bear on what it means to have access to services and what it means to draw on resources for caregiving.

These insights propelled the drive to become engaged in research with a view to revealing in a more complete way, the multi-faceted experiences of caregivers in rural settings;

experiences which disclose both the ability to draw upon a unique set of relationships existing in the community at times, while at other times experiences of feeling overwhelmed and deserted. My hope is that attending to the finely nuanced expressions of the rural caregivers' experiences as well as considering the informal resources that exist in rural settings at a community level will ultimately have an impact on quality of care so that the resources of clients, informal community supports and formal care systems can evolve in a way that it is more effective and mutually enhancing. Therefore there are three questions that this study seeks to answer.

a) What are the meanings of the personal experience of caring for a loved one at home at EOL in rural settings?

b) What motivates and sustains caregivers to provide care at home for their loved ones?

c) What specific meanings do caregivers place on providing this care to their loved ones?

Chapter Two: Literature Review

An in-depth search of the current literature related to this study's research area was completed utilizing five databases: CINAHL, Medline Ovid, Proquest Nursing and Allied Health Sources, Proquest Dissertations and Theses and PsychINFO. The initial database search took place from September 2014 to February 2015 with an update in January 2017 and dated back to the year 2000. Subject heading and key word searches included: rural health, rural health personnel, rural health nursing, palliative care, hospice and palliative nursing, terminal care, hospice care, holistic care, quality of life (QOL), end-of-life or end of life, phenomenology, phenomenology research, qualitative research, caregivers, caregiver support and home care services. A total of 45 articles were found and 15 were retained. Relevant articles of a quantitative or qualitative as well as those that combined methods and used mixed methods designs were selected. Articles that were not included were those with limited relevance to this study's focus, that is, when the research participants were patients or health care providers and not caregivers and/or that the research was not based in a rural context.

An overview of findings from the literature relevant to this study is provided below. Each study will be reviewed in regards to purpose, design, sample, reliability/credibility, findings, limitations, gaps and areas for future research. Although my study is qualitative in nature, as mentioned above, quantitative studies will also be reviewed as I believe their findings and identified gaps/areas for future research pertain to this study's subject area. While this study explored the lived experience of rural caregivers, this literature review will also include two studies that looked at the lived experience of nurses. These studies were included because they also examined caregiver experiences. Some studies with nurse participants as the focus were also included because they provided an interesting perspective on the extent to which nurses have insight into the ways in which the provision of and deficits in care affect the lived experience of caregivers caring for a loved one at EOL.

The literature review is organized into international studies, Canadian studies, and international comprehensive reviews to provide a sense of what has been done globally and nationally on the subject area. Please refer to Appendix A for related definitions to this study's subject matter (caregiving, family caregivers at EOL, caregiver needs, palliative care, EOL care, home-based care, hospice and rural).

Qualitative International Studies

Johnston, Milligan, Foster and Kearney (2012) completed a qualitative study that explored the lived experience of caregiver's experiences of caring for loved ones with a diagnosis of cancer at EOL. These researchers completed two sets of unstructured interviews spaced out two-four weeks apart. Sample size was 20; 13 females and 7 males who ranged in age from 30-93 from the United Kingdom (UK). It was not stated whether the participants were from urban or rural settings nor was the type of setting they were providing EOL care provided. Using a computer software framework approach data analysis method the researchers identified the following themes: a maintenance of daily life routine; getting ready to die; backing from loved ones; goals for physical activities of daily living (ADL), and help from health care professionals (HCPs). The authors of this study concluded that there is a need to examine the lived experience of caregivers of loved ones at EOL life dying from other disease processes other than strictly cancer (Johnston et al., 2012).

A qualitative study by Wilkes, White and O'Riordan (2000), set in Australia, examined the experience of rural family members providing palliative care to their loved ones with cancer.

The researchers also examined the experience of nurses who provided care for EOL clients and their family caregivers. The researchers utilized a cross-sectional design with unstructured interviews with a sample size of 19 family members and 10 palliative care nurses. The researchers demonstrated rigour by outlining their data collection process, coding methods and theme development. Findings included that families felt their primary physician should have been more of a main source of information on EOL symptom management/disease progression. Families also voiced feelings of not being provided with adequate knowledge to make informed decisions in crisis EOL moments. The families reported a need to be better informed of services available to them in the area (e.g. counselling, cooked meals) and for the information to be presented in a manner that fit with their learning style (auditory, visual, kinetic, or mixed).

Wilkes et al. (2000) suggest that HCPs must work with their clients to determine their learning style and then develop an education plan that incorporates their clients' preferred learning style(s) into it. These measures ensure that clients will be provided with a learning experience that is conducive to their success. Palliative care nurses researched in this study felt that family physicians and oncology centres need to be providing information to their patients that is consistent with palliative care plan objectives (comfort, improved QOL) and not engaging in false pretences related to unrealistic prognosis times. The study concluded that families need more information around available services, disease processes, prognosis, EOL and EOL symptom management. Although the authors did not discuss any limitations, one shortcoming noted in the review of this study was the lack of clarity around the kinds of practice settings in which clients and nurses were situated (urban or rural) and the education services/tools already available to them. The researchers concluded that there is a need for the development, implementation and evaluation of educational packages provided to families taking care of oncology patients receiving EOL care (Wilkes et al., 2000).

Authors Hatcher et al. (2014) completed a qualitative study using semi-structured interview methods to explore the experience and decision making around caregivers who transferred their loved ones from their rural home to the hospital for palliative care services. The sample consisted of six participants, three of which were female and three of which were male and all of whom lived in rural Australia. The interviews were conducted in two stages, the first interview occurred within one week of hospital admission and the second interview occurred three months later. The researchers maintained auditability by discussing their coding and thematic analysis methods using an inductive approach. To aid in the rigour of their study the authors report that they had codes and themes checked by two researchers and that they also completed member checking with their study's participants.

Limitations of the study noted by these authors included: small sample size, recruitment difficulties from a rural setting, and the possibility that those who did not participate might have chosen not to participate because of negative experiences and this therefore did not get captured in the descriptions. Hatcher et al. (2014) found three themes which include "(i) making the decision to transition to hospital; (ii) the transition from home to hospital; and (iii) the care in hospital" (p. 162). Findings by the authors suggest that unresolved patient anxiety and pain along with taxing physical demands on the caregiver are the main reasons given by caregivers for the decision to send their loved ones to hospital. It was found that caregivers discussed their options about moving the patient to hospital with their community nurses and their loved ones prior to transferring them. Overall the study found that a smooth transfer from the rural home to hospital was enabled as long as there was good communication among the caregivers and their community nurse. In this study all of the caregivers praised the care received at the hospital. An area for future research suggested by the authors was to complete a large scale study on the same subject area with a mixed method approach so that the findings could be generalized to the target population (Hatcher et al., 2014).

Quantitative International Studies

Although the following studies are quantitative in nature and do not aim to reveal the lived experience of caregivers, they were selected for review because they revealed important findings that invite further exploration and deeper understanding, which may or may not be done using multiple methods including qualitative approaches.

A study based in the United Kingdom (UK) by Ingleton et al. (2004) investigated informal caregivers of loved ones with terminal cancer who died in the home setting or a residential hospice in both rural and urban settings. The authors utilized a non-experimental cross sectional research design and sample size was 301 participants. The researchers discussed the reliability and validity of the satisfaction scale used for measurement and they supported their choice with reference to the literature, however, no Cronbach alpha scores were provided.

According to the findings, 25% died at home and the remainder died in hospices, hospitals and long term care facilities. Thirteen percent of caregivers were not happy with the place of death for their loved one. Dissatisfaction ranged from wishing death had occurred in hospital if they died at home or vice versa. A major finding from all participants was the general lack of information they felt they received around the EOL process as a whole. Thirty-three percent felt they did not receive adequate information about their loved ones' disease process or prognosis and 20% reported not being told their loved one would likely die. Of the caregivers in a home setting, 90% reported being satisfied with the nursing care provided and rated it as either good or excellent. Even though they reported that 90% of the nursing care was good or excellent, 40% of those respondents reported the need for more nursing support and 20% felt they needed more personal support worker (PSW) hours. The remaining 30% did not report needing any additional services. Seventy-two percent were satisfied with the physician managing their loved ones palliative care needs and reported that physicians listened well and formed mutual goals/care plans with them. The common areas of deficits in care reported by the caregivers were: Bereavement support, night nursing support, personal support, communication, and symptom control related mainly to pain.

Authors acknowledged that the retrospective nature of the method might have allowed for some inaccuracies given the recollection of events versus actual events that occurred. The authors noted that they only examined the caregivers' perspectives and that there is limited knowledge on patient's perspectives and that is an area for future research. Researchers also suggested future research could focus on the implementation and evaluation of uniform palliative care guidelines aimed at targeting the deficits in support voiced by the caregivers in this study (Ingleton et al., 2004).

Burns, Grande, Tieman, Abernethy and Currow (2015) investigated the providers of palliative care in rural and urban settings in South Australia. The study design utilized a randomized population survey analysis of routine survey findings obtained from the national health database. The study looked at 6, 849 bereaved participants' survey results from a mixture of urban and rural South Australia; 2, 205 of which were from rural South Australia. The researchers discussed the reliability and validity of the surveys used with reference to supporting literature but do not provide Cronbach alpha scores. It was found that there was almost identical access to palliative care services from rural and urban settings but that rural caregivers utilized the support of friends and family more than their urban counterparts. Researchers found that the same number of people died in a home setting in rural and urban settings and there were longer hospital inpatient stays in rural settings for EOL care. The longer inpatient hospital stays for patients based in rural settings was attributed to the limited hospice facilities in rural settings. Greater than half of the rural caregivers felt that caregiving services were better than they anticipated going into the decision to provide EOL care at home and 18% reported needing more information about disease progression and care plans from HCPs. Twenty-five percent of caregivers in the study reported a need for more PSW services at EOL.

In reviewing the survey data that was utilized it was found that the survey was not administered in any area less than 1000 people. This fact leads to questions regarding the relevance of the study in capturing a truly remote rural setting and whether the comparison of rural and urban settings would show more differences if communities with populations of less than 1000 people were explicitly sampled. The relevance of this quantitative study to aboriginal populations was questioned given there was a very low survey response from aboriginal persons. Burns et al. (2015) suggested the need to look into whether there is a difference in care in communities smaller than 1000 people and the extent to which the experience of the aboriginal population differs from non-aboriginal caregivers.

Qualitative and Mixed Method Research: Canadian Studies

Pesut, McLeod, Hole, and Dalhuisen (2012) completed a qualitative study with a secondary analysis of transcripts from two studies guided by two questions about nurses and caregivers experiences in rural palliative care in British Columbia. The one sample consisted of 26 female nurses with 10-25 years of experience in community palliative care and the other consisted of 46 male and female caregivers with less than two and half years care-giving experience. The researchers demonstrated rigour with detailed information about their study process, sampling methods, initial and ongoing coding processes and theme development arising from holding regular meetings to discuss analytic validity. Findings included that there is no organized framework for palliative care in the community setting and every organization has different policies and procedures to follow. Such variation in approach only adds more chaos to an already complex speciality. The study found that although palliative care champions are used to guide novice nurses in palliative care, this was done as a volunteer role. Study nurses voiced a need for palliative care teams in rural settings. The palliative care nurse participants practicing in rural settings expressed that they often know the clients, friends or family members of the clients. Knowing the client and family may enable a stronger relationship, a greater sense of loyalty and a stronger commitment to the provision of quality care to the dying person and to their family caregivers. According to this study, caregivers become preoccupied with time and are focused on trying to arrange and complete everything before this inevitable end date arrives. Caregivers expressed that they want nurses present but they do not want them to be intrusive and that the best nurses were the ones who called them and checked in and told them to contact them if they had any problems (Pesut et al., 2012).

Caregivers expressed they were not nurses and found it very difficult to try and learn the ‘cheat notes’ version of nursing in a matter of days. They further indicated that they regretted not having had more formal and proper education. The caregivers also voiced that having a primary family physician and a primary nurse would have improved their learning experience as they often felt they were taught differing approaches to care. Lastly, nurses voiced moral distress when outcomes were negative (dying in acute distress or pain) as nurses felt they were always going above and beyond what was professionally expected in order to support their rural clients/loved ones EOL needs at home. A limitation of this study was that the researchers completed a secondary analysis of pre-existing transcripts of data from other researchers. Since researchers were not part of collecting the data themselves from the very beginning, there may have been some limitations in picking up the finer nuances gained by the personal encounters. The researchers concluded that there is a need for future research to look more critically into the needs of rural EOL caregivers and nurses and start developing, implementing and evaluating uniform community policies and procedures (Pesut et al., 2012).

Taylor (2008) completed her Master's thesis for the University of Manitoba on the lived experience of rural female spousal caregivers looking after their husbands with cancer at EOL in the home setting. Taylor used a narrative research approach with semi-structured interviews and a sample size of five women. The themes that developed from the study were: Self-care, communication and support systems. The theme "self-care" represented how the woman's needs were put on the back burner while focusing on and providing care to their husband. Communication was found to be integral in every aspect of the experience, for example, if inadequate communication between the caregiver and physician occurred it would impact the whole experience. Support systems consisted of formal support (physicians, nurses, oncologists, home support) and informal support (friends, family and community members). In conclusion it was found that women would benefit from having social workers on palliative care teams to help improve service allocation, psychosocial support and advocacy for their needs.

Among the limitations of Taylor's (2008) study was that she used phone interviews rather than in- person interviews which limited the ability to catch non-verbal communication and develop rapport. According to the author, the small sample size did not reach the initial target number, and the restriction of the study to only persons with cancer were further limitations of this study. In discussing the need for future research it was concluded that there is a need to look at the full family impact of caring for a dying loved one at home and not only the female role. Further study into the experience of caregivers of loved ones with different disease processes other than cancer at EOL, different ethnic groups and different geographic settings is also needed. As well it would also be beneficial to study the experience of caregivers in non-heterosexual relationships (Taylor, 2008).

Robinson, Pesut and Bottorf (2012) completed a mixed method convergent parallel study using a questionnaire and semi-structured interviews to investigate how to support rural family caregivers providing palliative care. The sample consisted of 23 participants all of whom were female and from British Columbia. The researchers discussed briefly the reliability and validity of their questionnaire but did not provide Cronbach alphas. The study processes and coding approach were outlined only briefly. Thus, rigour could not be assessed. The four themes that they reported were: a sense of having to become the caregiver; having to become skilled in palliative care and learn more; providing care while answering to other regular roles and the need for extra help. Overall they found that nurses play a major role in supporting caregivers in the rural palliative care community. Limitations: The mixed methods used for this study combined a quantitative and qualitative approach making the study complex methodologically and potentially difficult to reproduce. According to the authors of this study, they felt that they had only skimmed the basics of what caregivers need for support in rural EOL care. They suggested that further research is required to understand more completely the role nurses can play in better aiding caregivers during this difficult process (Robinson et al., 2012).

Pesut et al. (2015) are currently working on a longitudinal mixed methods study utilizing community based research methods to trial a “rural palliative supportive service” (p. 3) intervention on members of two rural communities. The study results reported in this article provide an analysis of the first 17 months of the study. The sample to date consists of 23 patients, 48% of which are female and 52% are male; 10 caregivers, 40% of which are male and 60% are female. Participants in their sample ranged in age from 57-93 and were recruited from two rural communities with populations of approximately 10,000 and with no specialized palliative services. The intervention consisted of a nurse coordinator visiting patients and their caregivers every two weeks until the patient's death. The intervention also involved visiting caregivers within a few days after their loved ones death, then at the one and three month mark. The nurse coordinator's role involved completing health teaching on pain and symptom management, spiritual care, psychological care, advance planning and EOL planning with patients and their caregivers and then grief support for the caregivers after the loved one died (Pesut et al., 2015).

Pesut et al. (2015) utilized several valid measurement scales to collect their data such as: 'McGill quality of life questionnaire', 'palliative performance scale' and 'caregiver needs survey'. The authors point out that a limitation of their study is its longitudinal nature, at this time of reporting, the preliminary findings show that their sample size is too small to generalize any of its findings to the target population. The findings at this stage in the research suggest that visits by the nurse coordinator were welcomed by the rural communities and they have proven to be successful in helping patients and their caregivers cope with EOL needs at home as indicated by the positive QOL scale results (Pesut et al., (2015).

Quantitative Canadian Studies

Brazil, Howell, Bedard and Heidebrecht (2005) completed a study in Ontario looking at the preferred place of care and death of caregivers of palliative clients. They used a quantitative, longitudinal descriptive survey design. The sample size was 216 male and female bereaved caregivers (partners, children, extended family or friends) from rural and urban areas. The researchers created a six question survey, however they did not address reliability and validity of the survey (Brazil et al., 2005).

It was found that 77% of caregivers had a preferred place of death for their loved one and 88.3% wanted it to be at home. Sixty-eight percent of clients had a preferred place of death and that 93% wanted it to be at home. Rationales provided by caregivers who wanted their loved one to die at an institutional setting were the wish for their loved one to receive professional care around the clock in order to properly manage their EOL symptoms and needs. Caregivers who wanted an at home death valued the dignity, privacy and familiarity of the home setting at EOL. Interestingly this study found no difference in the number of community services needed in the home setting (3.8 mean) when compared to the services used in the institutional setting (3.9 mean). Only 12% of caregivers reported paying for additional services not covered under the publicly funded services when caring for a loved one at home. Fifty-six percent of the study population died in their home and although it is lower than the number of people who wanted to die at home, most caregivers reported in retrospect that they feel that their loved one died in the right place regardless of their original preference.

A study limitation in my opinion arises from the methodological challenges associated with attempting to derive interpretative meanings from quantitative data. This introduced the possibility of flawed interpretation of findings since the data collected was to enable quantitative analysis and were not in narrative format. Had the data been in narrative format, interpretation would have lent itself more readily to an auditable process. Although the researchers did not disclose the rate at which clients moved from home settings to institutions at EOL, in analyzing their data they concluded that there was a preference for death in an institutional setting because of the increased capacity to manage EOL issues. No additional information was provided by the authors in regards to what exactly the EOL issues were and this could be due in part to whether those issues were captured in the ED registration notes they collected data from. The researchers thus drew the conclusion that there is a need to implement approaches to improve environmental aspects of institutional settings to make them feel more like home settings. They conclude that the latter would be beneficial since although the majority of respondents (both caregivers and clients) expressed a preference for death at home, a significant proportion of clients died in institutional settings due to the perception that institutions provide more support for EOL needs (Brazil et al., 2005).

Lawson, Burge, McIntyre, Field and Maxwell (2008) completed a non-experimental design, retrospective study of palliative care clients who sought assessment in emergency departments (ED). The data was collected from a Nova Scotia ED database containing demographic and registration information. It was found that 75% of palliative patients enrolled in comprehensive palliative care programs at home did not visit the ED in the last six months of life and 25% who did visit the ED in the last six months of their life were not enrolled in palliative care programs. Sixteen percent of the palliative patients who visited the ED died within two days. The study did not provide a breakdown of patients from urban and rural settings but did indicate that 60% of the total number of females from rural settings chose to visit the ER and of these 57% were transported by ambulance. If the primary caregiver was a parent, friend, or other relative they were more likely to send the patient to the ED than when the primary caregiver was a spouse/partner suggesting that spouses or partners are more likely to care for their loved-ones until the end. More than half of the ED visits resulted in a hospital admission. Those who visited the ED were three times more likely to die in hospital compared to those who did not visit the

ED. Rural patients who visited the ED mainly visited in the evenings and weekends leading researchers to hypothesize that seeking help from emergency services might suggest a perceived lower availability of community based services at those times (Lawson et al., 2008).

A limitation of this study was that data were analysed from one large urban ED and this may have excluded a large number of palliative care clients who may have visited a local hospital near them instead. Another limitation is the use of pre-existing database files which are not able to disclose the concerns which led to decisions to seek help from institutional settings such as the ED at EOL. Researchers commented that there is a need for separate databases to delineate between individuals who died with a palliative diagnosis of cancer or another palliative care diagnosis such as a chronic disease process. The latter would allow for an improved analysis between palliative care clients accessing EDs with cancer versus another palliative care diagnosis. Researchers also suggested that studies are needed to look into ways to improve EOL symptom management in the home as often the reported reason given by caregivers for their visit to the ED was concerns about [an] uncontrolled symptom(s) and this lack of specificity in describing symptom(s) is a limitation to the study (Lawson et al., 2008).

Dumont, Jacobs, Turcotte, Turcotte, & Johnston (2015) completed a quantitative study to investigate the cost comparisons of palliative care services for the last six months of life between rural and urban dwellers. The authors used a longitudinal design and collected data through interviews conducted every two weeks until the patient’s death. Both the rural and urban sample participants came from various locations across Canada. The rural patient sample had 80 participants, 60% male and 40% female with a mean age of 67.9. The rural caregiver sample had 84 participants, 17.9 % male and 82.1% female with a mean age of 60.7. The urban patient sample had 125 participants, 47.2 % male and 52.8 % female with a mean age of 66.3. The urban caregiver sample had 127 participants, 35.4% male and 64.6% female with a mean age of 56.7 (Dumont et al., 2015).

These researchers utilized a non-parametric estimator to calculate various costs in their study and a bootstrapping method to obtain statistical confidence in their results. The authors also refer to various literature to support the reliability and validity of their methods used. The study found that it costs 16.4% more in Canadian dollars to provide palliative care services to rural dwellers (31,018) when compared to urban dwellers (26,652). The study found that while the patient/family costs associated with their palliative designation are similar between rural and urban dwellers, the rural dwellers had a higher cost burden due to transportation costs, prescription fees and other expenses. Limitations reported by the researchers include the use of descriptive and non-parametric estimator methods and the difference in the increased number of caregivers for urban dwellers compared to rural. Limitations also included how different provinces in Canada fund palliative care services and that urban and rural participant recruitment was completed by different individuals in their studies. The researchers suggest that future studies need to examine the different needs of rural and urban palliative care patients/caregivers and how that affects costs (Dumont et al., 2015).

International Systematic Reviews

Robinson et al. (2009) completed a systematic review of 79 quantitative and qualitative international studies on rural palliative care services in homes and institutions. The authors described their review process and discussed sample sizes, reliability/validity of measurement tools, rigour, credibility, limitations, gaps and areas for future research. Of the 79 studies, only 24 pertained to caregiver and patient perspectives and out of those 24 only 6 pertained to rural settings, were qualitative in nature and used sample sizes of 8-27. Out of the 79 studies, 28 of them looked at HCPs rural practice issues and found large traveling distances led to less time with clients and their loved ones. This led to limitations in properly educating caregivers and left HCPs feeling that they had left clients unprepared to manage psychosocial needs and EOL symptoms of palliative patients. The remaining 27 studies looked at rural health care services and found rural individuals seek palliative care mainly in hospitals, hospices and sometimes at home. It was pointed out that even though there is general acceptance that there is a lack of rural palliative care services and programs, only five studies looked specifically at implementation of new programs and evaluation of them (Robinson et al., 2009).

Out of the six studies on rural perspectives, none focused specifically on the perspective of what it means for rural caregivers to try to meet their loved one's requests to die at home in a rural setting. Instead these studies focused on the preferred place of death, pain management or negative EOL symptom management. Having reviewed the literature on caregiver's lived experience of caring for a loved one at EOL in a rural setting, the researchers identified that there is a only a very small amount of literature on how a rural setting- particularly remote area - influences the quality of the EOL experience of the client and their caregivers. In addition, there is a need for research able to elicit in detail the perspectives of rural clients and caregivers, the resources they call upon to persevere, and the issues that influence the decision to relocate or change settings for their EOL care in the last phases of their end stage disease process. More detailed examinations are needed into what it means to live out ones final days at home in a rural setting at EOL for clients, and what it means for caregivers to try to honour this request, while attempting to ensure that safe, quality care is offered to their loved one and that they as caregivers have adequate support (Robinson et al., 2009).

Funk et al. (2010) completed an international systematic review of qualitative literature from 1998-2008 on caregiving at EOL in the home setting. As part of this study they also reviewed 18 mixed method studies. In total, 105 articles were reviewed however; home settings were not differentiated into rural and urban. Of the articles reviewed, 46% were about current caregivers, 29% were about bereaved caregivers and the remaining 25% were a mix between the two types of caregivers. More than half of the studies were about caring for loved ones at EOL with cancer in the home setting. The authors described their review process and discussed sample sizes, rigour, credibility, limitations, gaps and areas for future research. It was found that caregivers voiced the need for more physical, emotional and educational support. It was also found that caregiving at home at EOL caused frustration, fear, anger, guilt, hopelessness, helplessness, sleep disturbances and stress; all of which often resulted in caregivers requiring mental health services following the death of their loved one (Funk et al., 2010).

Funk et al. (2010) also found that the negative outcomes from the caregiving experience often outweighed the positives leaving caregivers with the trauma of reliving distressful moments of loved ones suffering and feeling like they didn’t do enough to help their loved ones. The systemic review of literature included participants who had not passed the one year mark since the passing of their loved one. The study also found that often caregivers themselves rejected extra support when it was offered as they tended to choose not to focus on their needs during the process but instead to focus primarily on the needs of their loved ones. Depending on the category of caregiver, greater or lesser moral distress was experienced in relation to decision making. For example, spouses/partners felt more comfortable making decisions rather than caregivers who were friends. Lastly, it was found that when caregivers discussed the benefits of caring for their loved ones they also always brought up the negatives. However, they were left with a general feeling of accomplishment at the end of the process for having helped their loved ones move on and have also discovered a new found appreciation for the life and death journey.

Limitations for mixed method studies in this systemic review included small sample sizes and convenience sampling. Studies using both qualitative and mixed method approaches suffered from lack of clear terms for caregiver/palliative care and they failed to note the exact location of care (rural, urban, home or institution). These limitations made it difficult to assess the relevance of these findings to other target populations. The authors concluded that there is a need to explore the lived experience of caregivers in order for HCPs to be able to support them with improved interventions and services. More work needs to be completed in exploring the impact that geographic location has on the lived experience of caregivers providing EOL care at home. In addition there is a need for knowledge related to service accessibility from a qualitative stand point. Lastly this study suggests the need for more precision in documenting the process for determining who are the primary caregivers and secondary caregivers of loved ones at EOL in the home setting. The authors suggest that such information might reveal approaches which shed light on caregiver roles whether they are set in stone or whether are they more flexible in nature (Funk et al., 2010).

Stajduhar et al. (2010) completed an international systematic review of quantitative literature from 1998-2008 on caregiving at EOL in the home setting. In total, 123 articles were reviewed and were not differentiated into rural and urban home settings; instead all article findings were reviewed together. The authors described their review process and discussed sample sizes, reliability/validity of measurement tools, limitations, gaps and areas for future research. It was found that psychological distress was common in caregivers the first year after the loss of the loved one they cared for at home and resulted in problems with sleep disturbance, guilt and general post traumatic distress. Occupational and financial problems were very common among the caregivers who tried to manage looking after their loved ones at home while attending to their normal responsibilities at the same time. They also generally found that the caregiver had trouble providing the care that was needed for their loved one on their own and needed to rely on support from other services and individuals. Lastly, the researchers found that common terms such as “caregiver,” “palliative care” had different definitions across different studies. In responding to this issue, the authors created a definition list of common terms and they suggested that the terms be utilized going forward in this area of research for uniformity of terms (Stajduhar et al., 2010). This study is incorporating this advice and is using Stajduhar et al. (2010) definitions for terms that will be commonly used in this study. Definitions of commonly used terms are found in Appendix A.

Limitations of the studies reviewed by Stajduhar et al. (2010) included convenience sampling methods as well as small sample sizes making it difficult to generalize study’s findings to their target population. Another limitation was the lack of standard definitions for the researchers to refer to for ‘caregiver’, ‘palliative care’, ‘home care’; these issues made it difficult for researchers to compare results of one study to other studies and to assess the applicability of a particular study to one’s practice. When remarking on the need for future studies, researchers advised that future studies should utilize standard definitions for terms that arise. To help with the use of standard definitions, the researchers offer definitions that could be used. The authors felt that currently too many varying definitions are being used and it adds to confusion and difficulty with comparing research study outcomes in palliative care. The authors also suggested that future researchers also be more clear on the exact location of their study (rural, urban, home, institution or mixed) as many studies did not indicate a place or if it was a mix between home and institutional care settings. The researchers also felt there is a need for further theoretical and conceptual framework development to guide palliative care research in the home setting as this was lacking in most studies. They also suggested that further investigation is required into whether the approaches used by policy makers cohere with what patient and caregivers say about their needs. Lastly, more research is needed to assess more accurately the needs of caregivers in home settings when caring for their loved ones at EOL. This kind of research needs to be situated, and thereby to take into account how geographical location and access to services affects their experience (Stajduhar et al., 2010).

Summary of Gaps Identified in Literature Review

Several of the authors in this literature review call for future research on the lived experience of rural palliative caregivers, how individuals chose to become a caregiver, and on the education regarding EOL pain and symptom management provided to caregivers. This study fills a gap by providing rich description of the lived experience of rural caregivers, while addressing all three of the aforementioned areas for future research. No other study was found that addressed the lived experience of rural palliative caregivers, how they chose to be caregivers and their EOL education, which is the purpose of this study. In the next chapter I will outline the research methodologies utilized to answer the research questions.

Chapter Three: Research Methodology

This chapter outlines the research method being utilized to guide this research study on bereaved caregivers who provided care to their palliative loved ones at home in rural Ontario. Thematic analysis approaches will be discussed as well as the techniques used to support the rigour and validity of this study. The sampling methods used, setting for the study, participant recruitment and the interview process for collecting participant experiences will be explained in detail. In this chapter I also discuss the ethical considerations utilized in this research study with regards to consent and human participant involvement. Lastly, the risks and benefits of this study will be shared along with a discussion on the measures put in place to ensure participant confidentiality and anonymity.

Research Method

The purpose of this study is to access the depth of personal experiences as well as the internally interpreted meanings of the personal experience of caring for a loved one, at home, at EOL in a rural setting. As such I am interested in what motivates caregivers to provide EOL care to their loved ones, what sustains them in times of distress and challenge and I am interested in uncovering the meaning they place on providing this care to their loved ones. van Manen's hermeneutic phenomenology approach was chosen to guide this study since it is concerned with the life world or human experience as it is lived. According to van Manen (1990, 2016) phenomenology is the description of the lived experience and hermeneutics involves the interpretation of the lived experience from text or observation; together the description and interpretation of lived experience form hermeneutic phenomenology research. The focus of the research process is illuminating details and aspects within experience that may be taken for granted, with the purpose of creating meaning and achieving a sense of understanding (Wilson & Hutchinson, 1991).

Subscribing to the views of Heidegger about humans as concernful beings who are always concerned about their fate in the world, Laverty (2003) explains that hermeneutic phenomenology involves a:

> Co-construction of the data with the participant as they engage in a hermeneutic circle of understanding. The researcher and participant worked together to bring life to the experience being explored, through the use of imagination, the hermeneutic circle and attention to language and writing. (p. 30)

Similarly Koch (1995) shares that

> Hermeneutics invites participants into an ongoing conversation, but does not provide a set methodology. Understanding occurs through a fusion of horizons, which is a dialectic between the preunderstandings of the research process, the interpretive framework and the sources of information. (p. 835)

van Manen (1990) finds that hermeneutic phenomenology cannot be solely guided by a strict methodologic approach as that can lead to reducing the quality and meaning of the research conducted into something that is not as rich of a description of the lived experience. van Manen (1990) also discusses how the reflective writing that is hermeneutic phenomenology is in essence the method and in which “writing exercises the ability to see” (p. 129). By this phrase, van Manen invites an understanding that the process of hermeneutic phenomenology involves a process of writing that is complex, reflective and full of re-writing and that in the process of re-writing depth is achieved in understanding the lived experience and sharing with others. van Manen (1990) says

> to write phenomenologically is the untiring effort to author a sensitive grasp of being itself—of that which authors us, of that which makes it possible for us to be and speak as parents and teachers etc., in the first place. (p. 132)

Utilizing this approach, and at the outset of the study, I drew upon my own narrative as a rural caregiver for my palliative loved ones at home. The purpose of this practice is to enable a sensitive entry into the phenomenological region of interest (Haase & Johnston, 2012; Johnston, 2007), elicit dimensions of potential interest to be explored in depth and to provide a preliminary basis from which to open up conversations about differing and common experiences of caregiving among persons living in a rural setting. Reflecting on my own experience with the phenomenon being explored offered the opportunity to move into formulating questions reflective of the experience and to discover experiences that both resonated and differed sharply from my own experience.

Given that I came to this study with a personal lived experience as a rural caregiver, my experience was both an advantage and a challenge. Some phenomenologists such as Husserl felt that researchers needed to separate themselves by bracketing their pre-existing knowledge of the experience they were researching in order to avoid contaminating the findings, however, van Manen (1990) does not feel such 'bracketing' is needed or even truly possible. In contrast van Manen (1990) says "to be aware of the structure of one's own experience of a phenomenon may provide the researcher with clues for orientating oneself to the phenomenon and thus to all the other stages of phenomenological research" (p. 57). In this form of research authors tend to use "I" or "we" because as van Manen (1990) explains "one's own experiences are the possible experiences of others and also that the experiences of others are the possible experiences of oneself" (p. 58). Through the process of journaling in this study I remained aware of what surprised and puzzled me and what did not correspond with my own experience and expectations of what I thought participants would share. The latter approach sets up a methodological issue relating to rigour in that one can access one's experience but must at the same time ensure that one holds one's experience in abeyance. By maintaining this approach or stance, the unique experience of the participant comes through clearly and in a manner that is not unduly influenced by the researcher's own experience.

Moules, McCaffrey, Field and Laing (2015) in their guide to hermeneutic research write that often researchers do not start to ask the questions or look at an experience differently until after they have lived it. Moules et al. (2015) says

> Unless something like this happens to us - and we do not will it to happen – we often continue in our practices in unquestioning ways, assuming taken for granted discourses and ways of being around what we do in everyday practice. It is, however, the disruption of success in our everyday practices that allows a topic to emerge, in completely familiar, but also strange and disrupting ways. (p. 74)

As a nurse providing palliative care to rural dwellers, I had been aware of the difficult experience rural caregivers faced caring for their palliative loved ones at home but I did not deeply question the practices of professional caregivers. Nor did I have deep insight into the burdens born by caregivers and the conditions that sustain them on this journey. As Moules et al. (2015), suggest, it was only after I personally experienced caring for my loved ones myself, that I began to question many different aspects of the caregiving experience and my questions motivated me to undertake this research study.

Thematic Analysis, Rigour and Validity

van Manen's (1990, 2016) thematic analysis method was utilized to identify and develop the themes listed in the next chapter. According to van Manen (1990) thematic analysis is about trying to "unearth something 'telling,' something 'meaningful,' something 'thematic' in the various experiential accounts—we work at mining meaning from them" (p. 86). A theme is about the meaning of a point, it is a summary of sorts, and helps shine a light on the phenomenon the researcher is trying to gain further insight into. In relation to the experience being explored in a study, the theme helps get at the core of the experience and helps to describe it. Getting to the core is a glimpse into the mystery of the phenomenon as a whole (van Manen, 1990). van Manen (1990) expressively states that:

> Themes are the stars that make up the universes of meaning we live through. By the light of these themes we can navigate and explore such universes. Themes have phenomenological power when they allow us to proceed with phenomenological descriptions. (p. 90)

van Manen (1990) points out that no theme can ever capture the entirety of the whole lived experience and that although a theme's role is to shine a light onto a piece of the phenomenon being explored, the theme is not intended to account for its entirety. Themes can come from listening to audio recorded interviews, observations or reading text from transcribed participant transcripts (van Manen, 1990, 2016).

There are three approaches to isolating themes according to van Manen (1990, 2016) and often hermeneutic phenomenology researchers utilize a mixture of them. These approaches are 1) reading all of the text(s) as a whole and indicating the significant passages, 2) highlighting the phrases that are essential and affirming to the phenomenon being explored, 3) reading line for line of the text(s) and asking what the sentence(s) are saying about the phenomenon (van Manen, 1990, 2016). After the recorded interviews were transcribed, I conducted a thematic analysis of the participant transcripts to isolate themes and subthemes which constitute interpretations of meanings that participants gave to their experiences. I utilized a mixture of all three thematic analysis approaches by van Manen (1990, 2016). As a novice researcher inexperienced in the process of hermeneutical phenomenology I engaged in a process of “collaborative analysis” (van Manen, 1990, p. 100) with my thesis advisor whereby “hermeneutic conversations on the themes and thematic descriptions of a phenomena may also be conducted by a research group or seminar—these too are helpful in generating deeper insights and understandings” (p. 100).

Accordingly, and in order to gain experience with identifying themes, I coded each transcript and then drew passages with affinity for each other together under themes and subthemes. These coded transcripts and drafts of themes and subthemes were then shared with my thesis advisor and feedback was given. As I read each transcript, coded it and developed themes and subthemes and received feedback, patterns representing resonances in experience among participants started to emerge; these were simply noted until the final step. This final step involved reading across all eight transcripts and attending to the reverberations that echoed across them. This approach helped aid in the rigour and validity of the thematic findings that are presented in the next chapter.

van Manen (2016) makes it clear that other techniques related to rigour and validity techniques can include such procedures as member checking or triangulation which tends to be utilized in other forms of qualitative research methods (grounded theory, ethnography etc.). He makes the point, however, that such methods cannot be applied to validate a phenomenology research study. Instead van Manen (2016) advises the utilization of the following criteria when evaluating the validity of a phenomenology study:

> *Heuristic questioning*: Does the text induce a sense of contemplative wonder and questioning attentiveness?.... *Descriptive richness*: Does the text contain rich and recognizable experiential material? *Interpretative depth*: Does the text offer reflective insights that go beyond the taken-for-granted understandings of everyday life? *Distinctive rigor*: Does the text remain constantly guided by a self-critical question of distinct meaning of the phenomenon or event? *Strong and addressive meaning*: Does the text 'speak' to and address our sense of embodied being? *Experiential awakening*: Does the text awaken prereflective or primal experience through vocative and presentative language? *Inceptual epiphany*: Does the study offer us the possibility of deeper and original insight, and perhaps, an intuitive or inspirited grasp of the ethics and ethos of life commitments and practices? (p. 355-356)

The criteria described above for validity were kept in mind at all times when completing this research study. While as a novice researcher it is challenging to necessarily claim that I was able to awaken 'primal experience' or 'original insight', I do believe that the interpretive process utilized enabled an inspirited grasp of the moral principles, tenets and social practices that rural caregivers live out in caring for their loved ones. Lastly, van Manen (1990) shares the following test of validity for the themes uncovered in a phenomenology study:

> In determining the universal or essential quality of a theme our concern is to discover aspects of qualities that make a phenomenon what it is and without which the phenomenon could not be what it is. To this end the phenomenologist uses the method of

> free imaginative variation in order to verify whether a theme belongs to a phenomenon essentially (rather than incidentally) (p. 107)

van Manen (1990) also poses the following questions: “Is this phenomenon still the same if we imaginatively change or delete this theme from the phenomenon? Does the phenomenon without this theme lose its fundamental meaning?” (p. 107). I was guided by this test of validity particularly at the end of the study. This was a time for contemplating the narrative flow of the experience along with the intertwining and interpenetration of themes to each other. When contemplating the fit and flow of themes it became obvious that the parts were constituting the whole and that the emerging whole was determining how and where the various themes would fit. I felt that if we were to remove any of the themes it would leave a hole in the story and would not be a true reflection of the phenomenon being explored in this lived experience of rural caregivers.

Another criterion that has been used to establish rigour in qualitative research is auditability which is defined as “the researcher’s development of the research process in a qualitative study that allows a researcher or reader to follow the thinking or conclusions of the researcher” (Lobiondo-Wood & Haber, 2009, p. 549). An auditable process documents the decision trail related to the interpretation of meanings and how these meanings were organized under themes. This process was developed in consultation with my thesis supervisor as described above. This enabled the retrieval of each quote or excerpt used to develop each theme to be traced back to the original transcript and ensured a proper fit with narrative data (Koch, 1996). In this way the study design, process and thinking followed a systematic process and was documented throughout the course of the research to help aid in meeting the criteria of auditability (Lobiondo-Wood & Haber, 2009).

Sampling Methods, Recruitment of Participants and Setting

A purposive and snowball sampling method was used to select participants from the target population in order to ensure that the experience of participants fit with the lived phenomenon that was being explored. Purposive sampling is “a nonprobability sampling strategy in which the researcher selects subjects who are considered to be typical of the population” (Lobiondo-Wood & Haber, 2009, p. 560). Snowball sampling involves “subjects who meet the eligibility criteria are asked for assistance in getting in touch with others who meet the same criteria” (Lobiondo-Wood & Haber, 2009, p. 562-563). To be more precise, a sample was achieved through a recruitment method that involved selecting rural locations in the Eastern and Waterloo-Wellington Counties of Ontario, Canada. Once these communities were selected recruitment proceeded by posting and distributing study flyers (Appendix B). Study flyers were posted in cafes, shops, pharmacies, doctor offices and community boards. In addition to posting flyers, I completed two interviews with different local newspapers in the rural communities, whose journalists had noticed my flyers. The snowball sampling method came into play by also providing study flyers to colleagues in rural palliative care who could help me gain further access to the targeted population.

The concept of data saturation was used to determine when the sample size was adequate for this study. Data saturation is:

> A point when data collection can cease; data saturation occurs when the information being shared with the researcher becomes repetitive. Ideas conveyed by the participant have been shared before by other participants; inclusion of additional participants does not result in new ideas. (Lobiondo-Wood & Haber, 2009, p. 552)

When discussing samples, van Manen (2016) feels, however, that phenomenology researchers should view the adequacy of a sample in terms of the adequacy of gathering compelling ‘examples’ of the lived experience, rather than set numbers of participants. He takes this position because, according to his experience, phenomenology research findings aim to be compelling in what they teach us about lived experience rather than enabling generalization from a sample to a larger targeted population. Regardless of whether one takes the position that rigour is established by saturation of the data or by the compelling and richness of the narratives, it was noted with the execution of this study that there was strong resonance across transcripts in the descriptions of participants that led to themes. In addition, it is my contention that the nature of the quotes drawn upon to establish themes, speak clearly and convincingly for themselves.

Participants for this study were drawn from rural areas in Ontario, Canada. Rural was defined as an area outside of urban population centres that is composed of clusters of small towns and villages surrounded by agricultural lands, wilderness or undeveloped land (Statistics Canada, 2012). Participants in this study were chosen based on the following inclusion criteria: 18 years of age or older, primary caregiver of an EOL loved one who deceased at least one year ago and not longer than four years ago, loved ones who died in a rural Ontario home setting in a town or village of less than 16,000 people, and can communicate in English. Exclusion criteria involved not meeting any of the inclusion criteria and if the individual was experiencing any signs of psychological distress/complicated grief. This exclusion criterion was important as I wished to refrain from inflicting any further trauma on them. This study had 10 individuals volunteer to participate in the study however, two individuals did not meet the inclusion criteria as one individual cared for their loved one 10 years ago and the other was actively seeing a psychologist regarding the loss of their loved one(s). In total this study had eight participants from six different families from across the Eastern and Waterloo-Wellington Counties in Ontario, Canada and six interviews were completed. A fascinating phenomenon that developed was that two of the interviews completed were done as joint interviews as the caregivers felt they had experienced caring for their loved one together as a team and wanted to participate in the study as a team. Although the study aimed to recruit participants from towns or villages less than 16,000, the participants who volunteered for this study and who were included all came from rural communities with less than 1500 people. Participant age range was from 29 to 74. There were five female and three male participants and seven self-identified as Caucasian and one as Aboriginal. For more demographic information please see Appendix C.

Data Gathering

Richly layered descriptions of the experience of being a rural caregiver were invited by approaching participants to engage in a conversation with the researcher. The semi-structured research questions (Appendix D) were offered to be shared with the participants in advance of the interview as a way of helping participants to organize their thoughts in preparation for the conversation. All participants, however, declined the offer to be sent the questions and waited for the interview. The interview questions started with an open ended question about the lived experience as a whole and followed with probing questions to elicit more details about the experience as needed; this is consistent with van Manen’s (1990, 2016) interviewing techniques. All participants were given the choice of having the interview be conducted in their homes or a local café and all participants chose to conduct the interviews in their rural homes. As mentioned previously van Manen (1990) also noted that themes can be influenced by observations and for that reason field notes were kept during this study to collect thoughts preceding the interviews, thoughts about the setting and observations made during the interviews. All participants were given the choice of having the interviews audio recorded or not and all of the participants agreed to have the interviews audio recorded. Once all of the interviews were completed the participant interviews were transcribed by a professional transcription service in Toronto, Ontario.

Ethical Considerations

The ethical components of the study were guided by the Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada (Tri-Council) (2014) policy statement on the ethical use of human participants in research. As indicated by the Tri-Council (2014) all research involving human participants needs approval by independent research ethics boards (REB) of each institution prior to commencement of research. Approval to conduct this study was obtained from the York University REB for the period from July 24th 2015 to July 24th 2016 and was renewed until August 8th 2017; for certificate(s) see Appendix E. Participants were recruited in accordance with York University's REB process and protocols. Informed consent was received from all eight participants. At the time of the interview participants were provided with a demographic form (Appendix F) to complete, a copy of the interview questions and a list of local mental health resources (Appendix G).

Benefits and risks of study participation.

Benefits for study participants included an opportunity to share their stories, experiences, struggles and insights with a researcher who is specialized in rural hospice-palliative care and who has experienced a similar personal situation. Consistent with research by Dyregrov (2004) which engaged a narrative approach with bereaved persons and found positive outcomes accruing from the research approach itself, this study was described to participants as possibly offering the opportunity for participants to put certain challenges into perspective thereby enabling the discovery of new and positive meanings. Another possible benefit for study participants was described as arising from reviewing study results. Here it was explained that it is possible that they might come to understand that their own experiences are not strange or unique. In coming to this conclusion, it was explained that some relief might be experienced.

In addition to the benefits described above, it was suggested to participants that they might have the satisfaction of knowing that they are contributing to research intended to help HCPs better understand the experiences of caregivers in rural settings. With this knowledge, health care providers might be able to offer better care particularly to rural residents and their caregivers. As mentioned above, the expectations of positive benefit to participants' seemed realistic given the qualitative study by Dyregrov (2004) which used narrative analysis to explore bereaved caregivers experience engagement in research and found that 100% of participants felt positive outcomes following participation; none regretted participating.

As with any research into the lived experience around the loss of loved ones there is a risk that in reliving difficult experiences, distressing emotional reactions might occur. Although the prompts for the conversation (Appendix D) are ordered in such a way as to conclude the interview by inviting reflections on positive meanings and to solicit advice to health professionals and other caregivers which is not emotionally laden, it was noted that it could be possible that some clients might continue to experience distressing thoughts after the conversation had concluded. To mitigate this risk participants were provided with a list of local mental health resources (Appendix G) at the end of the interview along with an explanation on what they were for and how to use them. In an effort to ensure that none of the clients experienced ongoing distressing thoughts, the researcher contacted each participant within three days of the interview for a brief follow up conversation. The purpose of this conversation was to 1) Thank the individual for their participation in the study; 2) Assess how they were feeling and whether they were experiencing any persisting distressing thoughts as a result of the interview; 3) Refer them to a mental health provider as necessary; 4) Invite feedback on the interview itself. In the follow up conversations with the participants none of them were experiencing distressing thoughts and all of them were grateful for having taken part in the research study.

Another condition put in place to mitigate risk to participants pertained to the inclusion /exclusion criteria. These state that only participants whose loved one died more than one year ago would will be invited to participate in the study. The rationale for this is that research has shown that the rawness of the suffering associated with bereavement lessens significantly after one year (Funk et al., 2010). All participants were made aware of all benefits and risks of participating in the research study; they were informed that they could withdraw from the study at any time and they were further notified that all data collected pertaining to them and their experience would be destroyed should they decide to withdraw from the study at any point. All study participants were provided with a $30 gift card in recognition of their time and effort spent in participating in this study.

Confidentiality and anonymity.

The information generated by each participant was given an alpha-numerical code and documents were filed accordingly. Consent, demographic forms, audio and transcribed interviews were kept in locked document protectors which have only been accessible by the researcher and his thesis advisor. Documents containing personal identifying information of participants were kept in a separate locked document holder from the alpha-numerical coding list to preserve confidentiality and anonymity. Each participant was given a pseudonym to enable findings to be discussed anonymously in any resulting publications. All information supplied during the research study was held in confidence. In accordance with anonymity, the names of participants did not appear in this thesis and will not appear in any report or publication of the research. Participants were assured that all electronic documents and media (audio recordings) would be stored on password protected devices with the passwords known only by the researcher. The files themselves were encrypted. Data will be stored for 5 years and will then be destroyed in their entirety. In this way confidentiality and anonymity was provided for to the fullest extent possible by law.

This chapter outlined the guiding research methodology utilized in this study. In the next chapter I will present the study's findings by organizing them into themes and subthemes and drawing on extant literature in the discussion of the findings.

Chapter Four: Findings and Discussion

In the sections to follow, I share five themes and their subthemes that were discovered by dwelling with the transcripts of the interviews. All names of participants and their loved ones have been changed to ensure anonymity. By using fictitious names I will be introducing and tracing the voices of the participants and connecting them to the themes pertaining to dimensions of their lived experience.

As I visited my study's participants in their homes in rural communities across Ontario I felt a sense of tranquility as I left the chaotic metropolis highways behind me and drove across the worn two lane roads surrounded by the grazing livestock in the fields. An overwhelming sense of home filled me as I entered the communities and observed the local shops and the natural charm of the community members stopping to talk or smile at one another on the roads. I welcome you to come along with me on the journey into the findings of the lived experience of bereaved caregivers who cared for their loved ones receiving palliative care at home in rural Ontario.

In this chapter I present the following thematic findings for the study and discuss them in conjunction with supporting scholarly literature. The major themes (numbered) and subthemes (italicised) that will be presented are as follows:

1. Facing a Terminal Prognosis and Deciding to be a Caregiver
2. Being in it for the Long Haul
3. Drawing on Sustaining Reservoirs
    Family, Friends and Community
    Health Care Professionals
4. Haunting Concerns and Comforting Memories
    Distressing memories linger with the caregiver

Being at home allowed for comforting memories to be created

5. Reflecting on an Invaluable Journey:

Feeling Grateful

Offering Advice to Others

Theme One: Facing a Terminal Prognosis and Deciding to be a Caregiver

One cannot help but notice the different way of life as you enter the participants' intimate rural communities in Ontario. As you encounter the participants' rural communities you start to observe the unique charm of the people that Katie, one participant, describes as "close knit." Almost everybody knows one another on some level. This unique quality of rural life provides the context for a memory that Luke, another participant, shares about his wife now deceased: "She worked at the pharmacy for 21 years so the people knew her, she was known, and everybody knew her." As I entered each of the participant's homes I observed the treasures collected from a lifetime together, the unique set of furnishings that people had selected and the people that helped make the space their home. In my elaboration of this theme I will present common experiences described by participants as they reflected upon what it was like to receive the news of their loved-one's terminal diagnosis and the decision that followed shortly thereafter to care for them at home. I will then situate these findings where possible in a discussion of the extant literature.

Thematic analysis revealed that all of the participants, when faced with the terminal prognosis of their loved one, considered how to best spend the remaining time with their loved one. This in turn led to a description of how the participants decided to become a caregiver. In a surprising number of stories it became apparent that this decision occurred in the moment without much thought. Meredith, Katie, George, Megan, Luke, Anne, Diane and Edward reflect and share what it was like to receive the initial diagnosis and be met with a terminal prognosis for their loved one. The caregivers experienced an array of emotions (sadness, anger, numbness) and reactions (shock, confusion, denial) and relief from being able to move forward after months of not knowing what was ailing their loved ones. Katie explains:

> So eventually they sent him to the city and Dr. Roberts right off the bat says, like, clearly, let's do all this stuff… Mind you I am sure those three – I think it was three, four months that he was sick wouldn't have did anything. But it was the peace of mind knowing that, okay, now you have a diagnosis. Now we can continue.

As the gravity of the news sinks in, the relief of finally having a diagnosis gives way to the finality of the prognosis and the sense of having only a limited time left. George poignantly shares:

> As soon as I saw the diagram of the tumours, I knew this was like a train going to her destination and the only question was how long, how fast.

All of the participants in this study found that while receiving the terminal prognosis was a difficult experience, it allowed them to move forward with the process. This enabled choices and plans to be made. This experience of facing the implications of the diagnosis and having to make choices in their life is consistent with findings in the scholarly literature. A systematic review on honesty regarding a terminal prognosis with patients and their caregivers by Hancock et al. (2007) found that caregivers did not report having more anxiety from knowing the truth; they reported instead that it actually helped them to manage their expectations and make more meaningful decisions going forward with their loved one. The literature that I reviewed did not, however, provide evidence specifically on the extent to which caregivers were able to commit to the process of caregiving, *because* they know the time-frame is limited

As mentioned above, interviews with the participants in this study revealed a dimension of experience that was initially surprising to me; namely seven out of eight participants disclosed that it was when their loved one's terminal prognosis was communicated to them that the decision to become their loved one's caregiver was made in the moment. Despite my expectations and personal experience to the contrary, the decision of participants to care for their loved one at home appeared to be taken without much forethought and without a careful assessment of the services or support that would be available to them. Megan shines a light onto what it felt like for her and her family to decide, in the moment, to care for their mother at home:

> Like we didn't even think oh, well, we're going to need this support, that support…All three of us were like no, this is what we're doing and we didn't care… So then it just became-- I don't even know if it was like conscious, the decision it was just a given that we were going to take care of her.

When discussing with Katie how she came to decide to be a primary caregiver for her grandfather, she shares that she did not complete any prior information gathering and mentions how in the moment she felt simply that "there was no other way."

Dwelling with experiences recounted by Meredith, George, Anne, Megan, Diane and Katie about what it was like to decide to provide EOL care for their loved one at home reveals that knowing what to decide 'in the moment' does not appear, however, to arise out of nowhere. Rather, while some caregivers describe responding to the explicit requests of a loved one, other caregivers revealed that their decision arose in the tacit knowing that becomes possible in the context of intimate, loving, steadfast relationships. Diane speaks about her decision to make a commitment to honour her brother's wish to stay at home until the end:

> He [Diane's brother] was absolutely adamant that he was going to stay at home…We made a 'commitment' to him and we said to him 'We'll do the best we can to see you through.' None of us had any firsthand experience.

George speaks to his wife explicitly sharing with him what she wanted: “My wife was very clear that she would rather be at home” while Luke discusses how his loving relationship and obligation to his wife significantly impacted his decision to care for her:

> Basically its stuff you have to do, that’s how I took it. I – she was the love of my life for 40 years and I wasn’t ready to give her up without a battle, So, I took it upon myself to do it.

Eaves (2006) completed a study into the experience of rural African American caregivers for their loved ones who had suffered a stroke and found that deciding to care came out of an obligation for their loved one and being able to give back. In this study, the caregiver’s deciding factors can be seen to be influenced by the wishes of their loved ones and relational obligations and are thus similar to what was found in Eaves (2006) study.

In elaborating on deciding to be a caregiver most of the participants in this study shared that having their loved one at home eased the logistical difficulties that can arise from living in a rural community. They described the complications that they would have otherwise faced if their loved one had been hospitalized. Caring for their loved ones at home allowed them to conserve precious time for the most important things such as being with their loved one more. In discussion with Megan on choosing to be a caregiver at home rather than having her mother at an institution she shares:

> It wouldn’t have been the same because it was like a whole commitment of time here [at home] and it was comfortable and we all live close by…you’d still have to like rush home to do all your stuff at home and go to [the hospital] like she [loved one] would have spent a lot of time alone is my feeling.

Deciding to be a caregiver at home added a level of convenience to the caregivers’ already hectic schedule as George shares:

> You know from the selfish perspective you could say- well, it meant I wouldn’t need to travel somewhere to see her. It was all happening right here… I didn’t need to travel so that was great.

In reflecting on the considerations surrounding their decision to care for their loved one at home Megan, Edward, Anne, Meredith, Luke, Katie and Diane relate the feelings they had about the care they saw being offered in institutional settings at the time. Edward and Megan (father-daughter team) felt they could do much better in the sense that they could ‘read’ their spouse/mother more accurately, be more attentive to her, reduce her anxiety and thereby meet her needs more adequately. They shared a belief that caring for their spouse/mother at home had the capacity to extend their spouse/mother’s life while maintaining a higher quality of life (QOL). Megan outlines how her perceptions of the value of being able to care for her mother at home turned out to be true. She said her mother “would have died a lot sooner if she had to be in like hospice or hospital. She wouldn’t have made it…. It was her anxiety and stuff… [the difference was being] able to just relax being home.”

A research study by Hamano et al. (2016) examined whether there was a difference in survival times of cancer patients dying at home as compared to dying in hospital. The researchers found that there was a significant increase in survival time of patients receiving care at home compared to those in hospital and that this difference ranged from 13-36 days (Hamano et al., 2016). According to this study caregivers greatly aided in helping their loved one to achieve an overall better QOL in their home as it was felt that the environment allowed for comfort and familiar people. The combination of these factors was associated with a longer life span. A study by McWhinney, Bass, and Orr (1995) found that individuals who wished to die at home were more likely to achieve this outcome if they had support from an informal caregiver such as family or friends. These research studies resonate with the beliefs of the majority of my study’s participants who felt, in deciding to care for their loved ones at home that their loved one would receive better care, be more comfortable and live longer.

In this experience related to this theme we are introduced to what it was like for the participants to be suddenly faced with a terminal prognosis for their loved one. The time that follows the initial grave news appears to elicit a decision ‘in the moment’ which is that they will take their loved ones home for the rest of the time remaining. They suddenly decide to be a caregiver without thinking about how they will make it possible and choose to figure that out afterwards. It also becomes apparent that although they decide in the moment, the caregivers decision is informed by their loved ones wishes, obligations as a relative/friend, or with consideration for their already busy lives. It is also apparent that they believe that they will be able to provide their loved one with a longer and richer QOL by caring for them at home and until they die.

As we move onto the next theme it becomes apparent that upon deciding to become a caregiver in the moment participants thought about how difficult and exhausting the journey would be at times. In theme two we will discuss the “long haul” that rural caregivers face when caring for their loved ones at home at EOL, while providing a longer and richer QOL until they die.

Theme Two: Being in it for the Long Haul

As I visited participants in their rural communities I reflected on my own experiences growing up in a rural community and the evidence of the hard-working ethic that is prominent. Living in rural farming communities instills a particular appreciation for what you have because you know first-hand how hard you and others have worked over the long haul to maintain a livelihood and to do so with limited access to resources. I thought about those participants who were in the farming industry for their livelihood and I thought about my own neighbours who farmed. Consequently I was very aware of the early mornings, late nights and difficulties faced in order to yield the best profit from the land in order to be sustained economically. As I engaged with the transcripts recording conversations with participants I was mindful of the participants who had to travel a few hours to urban centres everyday just in order to have a job so that they could support themselves and their family.

After reading across the participant transcripts this theme unfolded between the lines of what the participants were sharing with me and what was left unsaid. When asked during the early part of the interview about their experience of caring for their loved one, stories of exhaustion, fear, and anxiety emerged strongly, however, by the end of the interview every participant described the overall experience of caring for their loved one in extremely positive terms. When invited to discuss forms of informal assistance or formal services that could have lightened their load, six of the eight participants offered no comment. Instead most expressed their appreciation for the support they had received.

Initially these end-of-interview declarations of the caregiving experience in such positive terms and as experiences that would be gladly repeated if necessary seemed at odds with earlier moments during the interview about their caregiving experiences, which disclosed the long and difficult roads and the hardships that came with being a rural caregiver. What was I to make of these apparent contradictions? Could this apparent contradiction be explained as an unintended interviewing artifact such as response bias (not gathering an honest or correct answer)? Might the discrepancies between descriptions of lived experiences and the overall enduring meanings ascribed to the overall experience, only be explained by dwelling with subsequent themes and particularly those that pertained to the resources and relationships that sustained rural caregivers over the long haul? Returning to the process of hermeneutical, phenomenological interpretation I was reminded of the importance of relating the parts to the whole and the whole to the parts and as van Manen (1990) says "writing exercises the ability to see" (p. 129). At this point in the interpretive process I chose to concentrate on what participants told me about the constant demands placed on their limited time, the anxious questioning of whether you are doing the right things and the general overwhelming sense of exhaustion. In the discussion of this theme I will discuss these findings in relation to relevant scholarly literature.

After deciding to become a caregiver and starting to grasp what that would entail, all of the caregivers described the process of realizing that they were now in this situation for the long haul and until their loved one died. All of the participants discussed how they were given approximate timeframes for when their loved one would die by doctors but they understood that nothing was for certain. As I read across the transcripts, I noted that each participant described making the commitment to care, no matter how tough it got and for the long haul. Meredith shares what it was like knowing she was now in this situation until the end and how it felt to be the caregiver of her father day in and, day out:

> We just knew we were in for the long haul, to the end, and that was it basically, we were… it was always on – always, always, always – like always, always, always, always go go go… many days in a row without sleep – it wasn't easy at all.

Stajduhar (2013) in her review of the literature on family caregiving burden at EOL also found that often caregivers suffered from high levels of fatigue and sleep deprivation secondary to the non-stop, around the clock care they were responsible for.

In this study I found that the majority of the participants were left in this 'on mode' state when being the primary caregiver for their loved one. The participants were always thinking about the care they were providing, the tasks ahead of them, the responsibilities they carried and whether they were helping their loved ones in the best way possible. Anne shares with us the thoughts that were constantly playing out in her mind:

> You know you have a lot of wondering going on, what's next, and I wonder if we're doing the right thing, and it was just - constant – it was like a wheel all the time turning.

Anne's words enable us to gain a sense of the inner turmoil she faced with her constant preoccupations about getting everything right for her loved one. A qualitative study by Totman, Pistrang, Smith, Hennessey and Martin (2015) investigated the lived experience of caregivers caring for their palliative family members with cancer in an urban setting and found likewise that caregivers were "constantly on the alert" (p. 500) and that it was because the caregivers felt "'you only have one chance to get it right" (p. 500). The findings from the latter researchers regarding urban caregivers are consistent with how the participants in this study, rural caregivers, felt with regard to trying to manage everything optimally so their loved one had the best possible experience.

Although the experience of being a rural caregiver was difficult at times and their minds were filled with an array of worries and troubling thoughts, it was also apparent that once they committed to being their loved ones caregiver there was no turning back, no matter how difficult the journey became. Katie shares with us how as her grandfather started to decline, what people in her support networks said to her and how she felt about continuing to be her grandfather's caregiver:

> I remember when it started to get – he [Grandfather] started to decrease then it was little more – like, Jamie [partner] kept saying, are you sure you are good to go? I said, well, I can't just stop now, halfway through. Like it's stupid, I have to continue and – I mean there was no other way.

Similarly Stajduhar (2013) found that caregivers often face a lot of anxiety and ambivalence about feeling obligated to continue caring for their loved ones even as it grows more and more difficult. In this study as each of the participants loved ones started to functionally decline and enter the EOL phase, the process of caregiving became increasingly taxing due to the emotional, physical and spiritual demands placed on all of the participants. Diane, George, Megan, Edward, Katie, Luke, Meredith and Anne took time off from work to focus all of their time and energy on caring for their loved ones at home. Megan opens our eyes to how she was feeling being the caregiver for her mother at EOL and how exhausting the experience was at the end:

> It was very trying at the end. Like we were all going around the clock… like I'm not – I mean like running, okay pretty much. If it wasn't changing her or doing laundry or making meals or…awake through the night…It was all hands on at the end. I actually could not believe how exhausting it was… I'd be sweating sometimes like just running around like a chicken with my head cut off.

It should be mentioned at this point that while that the experience of caregiver burden at EOL in rural settings may disclose some unique challenges because of the settings themselves, there are, according to the literature, experiences that are common to caregivers irrespective of whether they live in rural or urban settings. For example, a study by Guerriere et al. (2016) analysed the variables that lead to increased caregiver burden among caregivers providing palliative care at home in urban settings. The authors found that as the caregivers loved ones functionally declined and transitioned into the EOL phase, the burden for caregivers was substantially increased. Another interesting finding of these researchers was that the caregivers who took time off from work and devoted all of their time caring for their loved ones faced much higher levels of caregiver burden than those who did not (Guerriere et al., 2016).

Canadian researchers have also found that a widely varying range of roles and expectations are placed on caregivers looking after their loved ones dying at home and that these roles and expectations take a heavy toll on the caregivers wellbeing (Clemmer, Ward-Griffin & Forbes, 2008). In my study all of the participants took time off from work to care for the loved ones and all described carrying heavy burdens in relation to providing care such as was found in the scholarly literature on caregiver burden cited above. In this study I found that rural caregivers face an exhausting number of roles and responsibilities while trying to juggle caring for their loved ones needs at EOL in the home setting. Although this study did not set out to explore the aftermath or consequences rural caregivers face after their loved one dies secondary to the difficult and exhausting work involved in caring for their loved one, this study raises further questions for subsequent study that will be discussed in Chapter Five.

While seven of eight participants in this study were able to carry the heavy burden of care required of enabling their loved one to die at home, one participant shared his story of when it became too much to continue to carry the burden any further. Luke shared with me the story of the crisis that led to the decision to move his wife to hospice for the final EOL phase:

> I heard grrrrrr so I ran back, she [spouse] had fallen over her walker backwards, her head was on the floor, her eyes were open and rolled backwards and she was choking, choking, choking real bad. So, I panic, I grabbed her and sat her up and the walker slid and I laid her down and again she's gagging. So I'm looking at the phone, I'm looking at the window and what do I do here? I need to call Sherry [nurse] and what do I do here?

In that moment of terror for Luke, he received a call from his wife's visiting palliative care nurse. Luke explained what happened and the nurse asked if they were ready for hospice. It was in that moment that he said yes; up until that time he kept deferring that decision. A qualitative study completed by Waldrop and Meeker (2011) which investigated the events which made it unfeasible to continue to provide care at home in urban settings likewise found that events which generate fear, panic and powerlessness are among the characteristics of crises that influence the decision to move a loved one from the home to a hospice setting. In this study Luke shares that not only was moving his wife to hospice for EOL the best decision for his wife, but it was also the best place for him since he felt that hospice “is a place that they looked after her and they looked after me.”

As I bring the discussion of this theme to a close and as I anticipate introducing the next theme, several reflections and questions come to mind. Is it possible that the particular way of life in a remote community (i.e. a total population 1500 or less) predisposes individuals and families to expect hardship, make do with less, rely on themselves and yet at the same time welcome a ‘helping hand’? Does this unique balance of self-reliance and interdependence translate into a kind of empowered commitment and fortitude that enables caring for one’s loved one at home and ‘for the long haul’? While the findings pertaining to this theme do not enable me to answer these questions conclusively, nor do they account for why and how participants in the same interview describe being at their outer limit in terms of exhaustion and worry yet still insist that they would be able to do it over again and wouldn’t change anything, dwelling with the stories does afford an important glimpse into the burdens born by participants when they commit to caring for the long-haul. Shedding light on what sustains or otherwise jeopardizes the ability to care ‘for the long haul,’ I next introduce the theme: Drawing on sustaining reservoirs.

Theme Three: Drawing on Sustaining Reservoirs

In a comparison of the needs at EOL of rural dwellers versus persons who live in urban settings Kirby et al. (2016) discusses the disadvantages that rural dwellers face and the major gaps in available infrastructure, health care services and municipality services that ultimately make for a harder way of life. These are findings which resonate strongly with me as a person who has lived in a rural setting, cared for loved ones at the EOL, and practiced as a visiting palliative nurse. As a rural dweller you cannot simply walk a couple minutes to the grocery store, bank or movie theatre and a vehicle is required to go everywhere. The rural communities depend on towns that stock the bare minimum of staples such as basic groceries. A few have snack bars or restaurants and gas stations but it is usually the case that you have to drive to the nearest city for needs such as clothing or health care services. Being a member of a rural community calls forth the willingness to help your family, friends and community members when they need it because you may one day be in need of their help. As has been suggested in the previous section, it may be that this rural outlook based on the necessity of interdependence, as well as practices that build self-reliance provide guidance and support for getting through the hardships encountered in rural life.

One instance in which self-reliance cultivated in the context of an interdependent community is commonly seen is in situations where, for example, a community gathers after a fire to help rebuild the barn that has provided for the livelihood of a neighbour. The resilience of the neighbour in rebuilding in the face of such loss cannot be separated from the support that they receive. As I dwelt with the stories of participants and considered their unwavering adherence to their promises to care for their loved one for the long haul and when I considered this within the context of reduced access to formal services, and interdependent community practices, I began to notice that rural dwellers do have resources at their disposal. With this theme I explore the nature of these resources and how they are built.

In considering the resources that participants drew on, the concept of social capital came to mind. Researchers Frank, Davis, and Elgar (2014), who have studied how social capital in rural settings is amassed and expended define social capital as:

> The value accrued from belonging to groups, whether they are families, friendship networks, faith, work, or recreational groups. Not only do these groups contribute to a

> sense of identity, safety, trust, and belonging, they also help create norms of reciprocity and bonds of support that can be called upon in times of need. (p. 424)

In their study on the aftermath of an economic recession and its effects on the wellbeing of inhabitants from two rural towns in Ontario, Frank et al (2014) found that rural dwellers had been able to acquire a high level of social capital in their communities. This left them with a positive perception of having support that in turn reduced their overall stress level and depression during financially hard times. Nearly all of the participants in my study also spoke about their supports in ways that suggested they had extensive social capital through their support networks that were composed of family, friends, community members and HCPs. Reflecting on the stories they told about getting through this extremely difficult time, led me to my next question; a question to which a tentative answer is suggested by this study. Could it be that their social capital gathered over the years helped sustain them through the long and difficult haul that was discussed in theme two? Do HCPs constitute part of the social capital that is mobilized by caregivers as they care at home? In the passages that follow I will explore the social reservoirs that participants drew upon and then I will consider the question as to whether HCPs, because of their membership in the rural community, constitute part of the social capital that participants draw upon.

Family, friends and community.

Edward, Meredith, Katie, Megan, Luke, Diane, George and Anne spoke to the immense support that they received from immediate and distant family members. Family support for all of the participants came from sources such as brothers and sisters, in-laws, aunts, uncles, cousins, children and grandchildren. Support came in the form of home cooked meals, cleaning, running errands and visits to help lift their spirits. When invited to describe the resources they drew upon to be able to continue caring for their loved ones through the long haul, all participants first described family as their primary support. Megan shares the following: “The family, we could have asked them to do anything and they would have done whatever they had to do.” When invited to elaborate further they described the supports that were provided by friends, community members and HCPs.

Researchers Herz, McKinnon and Butow (2006) completed a qualitative study with caregivers who were looking after family members with a debilitating neurological disease process. They found that love for the family members was “a sustaining force for the carer” (p. 213). Similarly in my study it was evident that the participants’ love for and their connection with their loved one who was dying played a role in sustaining the rural caregivers through the difficult time. For example Luke said “basically it's stuff you have to do, that's how I took it…she was the love of my life.” Epiphaniou, Hamilton, Bridger, Robinson and Rob’s (2012) conducted a qualitative study about coping and support strategies for caregivers caring for their loved ones dying at home in an urban setting. Similar to the findings of my study, these researchers found that family members were most often identified by the caregivers as great sources of support when managing the care of their loved one dying at home.

In my search for literature that resonated or contrasted with the findings of this current study, I found very little literature with findings that pertained specifically to sources of support in rural settings. I did find some studies which focused on the lived experience of caregivers caring for their loved ones dying in urban settings. In these studies, caregivers were reported as often feeling very isolated (Kirby et al., 2016; Stajduhar, 2013; Totman et al., 2015). The findings of these researchers based in urban settings contrasted sharply with the predominate findings of my study which disclosed that caregivers often felt overwhelmed by the outpouring of help from their family and rural support networks.

In all but one conversation in which the participant described a deliberate decision to honour the wishes of his wife to maintain her privacy, participants described drawing on the reservoirs of family, friends and neighbours and not having a lot of time to themselves. Anne says "the whole family, oh yes we had them coming in at both doors." All of the participants in this study discussed how important it was to have support from their family, friends and their loved one's friends and none of them described having to provide care alone. They felt that if they had not had the support from their circle of friends that it may have resulted in them not being able to care for their loved ones at home as well as they did. Edward shines a light on this conclusion:

> I was so fortunate to have the help I had here… I think it would have really torn me down if I had have done all this myself, you know. I had to have the support from everyone that supported us, my girls, my friends, my – her [wife's] friends. You need that.

Researchers Kirby et al. (2016) and Epiphaniou et al. (2012) also found that friends of the family were quite often involved in supporting the caregivers with EOL care and were an overall tremendous asset.

Almost all of the participants in this study spoke about how they and their loved ones were a part of their rural communities for more than 20 years and that most of them were born and raised there. You cannot help but feel the connectedness among the participants and their rural community members a feature that Katie describes as "close knit." Nearly all of the participants loved ones were active members in their rural communities. Edward shares about his wife that "she worked in the community all her life." The only exception to this common experience was one described by one participant who shared that he and his loved one had moved to their rural community more than 25 years ago. In comparing his story to the story related by others it was apparent that he drew heavily upon family instead of neighbours and community members. Many of the participants related stories about how their loved ones had a history of always helping others in their rural communities and that the community came through for them in the end. Luke shares the support he received from his neighbours and co-workers when he was caring for his wife at home:

> Neighbours, they kept, even today they still put food in my mailbox… We were in the city [for appointments] I'd come home at nine o'clock at night and I'd have a cooler at the door from one of the guy's wives at work… the guys I work with all rallied and pitched in and gave me some gas money. They pitched in $100 and gave me a $100 gas card, which I was blown away by.

Researchers Kirby et al. (2016) found that members of rural communities who accessed the local community supports such as neighbours were able to successfully navigate the difficult journey. They found, similar to this study, that while participants were geographically isolated they were not isolated from the help of others. While family members, friends, co-workers and neighbours were described as providing support that sustained rural caregivers, the support of HCPs was also described as being essential in helping caregivers manage their loved ones care at home.

Health care professionals.

In this study it became increasingly evident how important having experienced palliative care health care professionals (HCPs) involved in the care was in helping sustain the rural caregivers through the long haul. Some participants had supportive HCPs involved from the start of their loved one's palliative care journey. These HCPs were described as members of the community and were described by participants in ways that suggested these caregivers had a deep sense of connection and accountability to the persons they cared for along with their caregivers. Two participants however, described care that was suboptimal in the beginning, which required the necessity to lobby vigorously to find a physician skilled in palliative care. This suggests that the desire to care compassionately by HCPs must be accompanied by the requisite skill – a requirement that cannot be taken for granted in rural settings. In this study once the participants had supportive and compassionate HCPs specialized in palliative care, they described the HCPs as being a source of knowledge, reassurance, compassion and security. Meredith shares with us the difference it made to have a skilled physician involved in her father's care and the impact it had on her and her family:

> Dad was very lucky with the doctor at the end… she took over and ran the show like it – as if it was her own dad. She cared for my father so incredibly well, you know, at one particularly bad day she came to the house three times…the doctor will be a memory forever, she came in here to look after us and him.

Funk, Allan and Stajduhar (2009) completed a qualitative study with caregivers who were presently caring for their palliative loved ones at home in an urban setting in western Canada. They found that caregivers gained a greater sense of support and security in the home setting when having their loved ones cared for by competent palliative care trained nurses and doctors.

Nearly all of the participants discussed how knowledgeable, compassionate and skilled the palliative care visiting nurses were. George discussed how he had a strong sense of security knowing that the nurses were always a phone call away and that he could always count on them to respond:

> Sandra [nurse] had told us to call her anytime and so that gave me a comfort level that I could get either her or one of the substitute nurses within an hour or two hours… it's very comforting to take someone like me to know that it's like calling in an airstrike. It's going to happen – maybe not within 5 minutes but they're on the way.

George was not alone in feeling that way as Edward, Megan, Anne, Meredith, Katie, and Luke also shared stories of feeling well supported and knowing that they could count on the nurses for help at any time.

The participants voiced that they were able to depend on the nurses for help and highly praised them for going above the call of duty in order to help meet the needs of their clients and their families. Luke shares the following with us that highlights how special his wife's primary nurse was to him:

> Whatever this woman [nurse] did, you know, she was an angel, she is still an angel. To go beyond and give us her personal [Cell No.] and she told me, she said, "Listen, I don't give this out, use it if it's an emergency." I never called her but I had that number.

Many of the participants in this study had nurses who shared their personal cell phone numbers and while most of the participants rarely called the nurses, knowing they had that number to call in a crisis was experienced as security. In this theme we are introduced to HCPs who live in the same rural communities as the study's participants and the majority of them went beyond their basic contract requirements in order to help sustain the caregivers at home. Lauder, Reel, Farmer, and Griggs (2006) analysed literature on rural nursing and the concept of social capital to gain a better understanding of the applicability of the concept to nursing. The researchers found that rural nurses who lived and practiced in the same communities as their clients are able to create more trusting relationships with clients because of the mutual understanding of their communities. In this sense the role of the nurse as a member of the clients' community was seen as adding to the social capital of the rural dwellers (Lauder et al. (2006).

Jack, O'Brien, Scrutton, Baldry and Groves (2014) completed a qualitative study in an urban setting in England on the experience of caregivers who cared for their loved ones at home who received help from hospice-palliative care trained staff. As with this current study, the researchers found that caregivers gained reassurance knowing the palliative care nurses were coming in to visit their loved ones and they felt well supported by the care the nurses provided. Also similar to what was found in this study, Pesut et al. (2012) found that caregivers expressed that they wanted nurses present but they do not want them to be intrusive and that the best nurses were the ones who called them and checked in and told them to contact them if they had any problems. The following question comes to mind and cannot be answered by this study. Is the capacity to care for a loved one at home sustained by the willingness of HCPs to go above and beyond the call of duty in providing a sense of security to caregivers? This question evoked further questions about rural versus urban HCPs and will be discussed in Chapter Five.

It was difficult to reconcile the extremely favourable comments of participants regarding HCPs especially considering how limited the health services are in rural settings (Kirby et al., 2016) and considering that the experiences of the participants were starkly different from my own. Were the participants who volunteered for this study a special group of individuals who had only positive experiences? Had the passage of time (up to four years following the death of the loved one) dulled their memory of the difficult times and predisposed them to remember only the positive aspects of their experience? Unfortunately there are no conclusive answers to these questions but rather, opportunities to reflect upon the limitations of this study – a topic I shall return to later in Chapter Five.

This study does however, clarify the difference that good medical and nursing care can make in enabling caregivers to feel that they have a reservoir of strength, compassion and skill to draw upon. Although minimal research is available on the interventions provided from HCPs skilled in palliative care that make a difference in the rural caregiving experience, I was able to find a randomized control trial by Hudson et al. (2015). The researchers investigated the effects of palliative HCPs providing psychoeducation interventions (empowering information to improve wellbeing) through phone calls or visits to caregivers in urban home settings in Australia. Their study found that caregivers who received the psychoeducation intervention from palliative HCPs had significantly less distress eight weeks following the death of their loved one compared to the control group. Although the latter study is on urban caregiving it is reflective of the stories being shared in this study about their palliative HCPs and how the knowledge shared by them helped sustain rural caregivers. While my study did not seek to study the influence of the skill level and availability of HCPs on the caregiver's stress level and ability to care for their loved one until the end, the study raises important questions that I shall discuss later in Chapter Five.

Researcher's Stephen et al. (2014) completed a qualitative study utilizing a secondary analysis of interview data collected on the use of 'CancerChatCanada' with cancer survivors, patients and caregiver participants. The online support forums are facilitated by counsellors with a psycho-oncology background with graduate level preparation and specialized in text base group facilitation. Through the online forum the participants were able to discuss and share their cancer experience(s) with a counsellor present. The study found that participants felt safe to participate online from the comfort of their homes, the space provided them with a way to release their feelings and they found meaning from participating in the support group (Stephen et al., 2014). I am left wondering about the possible positive impact that could come from having an intervention such as the one discussed above for rural palliative caregivers. I suspect that having access to palliative care counsellors/nurses with graduate level preparation in an online support group could significantly support rural caregivers caring for their palliative loved ones at home by helping connect them with other individuals facing the hardship they are.

As I return to consider the relationship of theme two to theme three, I note that theme two helped organize the stories from participants that described the rural palliative caregiver experience as something that is extremely difficult and exhausting; a very long haul. At the end of the discussion of theme two we were left with unanswered questions about what helps rural caregivers make it through such a difficult experience of caring for their loved ones dying at home. In this present theme we became aware of the tremendous sustaining reservoirs that aided in making the experience a positive one for the caregivers regardless of the difficulties they faced along the journey described in Theme Two. The reservoirs were seen as comprised of the sustaining relationships with family, friends and community members who were available to help in multiple ways. It was also found that qualified HCPs specialized in palliative care were integral in helping support rural caregivers during this difficult experience and were at times a source of knowledge and comfort for them. The sustaining reservoirs found in this theme appear to act as the source that nourishes the palliative rural caregiving experience through extremely difficult times. As the discussion of this theme comes to a close we are left questioning what effects the experience of caring for dying loved ones at home can have on rural caregivers. Up until now the experience has been described as an extremely difficult and long haul that requires a tremendous amount of support to sustain the caregivers through it. What toll does the latter experience then have on rural caregiver’s wellbeing following the death of their loved one? In the next theme we will explore the aftermath of caring for their loved ones at home as described by bereaved rural caregivers.

Theme Four: Haunting Concerns and Comforting Memories

Rural life can be filled with both positive and negative memories because of the geographical isolation and often having to make do with the lack of available services and resources. On the other hand, the untainted lands, thoughtful acts of kindness from neighbours, refreshing nature walks, abundance of wildlife and drives on warm summer evenings with starry skies above and the peaceful hum of crickets chirping can fill one with wonder and a strong sense of comfort. As I engaged with the stories of my participants understanding the difficulty of being ‘in it for the long haul,’ and noting the stamina they maintained by drawing deeply from reservoirs of sustaining relationships as well as the skill and generosity of HCPs, I wondered about the price paid by caregivers; what kind of toll did this experience take on them? What memories were they left with?

Unlike theme three, which dealt with the resources that caregivers draw upon to sustain them, and which related overall a positive experience, this theme gave further substance to aspects of theme two in which participants came to grips with what it meant to be in it for the long haul. In this theme we are transported to the time following the death of the loved one when the bereaved rural caregivers reflect on the journey itself and give us a glimpse into what they are left living with. This theme highlights the memories of bereaved caregivers which are not only positive; they are also distressing and haunting. I will now delve into the costs and benefits that appear to occur in the rural caregiver experiences with caring for their loved ones dying at home.

Distressing memories linger with the caregiver.

In describing their experiences as rural caregivers, nearly all of the participants were left with some troubling memories of their caregiving experience. It was apparent that these memories added to their suffering following the death of their loved one. Meredith, George, Megan, Anne, Katie, Luke and Diane recount distressing memories that haunt them, in some cases several years after their caregiving experience with their loved one ended. George and Megan discussed distressing memories that left them feeling guilt. These related to a delegated nursing task they were required to perform. Their experience in performing delegated tasks was not unusual since rural caregivers are often delegated difficult nursing tasks. This is because in remote rural settings it is almost unheard of to have around the clock nursing care provided. Sharing these memories with me appeared to be both important and difficult for participants. George, for example, gave permission for me to record all of our conversation except the particular details of a delegated act he had to perform in the absence of a HCP. It was this act that left him with ongoing questions and haunting memories. Megan however, shared the following memory she has been living with since giving her mother an injection of subcutaneous dilaudid:

> So as soon as we started dilaudid she [mother] went into a coma. So I feel like responsible, like we killed her… it's a kind of like a guilt feeling of shit, like I am – I injected that into her and now she's gone, like she's in a coma and she's never coming back out.

Listening to the distressing memories of participants related to delegated nursing tasks the rural caregivers were required to perform raised many questions for me. Are rural dwellers more likely than urban dwellers to experience distressing and lingering memories associated with the kinds of delegated nursing tasks they are forced to enact? As palliative care HCPs are we providing g enough education on the EOL medications we are drawing up for the caregivers to administer to their loved ones in the absence of HCPs?

Nearly all of the participants spoke of difficult memories of providing direct care that would normally be provided around the clock by trained nurses if their loved one was in an institutional setting. Meredith, Katie, Megan, Luke, Diane, and Edward spoke to how uncomfortable it was for them to complete nursing tasks that caused discomfort to their loved ones or stripped away their dignity. Megan says "that's the part where it's easier for a nurse in the hospital to be doing it to somebody because there's not that emotional connection." What Megan says resonated deeply with me as I found it very difficult to debride my mother's wound because of the pain it caused her. In everyday practice, however, I note that I am able to complete the task without feeling the same degree of anxiety. Katie shares how distressing it was for her to help her grandfather who was severely constipated:

> Oh, my god, it was awful. He was so constipated…it was the worst experience of my life…He is in the shower and there is stool everywhere - everywhere. He had made a mess. It was everywhere. I ended up having to dis-impact my grandfather, it was so awful.

Researchers Dahlborg-Lyckhage and Lindahl (2013) completed a hermeneutic phenomenology study with both current and bereaved caregivers of palliative loved ones in an urban setting in Sweden. The researchers found that it was quite difficult for the caregivers to provide hands on nursing care such as giving medications, completing wound dressings or painful procedures and that performing these tasks took a toll on their wellbeing. A qualitative study by Mehta, Chan and Cohen (2014) completed on urban caregivers in Canada found that managing their palliative loved ones pain alone without HCPs support led to feelings of distress and anxiety in caregivers. Although both of these studies are not situated in remote rural settings, the research resonates with the findings of this study in which caregivers were left with distressing memories that continued to haunt them in some cases several years after the death of their loved one.

Several participants also talked about the toll it took on them to watch certain scenarios play out before their eyes that can sometimes occur at EOL. Anne shares the terror of witnessing the gastric haemorrhage of her husband, without HCPs in attendance:

> That was a scary thing… that was terrible…we saw it happen and I'm telling you, we saw that happen…the haemorrhaging from the bowel was as much from the vomiting…my god.

Little research has been conducted on these types of very specific experiences that rural palliative caregivers describe in this study. In a qualitative study completed in an urban setting in

Sweden on family palliative caregivers who took care of their loved ones, Munck, Fridlund and Martensson (2008) found that caregivers encountered a loss of control and distress when unpredictable situations occurred in the home setting. These findings are consistent with what the participants in this study related when they discussed distressing memories of events that occurred unexpectedly. As bereaved rural caregivers shared their troubling stories about their journey, it became apparent that an abundance of positive memories were also recalled. These will be explored in the next subtheme.

Being at home allowed for comforting memories to be created.

As mentioned in the introduction to this theme, the memories that rural caregivers are left with are both negative and positive. This study found that all of the participants spoke of very special and comforting memories that were specific to the setting (rural and home) and their capacity to preserve the intimacy of their relationships with their dying loved one and other family members. All but one participant said that they felt those positive memories they shared with loved ones would not have occurred if they were in an institutional setting. Many participants spoke of beautiful memories that were formed from having neighbours, relatives and friends drop in spontaneously and they spoke with pride of their capacity to preserve family traditions around birthdays and holidays in their home setting even at the end of life. Edward showed a cherished photograph and shared a special memory of a precious time that occurred in the home when his mother-in-law and his wife's sisters gathered for the last time with his wife.

> Her mom [mother of the dying loved one] came up and to me that was a real nice time… We got some nice pictures of her [wife] with them and so on. So that was a nice time to remember, you know, some of her last memories - our last memories of her.

Some participants shared comforting images of treasured memories of events that not only sustained them through the caregiving experience but also continue to bring comfort months and years after the death of their loved one. Megan recalls the comforts of spending time with her sister upstairs in the spare room when they were caring for their mother who was dying:

> Melissa [sister] and I felt comfortable – feel comfortable here…So we love the spare bed upstairs and we had some good laughs ourselves through the night when we were totally sleep deprived and mom was actually asleep.

The intimacy the rural caregivers experienced by being in one's own home seemed to facilitate the opportunity for intimate bonding with their loved ones. This was because being in a place where one belongs, affords privacy, the confidence to move around and to configure and use the space as one wishes. The intrusions that inevitably occur with the daily routines in an institution do not occur in the same way at home. Meredith shared a beautiful memory she holds onto of the night her father's close friend and neighbour visited at the house to share a hand written letter about his feelings and thoughts about her father with everyone before he passed away:

> David - the man of the house came to see dad and he wrote him a letter and he read his letter to him at the end, so - or close to the end - it was a few days before dad died - and it was very emotional - it was one of things that stands out in your mind, you know and David is the kind of man who - he has to say what he has to say, so it was - it was really good, it was good for dad and good for David, that they were both able to say what they had to say.

Luke shares with us how being at home allowed him to have intimate conversations with his wife and create special memories for the two of them:

> You know, she told me her fears, I told her my fears. I tried to keep everything positive, made her smile as much as I could you know.

It also became apparent that being the caregiver for their loved ones dying at home opened up time to spend with their loved ones that normally would have been spent attending to busy life schedules. Being at home caring for their loved ones seemed to allow for the capacity to be fully present and to give their full and undivided attention to their loved one without worrying about work deadlines, commuting, extracurricular activities etc. George shares how meaningful it was for him to be able to be at home making memories with his wife:

> One thing I did which was really great like being able to be at home was – I spent quite a bit of time with her more so than when she was working and I was working. I wasn't having to feel like I needed to go away.

As I engage with the power and significance of these comforting memories in the context of considering other recollections that continue to haunt participants, and as I consider the fact that very little was explicitly verbalized about the gaps and limitations of formal services available to them, many questions arise and will be discussed in Chapter Five.

In pursuing published research relevant to answering these questions and others pertaining to what being at home means to caregivers, the research on the subject area pertaining to the benefits and costs experienced by caregivers who cared for their loved yielded a qualitative research study by Milligan et al. (2016). This study explored the experience of caregivers managing the palliative care of their loved ones care at home in urban settings in the United Kingdom. The study also explored how caregiver's experience impacted their perception of home. The researchers found that being at home allowed for the caregivers to have the opportunity to bond with their loved ones in a more meaningful way. However, it was also found that being a caregiver can negatively impact the caregiver's perception of their home after their loved one died because of constant reminders around them of the negative memories they endured during the process (Milligan et al., 2016).

Wong and Ussher (2009) found that caregivers reflected on being able to create meaningful memories in their private homes and the memories helped them cope with the impending death and afterwards during the bereavement period. These researchers also found, similar to my study, that by caring for their loved ones at home, they were able to spend more time and thus strengthen the bonds with their loved ones. While my rural based study did not find any negative lingering residue about the homes and setting in which the loved one died, my findings did resonate with the urban based findings of Wong and Ussher. As discussed above, my study substantiates the claim that being able to offer care for a loved one in the home affords the opportunity for enhanced intimacy and relationship building not only with the dying person but also with other family members. While a study comparing urban and rural caregivers caring for a loved one at EOL has not been done, to my knowledge, it does appear that similarities and differences do exist. It is beyond the scope of this study to discuss the ways in which caregiving is similar and different.

The theme, *haunting concerns and comforting memories,* enabled us to gain insight into both the dark and luminous memories of rural caregivers after caring for their loved one at home until death. Consideration of this theme raises questions about the conditions that enable positive memories to outweigh the negative ones for the caregivers, how they feel about the overall experience and the lessons they have learned from their experience that could be useful to others who may consider providing care for a loved one at home in a rural setting in the future. These are among the dimensions that will be explored in depth in the next and final theme.

Time spent dwelling with the transcripts revealed the unique and inspirational story of bereaved caregivers caring for their palliative loved ones at home in rural Ontario. Theme one gathered the stories about participants' experience of being faced with a terminal prognosis for their loved ones and having to decide whether to become a caregiver in order to be able to stay in their familiar rural communities. Participants' experiences assembled under theme two revealed the weight of the recognition that caring for a loved one at home would be a long, arduous and extremely challenging experience. Through the passages organized under theme three we became aware of the strength of participants' relationship to their loved one as well as the strong support networks that sustained them through their journey of caring. Theme four drew our attention to dimensions of the stories that revealed, that despite strong relationships and robust support networks, participants were not able to make it through the experience completely unscathed; in fact all of them were left with images that continued to haunt them or troubling questions about the care they had offered their loved one. On balance, however, all participants also described many comforting memories that not only seemed to help them cope during the experience, but also enabled them to move through the grieving process after the loss of their loved one.

As I reach the end of the participant transcripts and having reviewed my field notes on such observations as the body language and vocal tones of participants, I began to see a major theme unfold before me which spoke to the sense that participants had embarked on an invaluable journey. As I dwelled further with how invaluable this journey was felt to be, I discovered two subthemes. For this fifth and final theme I will uncover the meanings that caregivers gave to an experience they considered invaluable addressing specific aspects of the experience in a description of two subthemes.

Theme Five: Reflecting on an Invaluable Journey

Even though all of the participants in this study at times faced extreme challenges in caring for their loved one and despite the evidence that they continue to live with negative memories after the experience, the overall message was resoundingly positive.

Feeling grateful.

All participants described feeling grateful for the privilege of caring for their loved one.

Some described feeling contented that they had made the right decision and were thus able to live without regret. Others described feeling blessed and honoured to be able to have this unique opportunity, while others shared the pride they experienced in being able to complete the journey with the support of others particularly in a rural setting. Anne shares that she had: “no regrets whatsoever… I wouldn’t change an hour of it.” Anne was not alone in her feelings as Luke, Megan, Meredith, Katie, George and Edward share similar feelings when reflecting on the experience. Meredith says “I’d do it again in a second, yeah I would. It wasn’t easy…it was awful hard…but I’d do it again, I would.” Like Meredith nearly all of the participants in this study expressed that they would live the experience all over again if given the opportunity. Megan shares her feelings after reflecting on being able to care for her mother at home:

> I would never change what we did for a second. It was awesome to be able to care for her at home and it was very trying at times as her disease progressed and we were exhausted, but I think it was an honour to be able to do.

At the end of the interview, when asked to reflect upon the most significant meanings that stood out for them in caring for their loved one, several participants returned to the reasons they shared at the outset of the conversation for why they chose to be a caregiver at home in their rural communities. In returning to the decision, they added more. In particular they elaborated on the evidence that subsequently materialized to justify the soundness of the decision to become a caregiver. In expanding on the value of this decision they described the closeness to their loved one and the attunement to their loved ones needs that was, they believed, only possible when caring for their loved one at home. Many described it as a one of a kind experience that never would have happened the way it did had they been in an institutional setting. Meredith reflects on the experience of caring for her father at home compared to how she believes it would have been in hospital:

> It's sort of the big picture for me – everything that happened here [at the house], never would have happened in a hospital setting, so for that I'm grateful that we were able to do it.

Many of the participants viewed being a part of caring for their palliative loved one and the entire experience as a blessing. A search of a etymological dictionary on the meaning of the word 'blessing' describes it as a gift of sorts while the root of the word 'bless' has to do with giving thanks, feeling fortunate and finding fulfillment (Harper, 2016). I am reminded of the commonly used phrase "it was a blessing in disguise" that is used among people when describing an experience that was particularly difficult but provided them with a silver lining. Katie shares the following on how honoured she felt to be able to care for her grandfather at home:

> The whole time [it was a blessing], I think it was – yeah the whole time…I just remember that not everybody gets – like who gets an opportunity like this, really.

Edward, like many other participants shared how he was blessed because of the support he received that helped sustain him through the journey and for being able to provide the care he did for his wife at home:

> I was blessed because I had the support I had from my girls and you know I didn't have to do it all myself…It was a total blessing being to keep her here for this – for her last journey…it's born into us.

Meredith like several of the other participants expressed feeling fortunate and proud for being able to do what they did for their loved one given the shortage of services in a rural setting:

> Surprisingly when you consider we're such a teeny, tiny remote community really far from big city services, so I think we were very lucky.

Research has been limited on the rewards or benefits described by caregivers of caring at home for their loved ones at EOL and I was unable to find anything specifically on the benefits of caring for a loved one at EOL in rural settings. A search of CINAHL, Ovid and Proquest using keywords palliative, home, caregiver and interchangeably reward, gift, regret, grateful and thankful revealed very limited research into this area. There however, remains an abundance of literature on the burden and negative effects caregiving has on the caregiver’s health and wellbeing well after the loved one dies (Stajduhar, 2013). I believe that this study adds a dimension to our understanding of why and how caregivers in rural settings care for their loved ones since it has introduced us to some of the gifts that rural palliative caregivers experience when they are able to act in such a way as to build up a store of comforting memories. Theme five, *reflecting on an invaluable journey* adds to the understanding of rural caregivers experience by acknowledging that at ‘the end of the day’ caregivers in this study were able to place the arduous nature of ‘being in it for the long haul’ and being left with some lingering negative images and questions in perspective. The ‘big picture’ perspective evidently enabled greater weight to be placed on the positive significance of what had been accomplished versus the weight of the caregiver’s burden or the gaps in services that were experienced.

As I consider the significance of these findings several observations and questions arise. Among them are observations pertaining to the specific focus and methodology of the study. As well my expertise as a novice researcher and interviewer and the possibility that interviews done at several time intervals in the caregiving experience may have yielded differing experiences. This will be discussed further in the limitations chapter.

When I searched the literature on the experience of home-based caregivers who were not based in a rural setting I found a qualitative study which used narrative methods. Sherwood, Given, Doorenbos and Given (2004) explored the experience of bereaved caregivers who took care of a family member who died of a brain tumour at home in urban areas of the United States. The authors found that “the majority perceived the opportunity to provide care as a gift. Caregivers felt 'grateful,' 'blessed,' 'honoured,' and 'privileged' to provide care, often talking about an improved relationship with the care recipient" (p. 70). Wong and Ussher's (2009) urban study, also mentioned in my discussion of theme four, found that caregivers experienced a sense of reward from caring for their palliative loved ones at home and they expressed it as giving and receiving a gift. Similar to Sherwood et al., these researchers also found that the caregiving experience at home allowed for improved relationships between the caregiver and their loved ones (Wong & Ussher, 2009). Researchers Linderholm and Friedrichsen (2010) completed a qualitative study with bereaved caregivers who cared for their loved ones dying of cancer at home in urban parts of Sweden. It was found that although it was not an easy experience the caregivers felt rewarded for having done it. Among the benefits described in this study were the sense of satisfaction that came with supporting their loved ones wishes, spending more time with their loved ones and the certitude that if asked, they would do it all over again (Linderholm & Friedrichsen, 2010). The findings based in urban settings are consistent with what was found in this study with rural caregivers.

In contrast to my study, which invited caregivers to participate who had lost a loved one within the past four years, Henriksson, Carlander and Arestedt's (2015) qualitative study was with caregivers who were actively caring for their dying loved ones at home in urban settings in Sweden. These researchers found that caregivers felt rewarded through being able to give back to their loved ones by caring for them, strengthening their pre-existing relationships and experiencing a sense of self-satisfaction from helping them (Henriksson et al., 2015). Wong, Ussher and Perz (2009) completed a qualitative study on the rewards associated with the experience of bereaved caregivers who cared for their palliative loved ones at home in urban parts of Australia. The authors found that as an end result the caregivers were able to find their inner strengths and resilience by facing adversity in caring for their loved ones dying at home

(Wong et al, 2009). The researchers also found in their study that caregivers felt privileged to be a part of the journey in caring for their loved ones and that their time together either enriched their already strong relationship or helped heal previous problems between them. In contrast, in my study it was discovered that rural caregiver's relationships were enriched by the experience of caring for their dying loved one at home but nothing was shared by participants about repairing previously troubled relationships such as the latter researchers found. A finding by Wong et al. (2009) that did not appear in this current study on rural caregivers was that urban caregivers discussed a sense of personal growth from the experience itself and that it changed their perspectives on life and death as a result. I feel that my study did not discover this partly due to my novice research and interviewing skills, which will be further discussed in my chapter on limitations.

Offering advice to others.

Upon reflecting on their rural palliative caregiving experiences almost all of the participants in this study shared lessons learned or some form of advice for other individuals currently living the experience or thinking about becoming a caregiver. One of the areas of advice the participants provided was on making sure to communicate and arrange for the government funded services you require on top of the support you have from family, friends and community members. Diane shares the following as s a reminder of the need to be your own advocate:

> My advice would be to pound the table to get as much service as you can… if you don't look after yourself you can't look after somebody else.

Katie also says "make sure you have that support in case your need to – I don't know to let loose or something" as sometimes caregivers need to get away in order care for themselves. In the literature, having respite time away from the loved one can be integral to healthy coping during such a difficult caregiving experience (Stajduhar, 2013).

As was found in theme three having an integrated support network of family, friends and community members was imperative to helping rural caregivers be sustained through such a difficult life experience. It is then not surprising that Edward, Anne, Megan, Meredith, Luke, Katie and Diane voiced how important it is for people thinking about being a caregiver or living the situation to assess the availability of a huge support network. Megan shares the following about the need for a big support network that she describes as a 'team' and how to use the 'team' to make it work best from her experience:

> Have a big team. Seriously, like especially as it progresses…those last couple months were difficult and that's when you need the team…I mean like immediate family that always can be there or friends or neighbours if they're committed to that, but some people that are there in the home, you know doing it all together so that's what I mean by a team.

No other literature was found that described advice or lessons learned from caregivers in rural settings who provide EOL care to their loved ones. However, a search without the palliative keyword found one study that contained advice given by caregivers to other caregivers. Researchers Welch et al. (2014) completed a descriptive qualitative study on the experience of urban caregivers caring for their loved ones on hemodialysis at home in the United States. The authors found that caregivers advised having a team of people who you could count on to help you when you needed it such as family and friends and also professional services that could offer respite to the caregiver. Although this study is not specific to palliative care it is pertinent and consistent with the caregiving experience of this study.

In reflecting on the conditions that enabled caregivers to to care for their loved ones at home in their rural communities, all participants were able to take time away from work through different means such as compassionate care leaves. In turn the participants advised that for other caregivers currently living the experience or contemplating being a caregiver, they should consider taking time off from work to focus on their loved one. George shares the following on how he was fortunate enough to have that option to take time off from work to be with his dying loved one:

> I had started a leave from work so I was here all the time… I was very lucky not having to go to work which made a big difference.

Guerriere et al. (2016) found that caregivers of loved ones on palliative care at home in urban settings who took time off from work to focus solely on their loved ones needs faced higher caregiver burden throughout the active process. However, in my study, it was discovered that when the caregivers were reflecting on their experience they viewed the time taken off work in a positive light. Since this study is different in the sense that it focuses solely on bereaved caregiver's experiences and not on caregivers who are currently providing care to loved ones such as the study by Guerriere et al. (2016), this study raises some questions for me that the scope of this study cannot answer and will be addressed further in Chapter Five.

In this fifth theme, excerpts from participants' stories were gathered in such a way as to enable us to conclude that although the rural palliative caregiving experience was very difficult at times for the participants, all of them still felt grateful to have had the opportunity to care for their loved one at home. Participants were thankful for having the opportunity and though they experienced some haunting memories and lingering questions, they did not regret their decision to care for their loved one. Rural caregivers also felt fortunate or 'blessed' for all of the help they received from their tremendous support networks, all of which helped them to care for their loved ones at home. The findings in the extant literature on urban caregivers caring for their palliative loved one at home was similar to the findings in this study for the most part. Although the one research study on caregiver advice was not specifically aimed at the palliative population its findings were similar to the advice shared by the rural caregivers in this study about the importance of having support and accessing appropriate professional services.

At the end of this interpretive story, we are left with a remarkably consistent narrative of rural caregivers encountering tragedy and having to find strength to sustain the journey through the long haul. In the beginning of the story we learn that deciding to become a caregiver was decided in the moment, a fore-gone conclusion, but one that is replaced shortly thereafter with the recognition that the experience will be long and arduous and that commitment involves ‘being in it for the long haul’. In the middle of the story additional light is shed on how rural caregivers sustain their commitment to care as they describe the strength of their attachment to their loved one as well as the abundance of support from their family, friends, community members and HCPs. These are the sources that help them continue on until the end. At the end of the story rural caregivers described being left with some wounds but also an overwhelming sense of gratitude. After everything was said and done, the caregivers were thankful for having been a part of something as mysterious and unique as accompanying their loved ones to transition from this world to the next through the ups and downs that inevitably come with it.

Chapter Five: Limitations, Future Directions and Implications of the Study

In this chapter I will briefly review this study's central findings and discuss the extent to which these findings stimulate further thought with regard to practice, methodology issues and my experiences as a novice researcher. Limitations of this study will also be discussed with regard to measures taken or that could be taken in a future study to reduce their effects. I will also highlight areas that remain unanswered by this study as well as some tentative implications for rural palliative care practice as discovered from my exploration into the bereaved rural caregivers lived experience. Lastly, this chapter will discuss areas for future research pertaining to rural palliative caregivers, rural palliative HCPs and rural home-based palliative care practice.

Limitations of the Study

As with any research study there can be a multitude of limitations and I recognize that while the following limitations are not exhaustive of all possible limitations they do represent the ones most applicable to this study. First and foremost being a novice researcher and inexperienced in hermeneutic phenomenology methods was a limitation in this study. Although I have fairly advanced interviewing skills that come from my experience as a nurse completing health assessments, I do acknowledge that when carrying out this study I only had novice research interviewing skills related to open ended approaches used in phenomenology research. Novice interviewing skills may have resulted in not exploring the lived experiences of my participants as fully as would have been possible had I had more practice in interviewing. Had I been more adept at opening up areas for exploration with rural caregivers, I might have discovered experiences that resonated with the findings of an urban-based study by Wong et al. (2009) which found that urban caregivers discussed a sense of personal growth arising from their experience of caregiving and that it changed their perspectives on life and death.

My study found that all of the participants felt that the overall experience of caring for their palliative loved ones at home in rural Ontario was positive and that they all would do it over again if given the chance. Due to the emotional delicacy of the subject of this study it is reasonable to speculate about whether only participants who had positive experiences volunteered to participate and to wonder whether those who had negative experiences chose not to participate. Although no attempt was made to exclude persons from participating based on their overall ratings of the experience as negative or positive, it is consequently possible that I may have gained a limited view of the lived experience by having only those who had a positive experiences volunteer to be interviewed. This limitation of only recruiting caregivers with a positive experience was also expressed by researchers Hatcher et al. (2014).

Seven out of the eight participants in this study self-identified as Caucasian and this is a limitation in the sense that the lived experiences shared in this study may not be typical of other racial and cultural backgrounds in Canada. Although most rural dwellers are likely to be Caucasian there are particular ethnic and religious communities in rural settings that could be explored such as Dutch, French, German, Mennonite, Aboriginal etc. The particular ethnic and religious heritage may have some influence on social practices within small communities but it is beyond the scope of this study to illuminate those.

One of this study’s risk mitigation steps included preventing psychological distress by only selecting participants who lost their loved one between one year and up to four years ago. The fact that recruitment proceeded with this criteria in place could also be a limitation. With the significant passage of time it is possible that the participants were not able to recall the finer details of the lived experience and this resulted in descriptions that cast a more positive light on certain aspects of the experience. Researchers in this subject area are now starting to recruit participants three months after the death of their loved ones when they feel the most damaging part of the grieving process has passed. The researchers are starting to do this in order to obtain richer accounts and possibly more accurate accounts of the lived experience (Totman et al., 2015). Clearly more research into the lived experience of rural caregivers both active and bereaved need to be completed utilizing different research designs and over different time periods. Perhaps by exploring the phenomenon after different stages of time and grieving, we might gain a more in depth understanding of the phenomenon.

I recognize that it could be argued that my own lived experience(s) as a rural caregiver of palliative loved ones at home could be a limitation given the temptations to superimpose my own experience upon the experience of my participants. I do not, however, feel it is a concern because of the measures I took. These measures included becoming aware of my personal thoughts and opinions through journaling. I made efforts to be informed by my own experience while at the same time holding my own experiences in abeyance. I did this with a view to letting the unique voices of the study's participants emerge. As stated earlier, the guiding hermeneutic phenomenology methods by van Manen (1990, 2016) and Moules et al. (2015) utilized in this study do not require bracketing. Instead these methods take the position that it is not possible or desirable to attain an objective stance given that it is the researcher's personal experience(s) that play a significant role in shaping the work. The fact that there were several surprises along the way that contrasted significantly from my own experience(s), suggests that I was not superimposing my own experiences on the study.

To the best of my capability as a novice researcher, this study was guided by the rigour and validity measures set forth by the guiding hermeneutic phenomenology method by van Manen (1990, 2016). Although this study has its limitations, it can be seen that with the guiding methods this study has been able to provide a rich description of the lived experience thus contributes to the limited knowledge base on palliative caregivers in a home-based rural setting.

Implications for Practice and Areas for Future Research

The aim of this study and the guiding hermeneutic phenomenology method is not to generalize the study findings to target populations (van Manen, 1990, 2016) but instead to provide a rich description of the lived experience of bereaved rural caregivers who cared for their palliative loved ones at home. We can however, raise questions and draw tentative implications for practice from the descriptions of the lived experience that have been organized into themes and subthemes. Over the journey of completing this study I have kept a journal on areas that puzzled me, piqued my curiosity or invited further study. It is my intention to bring these observations and opportunities for future study to the discussion.

Theme one.

In theme one we learned about rural caregivers being faced with a terminal prognosis for their loved ones and we discover that participants in this study decided in the moment to be their loved one's caregiver. It was discussed that while the decision appeared to be spontaneous, in actuality it seemed to be made based on a prior and tacit understanding of their loved ones wishes, a strong bond between caregivers and their dying loved one and a sense of family and community support. There was no evidence that the information given by HCPs played a major role in the decision to become a caregiver. This finding should be interpreted with caution because it must be remembered that this study engaged participants whose loved one had died at least one year previously and some others' loved ones had died up to four years earlier. This amount of time that had elapsed raises questions about the accuracy of participants' memories in relation to the helpfulness of any information given to them by HCPs at the time the diagnosis was communicated. It also raises questions regarding the degree to which the information influenced their decision. Clearly further studies are needed in order to understand in detail how caregivers make decisions to care for their loved one at home and the factors that are implicitly or explicitly considered. Perhaps future studies on this subject area could recruit active caregivers who might be able to offer a different perspective because they are currently living the experience unlike the participants in this study. I also feel it would be beneficial to replicate this study and change the participant inclusion criteria to allow for recruitment of bereaved rural caregivers whose loved ones died no earlier than three months ago and up to one year ago.

In palliative care practice we often spend a great deal of time and monetary resources on preparing numerous resources such as handouts, media and arranging several meetings across the multidisciplinary team to enable family decision-making. Little is actually known, however, about whether and how family members use this information to make decisions. Some other questions that arise from theme one findings are as follows: 1) Should HCPs be providing more supportive and compassionate measures at the time of the terminal diagnosis?; and 2) What evidence exists that emotional needs are being met by providing information? Another related question is: Does the provision of compassionate care and meeting emotional needs first have an effect on the readiness to absorb the information that could lead to more informed decision making? A final question raised in theme one is: Does the potential caregiver's awareness of their loved ones terminal diagnosis make it easier to commit to be being a caregiver when one knows ones loved one does not have a long time to live compared to a situation in which the caregiving period could stretch to years? Further studies are needed to address these questions.

Theme two.

In theme two we bear witness to the exhausting and demanding work of being a rural caregiver over the long haul. We see how taxing the role is on the caregiver, the overall burden they are faced with and the toll it can take on their wellbeing. This theme invited further reflection on whether enough support and services to our rural palliative caregivers are being provided. After hearing the experiences of the rural caregivers I was left wondering if we could be doing more by way of services/support to help reduce their caregiver burden and risk for burn out. Would the provision of overnight support shifts that are often readily available in the urban settings be a source of respite for rural caregivers enabling them to get the sleep they require or simply time away to rest? Would providing more respite shifts during the day hours help reduce the burden on rural caregivers as well to allow them to re-charge? Providing cleaning services to rural caregivers could also perhaps reduce their responsibility load and allow them to focus more time on their loved one and themselves. This study has provided a glimpse into the needs of rural palliative caregivers and I agree with Stajduhar et al. (2010) who suggest that more research is needed to assess more accurately the needs of caregivers in home settings when caring for their loved ones at EOL and how geographic location and isolation affect those needs.

Reflecting further on the implications for practice of the exhaustion of rural caregivers, led me to consider ways to reduce the physical toll such caregiving takes. Currently supportive equipment such as hospital beds, commodes, grab bars, walkers, wheelchairs, lifts, ramps, as examples, are supplied in Ontario homes but at an ongoing expensive rental fee. Alternatively the client and their family can pay full price for it and own it afterwards. Rural caregivers are often left to make the decision between spending their money on ‘temporary’ use of equipment or foregoing using supportive equipment and putting themselves at risk for injury and adding to the physical demands of being a caregiver. This raises a very important question: Should we be providing this supportive equipment in the home as part of our government funded health care system?

An area that appeared in this theme with one of the participants was about when it became no longer feasible to keep their loved one at home for the last days of their life and when they decided to transfer their loved one to a hospice. I feel it would be beneficial to explore the experiences that give rise to the decision to move a loved one from a home-setting to hospice. Understanding these experiences in further detail will help palliative care HCPs to assist families in making decisions that are right for them.

Theme three.

Theme Three shone a light on the reservoirs that rural caregivers drew upon to get through the long haul of caring for their palliative loved one at home. Rural caregivers were able to draw upon support from their family, friends and neighbours. This support helped in significant ways by offering respite from the overwhelming caregiving and household duties. An implication for practice is that although rural caregivers have less access to formal services and supports, they may have considerable informal supports amassed through the interdependent roles they have played in their local communities. I think it is important for HCPs to welcome, build on and reinforce the strength of the social relationships that are truly sustaining. I am reminded of the research study completed around supporting cancer survivors, patients and caregivers through online support groups in a study by Stephen et al. (2014). I feel that future research utilizing that study’s methods for rural palliative caregivers both active and bereaved would be beneficial in helping support them further through their exhausting and difficult journey.

In this theme we also learned of the significant role that palliative care HCPs played in helping participants over the long haul. This study has provided a glimpse into how nurses can aid caregivers in caring for their palliative loved ones at home, which was a suggested area for future research by authors Robinson et al. (2012). Through discussions with the participants in this study it was found that almost all of the HCPs went beyond the call of duty when providing care to their loved ones and perhaps this retrospectively added to the caregivers viewing the experience on such a positive note. While this was laudable we cannot expect all palliative HCPs to always go to such great lengths because it can lead to burn out. Pask (2005) says that:

> Nurses who continue to act for the good of their patients, while suffering the effects of constraining influences upon them… sacrifice themselves, [and] illustrate for us dedication of a particular kind, dedication that incorporates an inclination towards self-sacrifice. (p. 251)

An implication that comes to mind from this is that perhaps we should be doing more to help support rural caregivers so that rural HCPs are not left feeling like they have to make up for what is missing in the provision of adequate palliative services in rural communities. I also feel more research is required to replicate the study completed by Pesut et al. (2015) which looks at the impact of access to specialized palliative care services and HCPs in rural communities. It should be noted that the field of palliative home care in rural and urban centres and the role of nurses and physicians in these settings offer many opportunities for research, I have chosen to restrict my comments on future research directions to the caregiving experience itself.

Theme four.

In theme four we learned about the distressing and comforting memories that remain with the rural caregivers long after their loved one has passed away. Some of the distressing memories come from crises that occur at EOL or from guilt stemming from advanced nursing skills that are often delegated to the caregivers to perform when the HCPs cannot be present due to the service constraints in a rural setting. While it is fact that palliative care HCPs only administer the dosages of medications sufficient to keep the individuals negative symptoms controlled and while standards of practice require that the administration of these medications and dosages are not enough to end the individual’s life, it is apparent from this study that when caregivers assume delegated acts such as administering such medication, they are left with distressing questions. It thus becomes imperative that knowledge be shared with caregivers so that they understand how their loved one will come to die and why. Caregivers should be made aware that while death may occur following the administration of EOL medications to control symptoms to make their loved one more comfortable, the dosages that they will administer are insufficient to be the sole cause of death. Death will instead come from a cumulative effect of disease progression and organ failure not simply from the medications themselves.

Given the evidence in this study of the distressing thoughts that lingered for participants as a result of their experience, it also seems important to include a bereavement visit by palliative care HCPs to the primary rural caregivers a few weeks to months after their loved one dies. Such a visit would facilitate a follow up on how they are coping, the opportunity to ask questions in the effort to improve a positive perspective on the tasks that they undertook, the chance to reduce stress and lingering negative ruminations and thereby to facilitate a healthy grieving process. In view of the apparent need for such an approach, more research studies that investigate the outcomes of bereavement visit(s) to the caregivers by the primary palliative care nurse at three, six and nine week intervals following the death of their loved one are needed. This approach would add to the three part bereavement visits/phone calls made in the study by Pesut et al. (2015) that was found to be beneficial. While the need for such visits was not explored systematically in this study, I do believe that there could be a therapeutic advantage.

The question is asked as to whether more time and resources should be invested in providing more thorough structured education via workshops and other instructional modalities for rural caregivers? This question arises in the context of considering that rural dwellers may be more likely than urban dwellers to experience distressing and lingering memories. While future studies are required to establish this, I hypothesize there is a higher burden of distressing thoughts given the necessity for rural dwellers to perform delegated nursing actions on a more frequent basis. Therefore future qualitative studies should explore rural palliative caregiver's self-identified gaps in their palliative knowledge when caring for their loved one, what education worked and has not worked for them and areas they find most challenging. Future studies exploring such areas as these have the potential to help provide HCPs with the basis for how to implement more meaningful education to informal caregivers. Thinking further in this vein, it seems that it would be beneficial to complete a research study that implements a three part intervention on palliative care education to informal caregivers. This might include implementing a pre-knowledge test, provision of the knowledge intervention and followed by a post-knowledge test. A qualitative study could be completed after the education intervention study to explore what having that education meant to the caregivers and how it affected their QOL.

In theme four we were also made aware of the many comforting memories that the rural caregivers experienced from caring for their loved one at home. Even though they also face exhaustion and very significant distress along the journey, are these comforting memories at once a way of coping and an indicator of positive coping with the grief following the loss of their loved ones? Further understanding of the attributes of rural caregivers who cope well with the caregiving experience and who also are able to process their grief in meaningful ways after their loved one dies, could add much to our knowledge about how to support caregivers effectively.

The questions raised about memories both positive and negative, call for future studies which seek to illuminate the conditions that promote the construction of positive meanings for caregivers and family members in rural settings. To further our understanding about the experience of family members who decide to opt for home-based care versus care based in institutional settings, the factors that influence their decisions and the conditions that influence the construction of positive meanings need to be understood in more depth. Are family members who care for their loved one at home more likely to describe positive memories of their loved one's last days than family members who describe what it was like to say good-bye to their loved one in an institutional setting? Could it be that it is the strength of comforting memories that enables rural caregivers to gain and preserve a perspective that "it was all worth it"? Future research is needed to start addressing these questions with a view to gaining a deeper understanding.

Theme five.

Through theme five we become aware that no matter how difficult the journey was over the long haul, rural caregivers felt grateful to have had the experience and expressed no regrets. The implication for practice here arises in the context of understanding that even though the lived experience had a lot of negative aspects at times, there are still many positive dimensions that appear to help the rural caregivers construct positive meanings in the midst of losing their loved one and after the loved one has died. The stories told by participants in this study invite palliative HCPs to focus more on what makes aspects of this invaluable journey positive for rural caregivers so that we may share those with our future clients. This may help caregivers to be alert to and follow a similar path toward the construction of positive meanings and fulfilling outcomes.

Conclusion

As I wrote and re-wrote this thesis and compared the parts to the whole, I began to truly understand what van Manen (1990) means by “writing exercises the ability to see” (p. 129). I saw the journey undertaken by caregivers who took care of their palliative loved ones at home to be one that is both tragic, demanding and profoundly meaningful. Although it is a journey characterized by fatigue, adversity and loss, it is also one that is sustained with the steadfast support of caregiver’s family, friends, neighbours and HCPs. It is rendered meaningful by the practices which enable the retrieval of positive memories and by the ability to interpret the overall experience as a privilege, blessing or gift.

The findings of this study offer something new in that they illuminate the formal and informal resources that are available to and valued by rural dwellers. The study also draws attention to the heavy burdens that they endure. In order to develop policies, services and health care practices that draw upon and reinforce the strengths of rural caregivers while reducing the toll that such caring can take, there is a need for future research. This research must identify in further detail the conditions that cultivate and support the capacity to care for one’s loved one at home and for ‘the long haul’.

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Appendix A

Definitions of Commonly Used Terms

Caregiving: "Assistance provided to individuals who are in need of support because of a disability, mental illness, chronic condition, terminal illness or who are frail. This can include attention to any of the needs of the person, including hands on care, overnight care, respite, shopping, collection of medications, taking to appointments, emotional support, bathing, etc. Caregiving is distinguished from 'normal helping' that occurs in the context of family relationships; rather, caregiving emerges because of particular needs for assistance" (Stajduhar et al., 2010, p. 587).

Family caregivers at end of life: "Individuals who provide any physical, emotional, and instrumental support and assistance to individuals with life-limiting illness that they view as family members. These family caregivers are not acting in a professional or occupational capacity. They may or may not be co-residing with the care recipient and the care recipient may be in either a home or institutional setting" (Stajduhar et al., 2010, p. 587).

Palliative care: "An approach to formal service provision 'that improves the quality of life of patients and their families facing the problem 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. Palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications" (Stajduhar et al., 2010, p. 587).

End of life care: "End of life care helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. This definition includes palliative, hospice, generalist, and specialist end of life care services and specific services and complex interventions offered to people with advanced, progressive, or incurable illness and their families, caregivers, or significant others during care and bereavement" (Stajduhar et al., 2010, p. 587).

Home-based care: "Refers to the location of where care is occurring, in this case the patient's or family member's home. In home-based care, family caregivers often feel responsible for most aspects of care even if receiving formal hospice and palliative home care services” (Stajduhar et al., 2010, p. 587).

Inpatient/institutional care: “Refers to the location of where care is occurring: in this case, an inpatient, acute, chronic, or long term care health care facility and, in some jurisdictions, free-standing hospice facilities. In institutional settings, legal responsibility for care is largely transferred to professional carers, although the family caregiver often continues to provide large amounts of care” (Stajduhar et al., 2010, p. 587).

Hospice: “Hospice Palliative Care of Ontario defines community residential hospices as a healthcare facility and registered charity that provides palliative care services by an interprofessional team with palliative care expertise 24 hours a day, 7 days a week in a home like setting for the individual and their significant others at no cost to the user. Facilities incorporated in a Community Residential Hospice consist of at a minimum: • Private residential rooms; • Community living room, kitchen and eating area: • Quiet area; • Tub/Shower room; • Public washrooms meeting accessibility regulations; • Dirty utility area; • Supplies area/station including secure medication room; • Administrative offices” (Residential Hospice Working Group, 2015, p. 2).

Rural: “Rural and small town refers to individuals in towns or municipalities outside the commuting zone of larger urban centres (with 10,000 or more population)” (Statistics Canada, 2001, p. 6). As well Rural was defined as an area outside of urban population centres that is composed of clusters of small towns and villages surrounded by agricultural lands, wilderness or undeveloped land (Statistics Canada, 2012).

Appendix B

Study Flyer

LOOKING FOR individuals who cared for loved ones that passed away at home in Rural Ontario

A gift card will be provided as a thank you for your time and participation

Contact Principal Researcher:
Travis Amell
RN, BScN, CHPCN(C), CDE
[redacted]

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Appendix C

Participant Demographics Chart

Gender	**Age**	**Relationship Status**	**Loved Ones Primary Disease Process**
Male: 3 (37.5%) Female: 5 (62.5%)	Ranged 29-74 18-39: 1 (12.5%) 40-59: 3 (37.5%) 60-80: 4 (50%)	Widowed: 3 (37.5%) Married: 2 (25%) Common Law: 1 (12.5%) Single: 1 (12.5%) Divorced/ Separated: 1 (12.5%)	Cancer: 5 (62.5%) Diabetes: 2 (25%) ALS: 1 (12.5%)
Education Level	**Ethnic/ Racial Group**	**Caregiving/ Healthcare Experience**	**Participant's Connection to loved one**
Gr. 8: 1 (12.5%) Gr. 12: 1 (12.5%) College: 3 (37.5%) University: 3 (37.5%)	Caucasian: 7 (87.5%) Aboriginal: 1 (12.5%)	No: 4 (50%) Yes: 4 (50%) Area in: PSW: 3 Nursing: 1	Spouse/Partner: 4 (50%) Child: 2 (25%) Sibling: 1 (12.5%) Grandchild: 1 (12.5%)

Appendix D

Guiding Interview Question and Prompts

Start interview with: What was it like to care for your loved one at home until s/he died?

Then as needed move onto the following prompts:

1. How was a home death decided upon? Who made this decision? (You, loved ones, friends, joint). How did you feel about this decision subsequently? Did it turn out to be the right decision or not? Did this decision change as the experience progressed?

2. When you made the decision, did you have much of a sense of what would be involved? Were you able to draw upon other people's experience in making your decision, i.e. did you know of anyone else whose family supported them to die at home?

3. When making the decision, did you seek any information on the experience? (Counsel, look up resources, etc.). To what extent was this information helpful/not helpful?

4. When you made the decision, did you think people would be there for you? If so, what people did you think you could rely upon?

5. To what extent did what you expected differ from how the events actually unfolded? Were there any major shocks or unexpected outcomes?

6. Were there any disappointments? If so, what were they? Does one stand out to you as your biggest disappointment?

7. Tell me about the kind of care you received from contracted agencies (PSW, Nursing, PT, O2, CCAC Care Coordinators etc.)

8. When you think back about all the health care professionals /support you received, people who came, are there any people or experiences that really stand out as helping you the most? Then flip to: is there anything health care professionals/support did that stands out that was distressing, disappointing or stressful?

9. Was there a time of day or day of the week that you felt it was more difficult to provide care to your loved one?

10. When you look back over the non-professional support you received (possibly from friends or neighbours), did it come from expected sources or also perhaps from surprise sources?

11. Was there a time when you felt truly supported /blessed during all of this coming loss? If yes, could you tell me about it?

12. When thinking back on the entire experience of caring for your loved one while they were dying at home, is there a time that will stand out in your memory that you will cherish forever?
13. As you reflect on this difficult, perhaps most difficult time in your life and if we could roll back time, what would be the things you would really wish could have happened differently?

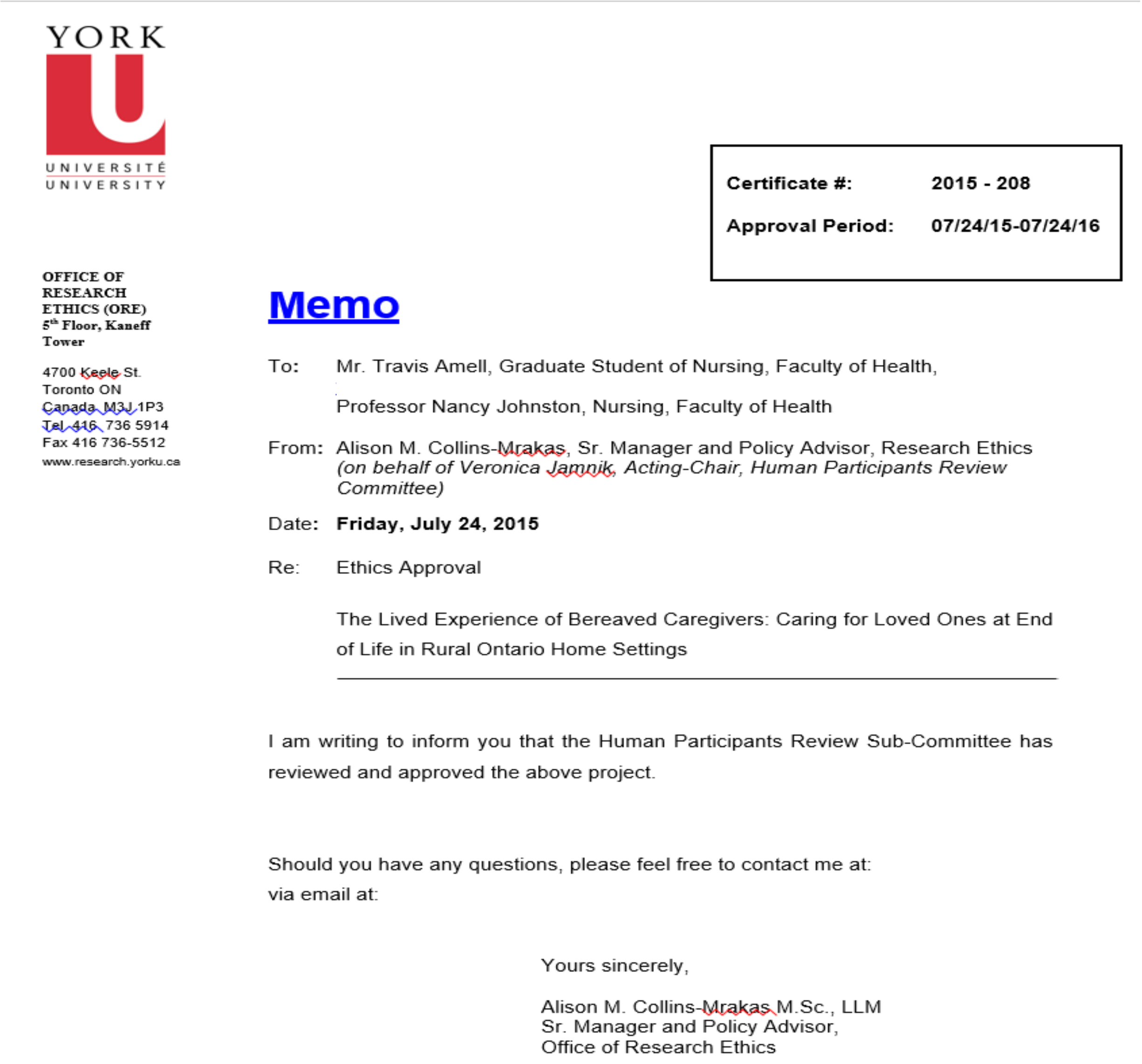
14. As your loved one was nearing the end of their journey, right near the end, how did you feel about them dying at home? Any second thoughts?

15. If you had advice to give to other families caring for loved ones at EOL at home, what would your advice be to them?

16. If you had advice to give to health care professionals interested in providing the best possible care for persons dying at home and their care-givers, what would your advice be?

Appendix E

Research Ethics Board Certificate(s)



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UNIVERSITY

Certificate #:	**2015 - 208**
Approval Period:	**07/24/15-07/24/16**

OFFICE OF RESEARCH ETHICS (ORE)
5th Floor, Kaneff Tower

4700 Keele St.
Toronto ON
Canada M3J 1P3
Tel 416 736 5914
Fax 416 736-5512
www.research.yorku.ca

Memo

To: Mr. Travis Amell, Graduate Student of Nursing, Faculty of Health,

Professor Nancy Johnston, Nursing, Faculty of Health

From: Alison M. Collins-Mrakas, Sr. Manager and Policy Advisor, Research Ethics *(on behalf of Veronica Jamnik, Acting-Chair, Human Participants Review Committee)*

Date: **Friday, July 24, 2015**

Re: Ethics Approval

The Lived Experience of Bereaved Caregivers: Caring for Loved Ones at End of Life in Rural Ontario Home Settings

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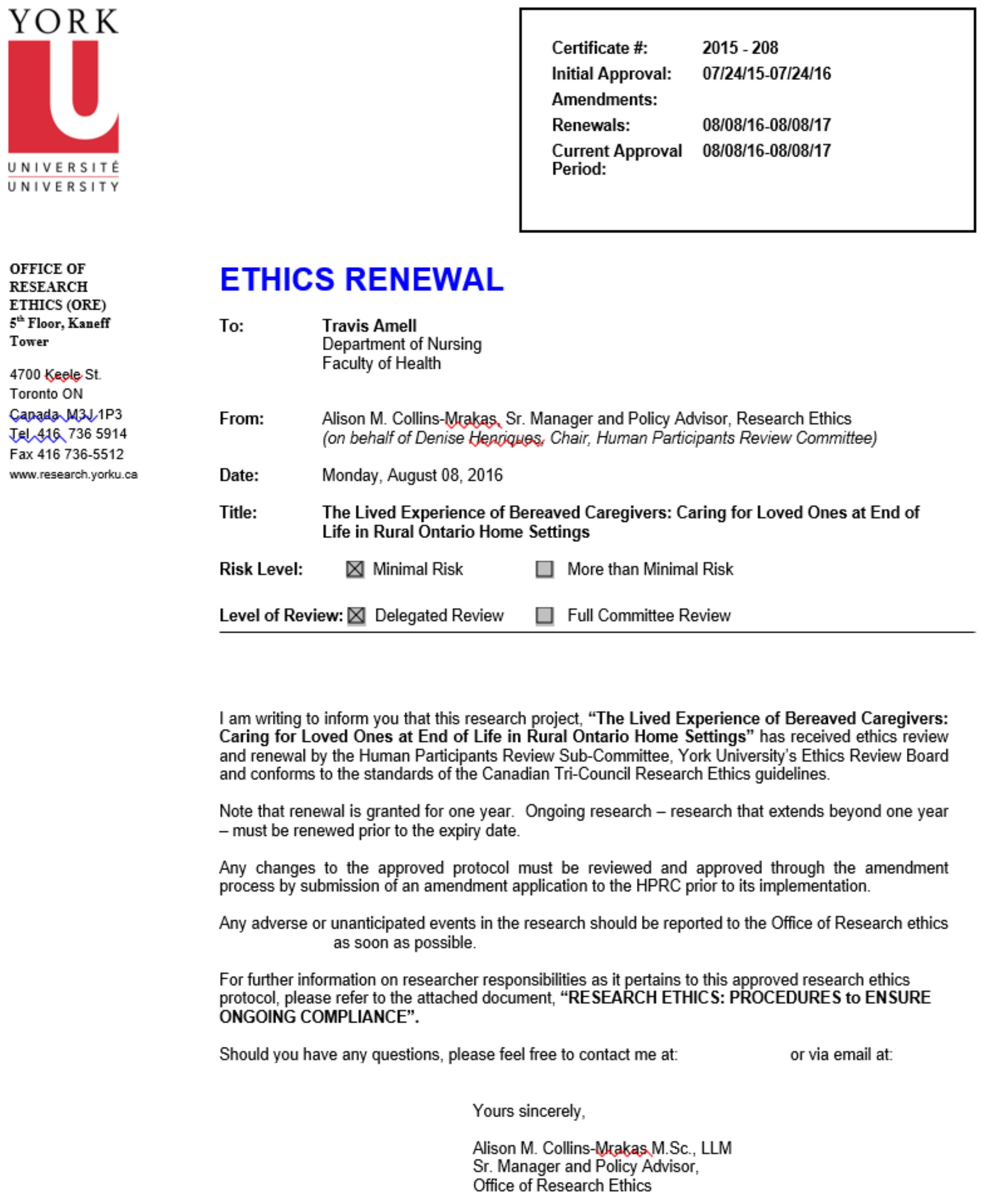
I am writing to inform you that the Human Participants Review Sub-Committee has reviewed and approved the above project.

Should you have any questions, please feel free to contact me at:
via email at:

Yours sincerely,

Alison M. Collins-Mrakas M.Sc., LLM
Sr. Manager and Policy Advisor,
Office of Research Ethics



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Certificate #:	**2015 - 208**
Initial Approval:	**07/24/15-07/24/16**
Amendments:	
Renewals:	**08/08/16-08/08/17**
Current Approval Period:	**08/08/16-08/08/17**

ETHICS RENEWAL

To: **Travis Amell**
Department of Nursing
Faculty of Health

From: Alison M. Collins-Mrakas, Sr. Manager and Policy Advisor, Research Ethics
(on behalf of Denise Henriques, Chair, Human Participants Review Committee)

Date: Monday, August 08, 2016

Title: **The Lived Experience of Bereaved Caregivers: Caring for Loved Ones at End of Life in Rural Ontario Home Settings**

Risk Level: ☒ Minimal Risk ☐ More than Minimal Risk

Level of Review: ☒ Delegated Review ☐ Full Committee Review

I am writing to inform you that this research project, **"The Lived Experience of Bereaved Caregivers: Caring for Loved Ones at End of Life in Rural Ontario Home Settings"** has received ethics review and renewal by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines.

Note that renewal is granted for one year. Ongoing research – research that extends beyond one year – must be renewed prior to the expiry date.

Any changes to the approved protocol must be reviewed and approved through the amendment process by submission of an amendment application to the HPRC prior to its implementation.

Any adverse or unanticipated events in the research should be reported to the Office of Research ethics as soon as possible.

For further information on researcher responsibilities as it pertains to this approved research ethics protocol, please refer to the attached document, **"RESEARCH ETHICS: PROCEDURES to ENSURE ONGOING COMPLIANCE".**

Should you have any questions, please feel free to contact me at: or via email at:

Yours sincerely,

Alison M. Collins-Mrakas M.Sc., LLM
Sr. Manager and Policy Advisor,
Office of Research Ethics

Appendix F

Demographic Collection Form

The Lived Experience of Bereaved Caregivers:
Caring for Loved Ones at End of Life in Rural Ontario Home Settings

Demographic Form

Please place an ‘**X**’ in the most appropriate box or briefly write your answer beside ‘Other’.

What is your Gender?

Female: ☐ **Male:** ☐ **Other:** ______________________________

What is your Age?

____

What is your Relationship Status?

Single: ☐ **Married:** ☐ **Common Law:** ☐ **Divorced/Separated:** ☐
Dating/Courting: ☐ **Widowed:** ☐

Other: ____

What Was Your Loved Ones Primary Palliative Disease Process?

Cancer: ☐ **COPD:** ☐ **ALS:** ☐ **Heart Failure:** ☐
Kidney Failure: ☐ **AIDS:** ☐ **Parkinson’s:** ☐

Other: ____
____

What is your Education Level?

Elementary (Gr. 8): ☐ **High School (Gr. 12):** ☐ **College:** ☐
University: ☐ **Diploma:** ☐ **Other:** ________________________

What is your Ethnic/Racial Group?

Asian/Pacific Islander: ☐ **African/Black North American:** ☐
Caucasian: ☐ **Indian:** ☐ **Aboriginal/Native North American:** ☐
Other:____

Did you have any prior Caregiving/Health Care Experience?

Yes: ☐ No: ☐

If your response was yes, please indicate in what:

Nursing: ☐ Medical Doctor: ☐ Personal Support: ☐
Physiotherapy: ☐ Pharmacology: ☐ Caregiver: ☐

Other: ____

What was your connection to your loved one?

Spouse/Partner: ☐ Child: ☐ Friend: ☐ Neighbour: ☐
Relative (cousin, aunt, uncle, in law etc.): ☐ Other: ____________________

Appendix G

Mental Health Resources

Mental Health Resources

Waterloo-Wellington

Ontario Mental Health Help Line

Phone: 1-866-531-2600

Website: http://www.mentalhealthhelpline.ca/ (for online chat messenger)

E Mental Health Services

http://www.ementalhealth.ca/

GUELPH

Canadian Mental Health Association

Address: 147 Wyndham St. North
Guelph, ON
N1H 4E9

Phone: 519-836-6220
1-888-255-2642

Fax: 519-836-6237

Self Help Alliance: 519-763-4014

Address: 485 Silvercreek Pkwy North, Unit 1
Guelph, ON
N1H 7K5

Phone: 519-836-4991

Fax: 519-836-7459

IGSW Guelph Office

Address: Guelph – Hospice Wellington
795 Scottsdale Dr.,
N1G 3R8
Phone: 519-763-3838

Fax: 519-763-3880

KITCHENER

Canadian Mental Health Association

Address: 67 King St. E.
Kitchener, ON
N2G 2K4
Phone: 519-744-7645
1-877-627-2642

Fax: 519-744-7066

Self Help Alliance: 519-570-4595

Address: 130 Weber St. W.
Suite 202
Kitchener, ON
N2H 4A2

Phone: 519-576-2333

Fax: 519-576-8980

WATERLOO

Canadian Mental Health Association

IGSW Waterloo Office
Address: Community Support Connections
420 Weber St N,
N2L 4E7

Phone: 519-772-8787

Fax: 519-880-8849

CAMBRIDGE

Canadian Mental Health Association

Address: 3-9 Wellington St.
Cambridge, ON
N1R 3Y4

Phone: 519-740-7782

Fax: 519-740-0461

Self Help Alliance: 519-623-6024

Address: IGSW Cambridge Office
Community Support Connections
887 Langs Drive, Unit 4A
N3K 5K4

Phone: 519-772-8787

Fax: 519 – 653-3107

FERGUS

Canadian Mental Health Association

Address: 234 St. Patrick St. E.
Fergus, ON
N1M 1M6
Phone: 519-843-6191
1-800-265-7723

Fax: 519-843-7608

MOUNT FOREST

Canadian Mental Health Association

Address: 392 Main St. N.
Suite 1
Mount Forest, ON
N0G 2L2

Phone: 519-323-4004

Fax: 519-323-3771

Champlain

Ontario Mental Health Help Line

Phone: 1-866-531-2600

Website: http://www.mentalhealthhelpline.ca/ (for online chat messenger)

Mental Health Crisis Line

Phone: 1-866-996-0991

Website: http://www.crisisline.ca/

Cornwall Community Hospital's (CCH) Mental Health Programs

The following adult community mental health services are all under a single point access and referral model.

- Adult Counselling and Treatment Services - Tri-County Mental Health Service
- Outpatient Mental Health Program
- The Psychogeriatric Service - Tri-County Mental Health
- First Episode Psychosis Program
- The Assertive Community Treatment Team

Phone: 613-932-9940 or 1-800-465-8061

Fax: t 613-932-9945at

Address: 132 Second St. Suite 104, Cornwall Ontario K6H 1Y4

E Mental Health Services

http://www.ementalhealth.ca/

Canadian Mental Health Association

Address: 329 Pitt Street
Cornwall, ON K6J 3R1

Phone: (613) 933-5845

Fax: (613) 936-2323

Email: office@cmha-east.on.ca

Website: http://www.cmha-east.on.ca/