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**“COMFORT, COMFORT MY PEOPLE”: A QUALITATIVE STUDY
EXAMINING DYING PERSONS’ AND THEIR CAREGIVERS’
EXPERIENCE OF SPIRITUAL CARE AS AN AID TO HAVING A GOOD
DEATH IN GREY AND BRUCE COUNTIES, ONTARIO**

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“COMFORT, COMFORT MY PEOPLE”:
A QUALITATIVE STUDY EXAMINING DYING PERSONS’ AND THEIR CAREGIVERS’
EXPERIENCE OF SPIRITUAL CARE AS AN AID TO HAVING A GOOD DEATH IN GREY
AND BRUCE COUNTIES, ONTARIO.

By

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THESIS/DISSERTATION

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In partial fulfilment of the requirements for

The Doctor of Ministry in Spiritual Care and Psychotherapy

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Abstract

Dying persons and their caregivers encounter several needs as part of the dying journey. Spiritual care, when offered effectively, can help address many of those needs. When people's needs are fulfilled, their suffering is lessened and there is an increased possibility of them experiencing a good death. However, when spiritual care is not offered effectively, dying persons and their caregivers often continue to face unalleviated suffering which limits their ability to experience a good death. This research project explores how dying persons and their caregivers experience spiritual care in their homes as an aid to dying well and having a good death in Grey and Bruce Counties, Ontario, Canada. The research further examines if the rural nature of this geographical region affects the participants' experience of spiritual care as part of their dying journey.

A phenomenological research study was conducted using semi-structured interviews with ten dying persons and nine caregivers residing in Grey and Bruce Counties. The study participants provide detailed descriptions of their understandings of spiritual care and who is able to offer it. Interpretive phenomenological analysis was employed to code the research data and discover emergent themes. Results of the study indicate how spiritual care can help dying persons and their caregivers experience connection and support to people and traditions they consider necessary to die well. The effective delivery of end-of-life spiritual care also provides personal inner resources including hope, comfort, self-worth, strength to cope, and peace of mind. Participants consider these to be factors that contribute to a good death. Dying persons and their caregivers also expressed how residing in the rural region of Grey and Bruce Counties contributed positively to their experience of a good death.

Based upon the research findings the researcher presents recommendations for best practices in end-of-life spiritual care. These practices would support the important role spiritual care has in helping dying persons and their caregivers address needs, relieve suffering, improve quality of life and enable the experience of a good death.

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Dr. Kristine Lund served as my thesis advisor who wisely and affirmatively shared of her deep breadth of knowledge and skills. I am thankful for her encouragement and insight which helped to make this a meaningful and exciting learning experience. Dr. Thomas St. James O'Connor, Dr. Colleen Lashmar and Dr. Brice Balmer served as members of my advisory committee. They also offered important reflections and commentary during this journey and I thank them for their support and encouragement. It is important to express my appreciation to Donna Mann who spent a significant amount of time and energy reading, reviewing, coding and theming the research interview transcripts. My conversations and communications with Donna both affirmed and granted insight into the findings of this project.

There are other community groups and people who supported my work and need to be acknowledged. I thank the church family of Faith Lutheran Church where I serve as the parish pastor. Their offers of prayer, encouragement and finding time to enable me to write the thesis paper have been appreciated immensely. I also thank the people of the Saugeen Memorial Hospital, the Saugeen Memorial Hospital Foundation, and the Grey-Bruce Healthcare Chaplaincy Council for all their various forms of support during my years of study. It is also important to thank my day-chaplain colleagues who supported me with prayer, wisdom and efforts to find willing participants for the study.

Dr. Angela Schmidt is my colleague, supervisor, school-mate and friend whose endless encouragement, inspiration and sharing of wisdom will always be appreciated and remembered.

Finally, I thank my dear wife Margo for bearing with me as I disappeared into thesis work during the last couple of years. Her love, patience, understanding, support, prayers, encouragement and listening ear have meant more to me than words can describe.

I wish to dedicate this thesis to all dying persons.
May your voice be heard and your care be fulfilling.

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Chapter 1: Introduction

“In this world nothing can be said to be certain, except death and taxes.”

- Benjamin Franklin in a letter to Jean-Baptiste Leroy, 1789

Death is one of life’s only guarantees and all of us will go through a process of dying. For some this process is quick and painless. For others, dying appears as a long journey fraught with pain, struggle and suffering. I am a professional spiritual care provider who has been invited to journey with dying persons and their families who fall into either category and many others whose journeys come somewhere in between the two ends of the spectrum. My work as a spiritual care provider has also granted me the opportunity to be a witness to what I would describe as some people ‘dying well’ and having a ‘good death’ while the same could not always be said for others. What is it that allows some people to die “well” while others do not? Does the spiritual care I offer contribute to the dying person’s and his or her family’s well-being? Could my spiritual care be different in some way, more effective, thereby contributing to the dying person experiencing a ‘good death’?

It is with these questions in mind I state the deeper intent of this research project. The question I explored through this research study is: **How do dying persons and their caregivers experience spiritual care in their home as an aid to “dying well” and having a “good death” in Grey and Bruce Counties, Ontario?** The purpose of this study is to explore with a sample of dying persons and their caregivers what they see is spiritual care, how they think it has helped them so far in their dying journeys and ways in which it might be improved both for themselves and anyone else facing their dying journey. It is anticipated that the knowledge generated from this study will result in detailed insights coming from the participants’ experiences which in turn can grant opportunities for reflection on how spiritual care is currently being offered to dying persons and their caregivers. These understandings will highlight further how spiritual care

needs to be considered so that it might evolve as an improved resource for dying persons in their final journey. This project utilizes a qualitative research methodology to explore and illustrate this phenomenon. The participants in this study include a purposively selected group of ten dying persons and nine caregivers residing in Grey and Bruce Counties.

In this chapter I will begin by providing a detailed personal and professional overview of the background and history leading to my research topic. I then present an overview of the research methodology I will employ in this project. The next section provides an overview of my background as the researcher. Finally, the chapter concludes with a brief overview of this research project's successive chapters.

Background and History

Death. No person can escape it and as human beings we know that each of us must someday face the end of our lives. Death is guaranteed for every person and how we die will be as unique an experience as the individuals themselves. Some of us will live well into our senior years and simply lie down in bed one evening as we peacefully fall asleep never to wake up again. Others will face an accidental and tragic end in a death the general population has come to describe as 'dying too soon' or 'before the person's time'. Still, other people from various walks of life will someday find themselves in their doctor's office listening in disbelief as their physicians say 'I'm sorry to tell you the tests have come back positive – you have cancer.' If not a diagnosis of cancer, then perhaps some other terminal illness. In any case, news of a terminal illness is enough to make a person feel like the weight of the world is suddenly crashing in on her or him. Where before dying and death were merely faint whispers residing in the nether regions of a person's life waiting to speak more loudly sometime in the distant future, now the

voices of dying and death are suddenly brought into a conversation people do not necessarily wish to have, but must have anyway.

In the spring of 2005 I was forced to have this conversation and I definitely was not desiring it. The results were in. After a battery of tests and exams over the previous year, my wife and I now awaited news of the results as we sat in a specialist's office at the hospital in Owen Sound. "You have a disease called Adrenoleukodystrophy", the doctor said. I questioned, "Ok, what does that mean?" He replied, "It's a rare disease that affects about 1 in 20,000 people and is neurodegenerative in nature." My questioning eyes cued him to continue. "The slight limp you've been experiencing as you walk will continue to get worse," he said. "How much worse?" I asked. "I'm sorry to say that unfortunately you could end up in a wheelchair and then a vegetative state which would eventually lead to death," he responded. "Could?" I questioned. The doctor continued, "Yes, although it's a rare disease, this tends to be the typical trajectory of the disease." "How long for this to happen?" I asked him. "Historically, the prognosis ranges from about 10 to 20 years, but certainly varies from individual to individual. I'll have you come in for regular check-ups so we can monitor the disease's progression." There it was: news of a terminal illness – the weight of the world crashing in on me. Death and dying staring me in the face and demanding I have a conversation with them. Plus, this wasn't a conversation they wanted to have only with me. One person may receive a terminal diagnosis, but its effect touches a whole family. Yes, a diagnosis is a personal experience, but it's also familial. News of my prognosis shook my wife's world too, especially as our minds raced to the future and we thought about her becoming my primary caregiver when the effects of this disease progressed. Our dreams of holding each other's hands in our golden years as we sat in a couple of rockers now changed. The way we had imagined growing old together had to be given new

consideration. The thought of dying was no longer a whisper in our lives, but the constant voice of an uninvited guest who kept nagging at me every time I walked and experienced the awkwardness of my gait. So began my conscious and undesired journey with dying and death.

Initially, my greatest struggle with this terminal diagnosis was not physical, but instead psychological. I was gravely concerned about the way I would die. The very thought of being in a vegetative state before eventually dying weighed heavily on me. Until the onset of this disease I had always been a person who appreciated being in control of my life and having full use of my physical functions and mental capabilities. Early on as I reflected on my prognosis I surmised that to lose these things, personally for me, would be worse than death itself. At least death would bring an end to a state of being in which I did not want to exist. Death would free me from any unwanted suffering the dying process would bring. These musings ignited my mind to remember how as a child my family would take our family pets to the veterinarian and have them put down, or euthanized, if some ill-fated or life-limiting condition befell them and we could no longer take care of them properly. I recall my parents instructing me and my sisters that if there was nothing more we could do to alleviate the animal's suffering, it was kinder to have a pet euthanized than to have them suffer. Given my recent diagnosis this made me question: if my disease should cause me to suffer greatly the effect of ill health, would it be kinder to end my suffering through some form of euthanasia?

My curiosity was peaked and in consideration of the question I began exploring a plethora of information that was available pertaining to people with terminal illnesses who were seeking to end their lives through a form of euthanasia. I was surprised to read in the media of a great variety of people from across the globe who knew they were actively dying and were requesting assistance to end their lives. Indeed, I also learned of some places like the

Netherlands and Montana, Oregon and Washington in the United States that have legalized Physician Assisted Suicide as a means to ending a person's life. Currently, other places like British Columbia and Quebec continue to debate such issues in courts and legislation. I also began to notice a common theme arising in the reason for such requests as I perused the stories and examined various studies relating to care at the end of people's lives and why people would request assistance to end their lives. The commonly cited reason for people's request to end their lives was so that they would not have to suffer. Their suffering, as they described it, came in many forms, but was often a form of suffering that could have been helped or even prevented, especially if the care they were receiving had tended more adequately to their needs. Physical suffering could have been addressed through better administration of pharmacological resources. The availability of effective counselling could have addressed various forms of mental anguish people were experiencing as part of the dying process. Companionship could have alleviated some of the loneliness dying persons were experiencing. Spiritual care may have helped to bring comfort and peace of mind to some of the spiritual struggles people were going through as they were dying. Better care to a dying person's needs appeared directly proportional to their sense of well-being and a diminished experience of suffering. Conversely, poorer care was often equated with increased suffering. Inattention to a dying person's needs resulted in a perceived deficiency or gap in the delivery of care. Time and again it was described how improving care to dying persons could in turn reduce their perceived and actual experiences of suffering. This, then, could also reduce the possibility of a person's request to end his or her life. Quite ironically, Derek Humphry, executive director of the Euthanasia Research and Guidance Organization in Junction City, Oregon, argues that right-to-die activists deserve a share of the credit for sparking an interest in palliative care. "In an odd way, the right-to-die movement has improved the

quality of care of the dying in American enormously” (Worsnop, 1997, p.775). Indeed, the growing interest and debates regarding Physician Assisted Suicide and other various forms of euthanasia has also sparked a growing interest in hospice and palliative care as a means to helping people die well.

I was struck in this initial search primarily by the revelation that improved end-of-life care could help to alleviate the various forms of suffering a dying person might be experiencing along with his or her family. Unfortunately, as a review of empirical evidence will show later in this research paper, deficiencies and gaps do exist in palliative care, needs go unmet and the result is unnecessary suffering in the dying process. If these gaps could be addressed there could be the potential for less suffering in a dying person’s journey. This could in turn improve a dying person’s quality of life and result in an increased opportunity of the person dying well and actually experiencing a good death. Dr. Balfour Mount, a veteran Montreal surgical oncologist instrumental in the development of palliative care programs in Canada affirmed this sentiment. During his lifetime of developing palliative care programs and caring for dying patients he reflected the belief that palliative care, if offered and administered properly, would not only help to eliminate a dying person’s suffering but also reduce if not remove altogether any desire to consider ending their lives. (Schadenberg, 2013)

My personal prognosis inspired these initial discoveries and soon developed into a deeper quandary for me regarding professional practice. In many of these studies it was noted how spiritual care could also be employed as an effective resource to tend to the needs of dying persons and aid in alleviating their suffering. Further, as the literature review chapter will demonstrate, studies have shown how spiritual care could actually improve a dying person’s quality of life at the end of his or her life. I had always assumed the care I offered as a spiritual

care provider had been useful, but now I was compelled to reflect upon it more seriously. As a professional spiritual care provider I wondered how effectively I had offered spiritual care to dying persons over the years. Did the spiritual care I offer to dying persons and their families help alleviate any suffering they were experiencing? Did the spiritual care I offer the dying person and their family help to improve the quality of their end-of-life journey together? Did the spiritual care I offered the dying person help them to die well?

As I challenged myself to reflect on these questions a narrative from my recent past readily came to mind that I share now for illustrative and reflective purposes.

“We’re wondering if you would be willing to do Dad’s funeral. He – we – appreciated your visits so much and the care you’ve given us during this time. It’s really helped us and made a rough time not so bad. We know Dad would appreciate it if you could do his funeral. So would we.”

Four days earlier I had never before met the deceased father or any of his family. The charge nurse of the in-patient ward referred me to this family during one of my routine visits to the local hospital where I am the part-time chaplain. The family hadn’t requested a visit of me. The referring nurse simply thought the family might appreciate a visit from me if I had time to drop by the patient’s room. The patient had an inoperable brain tumour and after months of unsuccessful treatments had been told he was nearing his death. I entered the palliative care room where I introduced myself as the chaplain to the patient and family and asked them if they would like a visit. With somewhat quick, questioning glances to one another they looked for clues in each other’s faces as to whether or not they would collectively like a visit. Dad smiled slightly with a gentle nod of his head and the rest of their faces then softened in turn. Eventually

a woman who I later learned was the patient's eldest daughter said "Yes, we'd like that." So began a three day journey offering spiritual care to 'Dad' and his family.

We had what I would describe as a pleasant visit during our first encounter with basic introductory questions enabling us to become better acquainted with one another and the situation 'Dad' and his family were facing. The only talk about religion or spirituality in our first conversation was to inform me that the family had always considered themselves 'spiritual', but not 'religious'. "We don't go to church or anything like that, but we believe in God," the eldest daughter shared. As I sensed our initial visit coming to an end I asked the patient and family if there was anything I could do for them before departing from them. "No, not at this time", came the response. I offered, "Would a prayer be helpful?" "No, not right now. Maybe when you come back," was the answer. "Ok," I thought to myself, "One more question I usually ask, just in case..." I ventured, "Is there another minister or spiritual care provider you'd like me to get in touch with for you?" This time 'Dad' replied, "No, that's ok. We don't have anyone we normally associate with, but I wouldn't mind if you could come back again." Indeed, I could and I did each of the following days. As I met with the family over the next couple of days it became a practice to gather around 'Dad's' bedside and say a prayer. Then on the day that 'Dad' died I was again keeping vigil with the family at the father's bedside when he breathed his last breath.

This is only one encounter among many similar experiences I have participated in during my years as a professional spiritual care provider. Yet, in this particular story and in similar experiences I have had in my work, I have often wondered what would have happened if I hadn't shown up that first day. What if the patient had been able to remain at home during 'Dad's' last days before death? It certainly appeared that the patient and family appreciated the care I offered them in their time of need. So much so that the now bereaved family further sought out the

possibility of my extended care to officiate at their father's funeral. If the patient and family had never met me, would they have received spiritual care in some expression or another that would have supported them during the patient's final days? Or would they have been missed? Would their needs regarding spiritual care have remained unattended? Would they have experienced a gap in the system of spiritual care? Certainly, the family described the care I offered them as helping make a 'rough time not so bad.' If the patient and family had not received spiritual care in this way, would the 'rough time' have remained 'bad'? Would they have had to endure undue suffering that in part could have been alleviated through spiritual care? Did spiritual care help the patient to die well and have his family touched in a positive and supportive way in the process? Perhaps more than anything the essence behind the reasoning of these questions is directly in line with the question I seek to answer through this study: what was the dying dad's and his family's experience of the spiritual care I offered as an aid to dying well and having a good death?

This one story is a common narrative I regularly hear recounted in a similar form by my colleagues in chaplaincy and other spiritual care professionals in Grey and Bruce Counties. The context and characters may be slightly different. It might be a mom, grandma or uncle who is dying at a nursing home or some other hospital in the region. Still, the family members gather around the deathbed to hear scripture read or pray with the resident chaplain or spiritual care provider who they only met just days before. Many times after the loved one's death the spiritual care provider hears from the family how his or her care helped to make a bad situation better, to bring comfort and peace amid the suffering the dying person and family were experiencing, and to help the person die well and the family know a good death.

Yet, for every story of spiritual care tending to the needs of a dying person and family there are also as many stories of needs going unmet by a lack, deficiency or gap in spiritual care. Times when a dying person may have wanted to see a chaplain and one was not available. Or perhaps a family called their resident clergy person but could not reach him or her. The family left a message on the machine requesting he or she come to ‘Mom’s’ home as quickly as possible because she’s dying and would really like the minister to pray with her. Unfortunately the minister doesn’t get the message until the next day after ‘Mom’ has already passed. Personally I know my full-time congregational duties limit the available time I can dedicate to my responsibilities as the part-time chaplain at the local hospital. In between visits I sometimes notice obituaries in the paper stating someone died during the brief time frame when I was unable to be at the hospital. Did they receive some form of spiritual care in my absence, if it was their desire? Or did that component of care end up being missed? Again, I am not alone in these wonderings. My spiritual care colleagues in Grey and Bruce Counties concur with similar stories of frustration and missed opportunities to offer spiritual care to dying persons and their families.

It is the culmination of all these personal and professional experiences and reflections that have excited me to explore the topic of this research project. Indeed, spiritual care at the end of a dying person’s life may help to alleviate his or her suffering and improve the quality of the dying journey so that she or he may die well, but admittedly gaps and deficiencies exist in the provision of spiritual care which have the potential to limit how well a person might die. Therefore, the specific research question arising out of this problem that I intend to examine is this:

How do dying persons and their caregivers experience spiritual care in their home as an aid to dying well and having a good death in Grey and Bruce Counties, Ontario?

It is anticipated that through a better understanding of the experiences of dying persons and their caregivers, more informed decisions and actions regarding spiritual care can be considered for inclusion in the palliative care offered in this region. New understandings of dying persons and their caregivers' experiences will hopefully assist palliative and spiritual care providers to determine how best to incorporate spiritual care into the provision of care for dying persons. This, with the hope that needs are better addressed and the quality of care is improved. As a spiritual care provider who lives and works in this geographical region and has also been diagnosed with a terminal illness, it is my intention to consider what these new understandings arising from participant experiences mean for my personal and professional well-being and practice. To shed light on the participants' experiences and discover meaning in their sharing, the following are also given consideration as sub-questions to the main research question:

- 1) What is the participants' understanding of spiritual care?
- 2) What does 'dying well' or a 'good death' mean to them?
- 3) How do they envision spiritual care as a resource to dying well?
- 4) In what ways do dying persons and caregivers think spiritual care needs to be improved in Grey and Bruce Counties so it is more beneficial for recipients?
- 5) How do they think residing in Grey and Bruce Counties might affect the care they receive?

The following section provides an outline of the approach I utilized to conduct this research study and address the research question.

Research Methodology

In order to explore this question and discover dying persons' and their caregivers' experiences of spiritual care as an aid to dying well, it is important to have participants in this study define and describe their experiences in their own way. A qualitative study is engaged to explore these definitions and descriptions. In particular, a phenomenological qualitative study is employed as a way to find meaning from the participants' experiences. In this type of qualitative study, researcher and participants co-construct the narratives through the questions that are asked by the researcher. With the approval of Wilfrid Laurier University's Research Ethics Board, I studied the experiences and perceptions of 10 dying persons and 9 of their caregivers all residing in either Grey or Bruce Counties. Participants who were dying persons were aware of their palliation. Caregivers who participated in the research interviews were primary caregivers comprised of family and friends. I selected this criteria purposefully as I desired to learn the experiences of non-professional caregivers who consisted of family and friends. Therefore, professional health care workers were not considered for inclusion in this study and were excluded from participating in the research interviews.

Semi-structured interviews were the primary source of data collection. Field notes and a research journal complemented the interview data. All interviews occurred in the homes of the participants except for one which occurred in the Owen Sound site of Grey Bruce Health Services. The intent of the initial study design was to interview dying persons and their caregivers in their homes where we would also explore together their experiences of spiritual care while in their home settings. It was not my intention to interview dying persons who were in an institutional setting like a hospital or nursing home. However, as the study progressed I was referred to a dying person who deeply desired to participate in the study. Shortly after our

initial telephone conversation this person was admitted to hospital and still desired to participate in an interview. After obtaining the necessary approval from hospital's ethics committee an interview was conducted with this dying person in her hospital room. During the interview the participant was encouraged to reflect on her experiences of spiritual care when she was in her home setting. The information obtained through interviews with all 19 participants formed the basis for the overall findings of this research study. Interviews were audio-recorded when permitted by the participants and transcribed later by the researcher for purposes of data analysis. One household containing one dying person and one caregiver did not wish to have the interview audio-recorded. In this case I documented their responses in hand-writing.

I employed an interpretive phenomenological analysis to analyse the interview transcripts and responses for codes and an eventual understanding of themes emerging from the data. To assist in ascertaining the reliability of these findings I conferred with a spiritual care provider of the CCAC in Waterloo County who specializes in spiritual care to dying persons in their homes. Waterloo County is located to the south of Grey and Bruce Counties and separated from the two by Wellington County. During the entire research process I regularly shared my reflections and emergent findings with a colleague who offers spiritual care throughout Grey and Bruce Counties. She in turn offered reflections and insights in the process of my research study. Her work affirmed my research findings and help to clarify the themes I saw emerge from the data.

A more detailed explanation of the complete Methodology utilized in this study will be presented in Chapter 3 of this paper.

The Researcher

I have entered into this research and interpret its findings from the viewpoint of being a Christian who has been an ordained minister in the Evangelical Lutheran Church in Canada since 1999. Since ordination I have served two congregations. The first congregation I served for three years maintained a membership of approximately 400 people and was in the rural setting of the village of Milverton, Ontario. My successive and current ministry is in a congregation of approximately 250 members in the town of Port Elgin, Ontario. This town is located in Bruce County and I reside on a farm 10 kilometers east of the town. Bruce County also represents one of the geographical regions contained in this study, the other is Grey County which neighbours the eastern border of Bruce County. During my tenure as a parish pastor I have been honoured to offer spiritual care to slightly over 100 people who were dying and their respective families. I offered this care in settings such as the dying persons' homes, nursing homes, hospital emergency departments, in-patient wards, and palliative care wards. Since January 2010, I have also served as a part-time Day Chaplain at the local hospital in Southampton, Ontario. This is a sixteen in-patient bed hospital with an active emergency department serving approximately 21,000 out-patients a year. In my role as the hospital chaplain I regularly offer spiritual care to dying persons and their families. This occurs in the dedicated palliative care room of the hospital's in-patient ward as well as in the general in-patient hospital rooms where some dying patients also live out their final days. Together, the towns of Port Elgin and Southampton form an amalgamated municipality named Saugeen Shores with a combined population of approximately 15,000 people.

As a spiritual care provider in these various capacities I also believe and have maintained in my years of ministry the importance of paying attention to people's needs, in particular, their

unmet needs. Where there is an unmet need in a person's life, I believe there is also an opportunity for ministry to occur through spiritual care. This is the inspiration for my involvement since 2007 as the organizer and lead facilitator of the Grief Support Group of Bruce-Grey. One day years ago while offering care to a bereaved widow in my congregation she explained how she was travelling two hours (one way) each week to be a part of a grief support group in the urban center of Kitchener-Waterloo, Ontario. When I questioned her as to why she travelled this distance for a grief support group she informed me it was because there were no services like that available anywhere in Grey and Bruce Counties. Learning of this deficiency in the system of care in my region I took it upon myself to make some inquiries into what would be required to develop a grief support group program that could effectively serve residents of Grey and Bruce Counties. I quickly discovered a few other people interested in developing this idea and together we worked with the Victorian Order of Nurses (VON) Care and Support Coordinator for Grey and Bruce Counties to develop a specific program to serve our region. That original program continues today to serve residents in Saugeen Shores and the surrounding region. In the same time, the VON was inspired from this venture to seek out willing developers for grief support groups in other areas of Grey and Bruce Counties and to date four other programs have become available for those who might need them. Learning of one person's experience of ineffective availability of grief support for her journey inspired me to explore what might be done to minister more effectively in this regard to people in our area. In the same way, it has been an underlying and in-dwelling hope of this research project to explore dying persons' and their caregivers' experiences of spiritual care to see how this care might be helping them to die well. If from their stories and experiences it is discovered there are areas where spiritual care providers could be offering more effective spiritual care to dying persons and their caregivers –

according to what they see spiritual care as being for their dying journey, then my further hope would be to consider the steps that need to be taken to address the gaps people see existing in the system. Certainly, while I was developing my research proposal for this study I engaged in conversation with various hospice providers in Grey and Bruce Counties. These initial conversations proved fruitful in the sense that these providers are now curious to learn about the research's findings. These hospice providers have shared verbally with me that if the results are indicating shortfalls in the participants' experiences of spiritual care, then it will be important to work collaboratively to address any concerns in the current system. Indeed, as the Case Manager from South-West CCAC shared with me "If spiritual care is something our clients are wanting and needing and if we're not providing it, it's definitely something we'll have to consider incorporating into our program."(personal correspondence)

I also enter into this research study as a married person who has been diagnosed with a terminal illness since the spring of 2005. The old adage says 'who pastors to the pastor in his or her time of need?' Since my diagnosis I have reflected deeply on how I have been 'pastored to' in my time of need. This 'pastoring' has come in many forms as offered by colleagues, friends, congregants, and certainly my wife. Although I believe the spiritual care I have received has aided in my experiences as I deal with a terminal illness, there have also been occasions when I felt as though I had needs that were not met sometimes through the ineffectiveness of the care I was receiving or by not receiving care at all. I realize I carry these reflections and biases with me into this study. My illness has also progressed to a stage where I now walk with the assistance of a cane. As a younger person in his early forties this often serves as a point of curiosity for people to question my need for a walking device. When questioned by the participants during the research interviews I openly shared with them my own journey with a

terminal illness. I experience a common connection with other people I meet who have a terminal illness. They can understand and appreciate what it is like to live with dying and death constantly hanging over your head. I trust in these research interviews, participants may have also experienced that sense of common connection which may have granted them a trusting freedom to share more deeply with me of their dying journey.

I also share with the reader a perspective on my theological worldview and how I believe people come to know what they know in their lives. These views will help the reader understand more clearly my approach to spiritual caregiving and the design of this research project. I have previously stated I am a Christian spiritual caregiver and as such my theological worldview stems from my understanding and practice of the Christian faith. As a spiritual care practitioner and researcher I believe people come to know a gracious and loving God who has revealed God's self through the writings of the Old and New Testaments of scripture. This understanding of Christianity also embeds a fulfillment of God's promises to humankind contained in these scriptures and that God has come to dwell among humankind in the person of Jesus Christ. Through God's indwelling with humanity in Jesus Christ we have had the opportunity to know and understand God's love and forgiveness for us through the teachings and life of Jesus. Also, through God's living among us in Jesus I believe God knows deeply the extent of our human condition. As such, God knows intimately the joys and sufferings we face as humans. It is my further understanding that God continues to come to us and be with us in spirit in the joys and sufferings we experience in this life. In relation to the current research study this means we are not alone in our suffering, but can know God's presence with us in our experiences of spiritual care and the people, places and things that help us appreciate a sense of the divine with us.

Finally, my Christian theological worldview also understands that we have a God who desires to be in relationship with us. This same God calls us to be in relationship with fellow believers as a way to grow in our understandings of the nature of God and our faith. Through communal and personal theological reflection on our experiences of God we also have the ability to learn new insights about God and the implications these insights may hold for our faith journeys. This fits well with this project's research methodology that works in collaboration with the participants to enter into a place of reflection as a way to understand more deeply their experiences of spiritual care and their sense of the divine as they understand it in their dying journeys. Working collaboratively through the research interviews with the participants, it was also hoped this research project would grant affirmation and insight into the spiritual care experienced by dying persons and their caregivers. From this we have the ability to learn something new about these participants' experience of spiritual care in their dying journey and the resulting insights and implications for the practice of end-of-life spiritual care.

I now conclude this introductory chapter with a brief overview of the contents contained in the successive chapters of the paper.

Overview of Research Paper

Chapter 2 – Contains a review of the literature related to this research study. The chapter begins with a review of the current state of palliative care in Canada, its development and current practices. This chapter continues with an examination of literature related to the provision of spiritual care as a component of palliative care. There is also an exploration of studies related to dying persons and caregivers perceptions of dying well and what constitutes a good death. The final portion of this chapter reviews literature that explores whether or not geographic location,

for example a rural setting, affects the experience of spiritual care received by dying persons and their caregivers.

Chapter 3 – This chapter provides a detailed outline of the research project’s methodology. It was shared earlier in this introductory chapter that a qualitative research study was employed for purposes of this project. The study contained a purposive sample of 10 dying persons and 9 caregivers who resided in Grey and Bruce Counties, Ontario. These participants took part in a one-time semi-structured interview with the researcher. A form of interpretive phenomenological analysis was engaged to code interview transcripts and derive themes arising from the material.

Chapter 4 – This chapter is a presentation of the themes arising from the research interviews. Four dominant themes are reviewed: end-of-life spiritual care providing connection and support, end-of-life spiritual care providing personal inner resources, end-of-life spiritual care providing peace of mind, and the benefits of end-of-life spiritual care in a rural setting. The theme ‘spiritual care as connection and support in the dying journey’ will be broken down further to illustrate how connection and support occurs through a minister, laity, God or a sense of the divine, other care providers, family and friends, support groups, nature and physical contact. The next theme ‘spiritual care provides personal inner resources’ will focus on participants’ experiences of hope, comfort, self-worth, and strength in coping. The third theme ‘spiritual care provides a sense of peace in the dying journey’ describes how this occurs through guidance on the dying journey, fears being relieved, completing unfinished business, and experiencing peace in the family. The final theme regarding ‘the rural setting of Grey and Bruce Counties being perceived as an aid to spiritual care’ will describe three particular aspects that participants attribute to the effectiveness of care in a rural setting: a sense of friendliness and being ‘closer-

knit', the tendency to 'watch out' for one another, and the positive experience of end-of-life services and resources.

Chapter 5 – This chapter places the research study's themes into conversation with the content of the literature review in the following categories: connection and support, personal inner resources, a sense of peace, and rural appreciation. The chapter continues with a presentation of the interrelatedness of the research study's themes. This is followed by a description of the limitations and strengths of the current study, a presentation of considerations for future research, and recommendations for spiritual care practice arising from the current study.

Chapter 6 – This chapter contains a theological reflection on the experiences of the current research study and more specifically on the theme of spiritual care providing connection and support in the dying journey. The theological reflection model employed for this task is from the Spiritual Wisdom tradition and is described in *The Art of Theological Reflection* (1994) by Patricia O'Connell Killen and John de Beer. A thorough description is provided in this chapter of the steps involved in this method of theological reflection. I then engage in this process and provide a description of the emerging insights for the reader's consideration. The chapter concludes with an overview of the implementation of these insights. A brief section of concluding thoughts follows the theological reflection.

It is important to consider what others have offered scholastically and empirically to the conversation of spiritual care to dying persons and their caregivers. To do this we now turn our attention to a review of the pertinent literature.

Chapter 2: Literature Review

"How people die remains in the memory of those who live on."
- Dame Cicely Saunders

The purpose of this research study is to examine how dying persons and their caregivers experience spiritual care in their homes as an aid to dying well and having a good death in Grey and Bruce Counties, Ontario. Literature and studies related to spiritual care for dying persons specifically in Grey and Bruce Counties is essentially non-existent. This research project, then, serves as a small but important voice to add to the initial conversation of improving hospice palliative care that has recently slowly started to take place in these counties. Although some studies have explored issues related to physical health and dying in Grey and Bruce Counties (Wonnacott and Ferguson, 2011), I was unable to locate any resources specifically addressing spiritual care as part of the palliative care offered to address end-of-life health concerns. There are, however, various studies and reports from across Canada and internationally that address the issue of palliative care in general as part of end-of-life care to dying persons. These studies were conducted primarily with dying persons who were hospital patients, hospice patients and in a minimal number of cases residents in their homes. Studies pertaining to end-of-life care and caregivers appeared limited. In some cases spiritual care receives brief mention in these articles and is worthy of an examination in this review. Before looking into this, however, the phenomenon under study of 'how dying persons and their caregivers experience spiritual care to help them die well' is rich in various elements that need to be considered individually by the literature before examining how they might contribute to the research question as a whole. Any exploration related to care for the dying also needs to examine the concept of palliative care and its provision as a resource for care at the end of a person's life. Therefore, this literature review will first examine material related to palliative care, its origins, purpose and experience in the

Canadian context. The reader will then have a better understanding of how the other elements of the research question related to spiritual care and a good death come forward from the intended goals of palliative care. As such, the review will then explore literature related to spiritual care and the role it plays, along with spirituality, in contributing to the efforts of palliative care as an end-of-life resource for dying persons. A review of studies will be presented examining how the effective delivery of spiritual care can contribute to the quality of life people may experience as part of their dying journey. Inherent in this concept is the need to examine the discrepancy that may exist between the care dying persons hope to receive to address their needs and the care they actually do receive. The discrepancy that often exists between the two serves as an indicator to how well or how poorly dying persons perceive the quality of care they are receiving.

Depending upon how well they believe their needs are being met during the dying process will also affect how they perceive their experience of dying well and having a good death. Therefore, the literature review will also examine studies and articles that explore the concepts of dying well, a good death and dying persons' perceptions of each. Finally, how all of these aforementioned elements exist for dying persons and their caregivers within the geographical region of this particular research study also needs some consideration as part of this review.

Grey and Bruce Counties in Ontario are primarily rural in nature with the largest urban centre having a population of 21,688 people (Statistics Canada, 2011). One needs to consider if rural and urban contexts might affect the provision of palliative and spiritual care as an aid to helping people die well and have a good death. Therefore, an examination of literature concerning this issue will conclude this chapter.

Palliative Care

Origins and Early Beginnings of Palliative Care in Canada

Palliative care finds its roots in the history of the modern hospice care movement whose moniker ‘hospice’ traces its meaning back to the 4th century of the Common Era. During that time period there was a Roman matron named Fabiola who in commitment to her Christian beliefs was known for opening her home to pilgrims, the sick and the destitute. At that time she chose the word ‘hospice’ to refer to the guests or strangers, their hosts and the relationship that developed between them as true hospitality. This emphasis on the personally shared relationship of hospitality among people has carried down through the ages and remains central to the philosophy of the modern hospice today. The more recent history of hospice dates back to the mid 1960’s when Dame Cicely Saunders first conceived of the modern hospice movement in the United Kingdom as a way to care intentionally for dying persons (Saunders, 1996). In 1967 she established the first modern hospice facility, St. Christopher’s Hospice in London, England, where the aim was to help people not only die peacefully, but to live until they died with their needs and their potential met as fully as possible (Saunders, 2000). Numerous people visited St. Christopher’s in its early years to observe its functioning and philosophy in action. One such person was a Canadian named Dr. Balfour Mount from Montreal who today is known as the person instrumental in developing Canada’s first palliative care programs. After visiting St. Christopher’s Hospice, Mount returned to Canada inspired to bring the hospice philosophy of holistic care to dying persons in Canada. Dr. Mount would come to coin the term “palliative care” in 1975 so that one term would be acceptable in both English and French as he brought the movement to Canada. At that time palliative care programs developed primarily within larger healthcare institutions, while hospice care developed within the community as free-standing,

primarily volunteer programs. Over time these programs gradually evolved from individual, grass-root efforts to a cohesive movement that today aims to relieve suffering and improve quality of life for those who are dying from an illness. To recognize the convergence of hospice and palliative care into one movement with a common vision of practice, the term ‘hospice palliative care’ was coined. While ‘hospice palliative care’ is the nationally accepted term in Canada to describe care aimed at relieving suffering and improving quality of life, individual organizations may continue to use “hospice”, “palliative care”, or another similarly acceptable term to describe their organization and the services they are providing (Canadian Hospice Palliative Care Association, 2002).

Purpose and Experience of Palliative Care in Canada

Holewa and Higgins (2003, p.219) declare “palliative care is an answer to the prophetic plea of Isaiah 40:1 “Comfort my people!”” Indeed, the goal of palliative care is to comfort people – dying people. This comfort comes through an effort to alleviate any suffering a dying person may be experiencing, thereby improving their quality of life as much as possible until death comes. This notion is supported by the World Health Organization’s (WHO) definition of palliative care, which states,

Palliative care is an approach 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. (retrieved from WHO website www.who.int/cancer/palliative/definition/en/).

Carstairs (2010) states 90% percent of Canadians who die can benefit from palliative care. This corresponds with Plonk and Arnold's (2005) finding that only 10% of the population dies suddenly and therefore have no opportunity to benefit from palliative care. Carstairs (2010) also notes how the focus of palliative care is on preserving the quality of the recipient's life so that their suffering is minimized, but their experience of life is not.

So then, one might ask: how well are dying persons in Canada being comforted through the provision of palliative care? Is there a need for more research into dying persons' experiences of the care they are receiving? A review of the literature related to the current situation of palliative care in Canada would seem to affirm – 'Most definitely!' – there is a need for more research nationwide, provincially, and even with regards to smaller geographical areas as in the interest of the current research study. The Honourable Sharon Carstairs of the Canadian Senate was tasked with exploring that very question of palliative care provision during her time in office. In 1995, Carstairs was part of the Special Senate Committee on Euthanasia and Assisted Suicide that issued a report titled "Of Life and Death" (Carstairs, 1995). This report documented the disparities that existed across Canada regarding access to quality palliative care. Dudgeon and colleagues (2007) note how during this time other studies (see Romanow, 2002; Bruera et al, 1999; Wiles et al, 1999) conducted across the Canadian landscape noted similar disparities as well as other gaps in the quality of palliative care. These disparities included a lack of integration between health care and palliative care providers, unrelieved pain and symptoms, a lack of training in palliative care, and a lack of health care professional capacity in Canada. In 2000, the Canadian government formed a follow-up Senate committee that discovered and reported new concerns: inadequate collaboration among the various levels of government, a poor allocation of resources, and insufficient attention being paid to the end-of-life needs of

Canadians (Carstairs, 2000). These various reports served as a catalyst to inspire the federal government to take action and start addressing the deficiencies documented in palliative care in Canada. Actions included items like developing a national palliative care program and improved home care for dying persons. Still, even with the Canadian government taking these initiatives, recent studies and reports indicate palliative care in Canada still needs improvement if it is to serve as a resource that will help meet the needs of dying persons who are hoping to have a good death.

More recently, various reports have continued to examine the current practices of palliative care in Canada. In 2011, a Parliamentary Committee on Palliative and Compassionate Care issued a report on the state of palliative care in Canada. In the report the committee states that every Canadian is entitled to adequate palliative care to address end-of-life issues which may involve forms of suffering and discouragement. The committee further claims the issues involved in providing compassionate care are important to every Canadian. At the same time the report also notes how Canada is not providing adequate palliative care for all who need it. In fact, the committee notes that depending on where a person lives in Canada, only 16-30% of those who need palliative care receive it. Further, the committee notes that adequate palliative and end-of-life care will become increasingly essential as the number of Canadians requiring these services grows in future years. This growth is expected to occur shortly as the Baby Boomer generation begins its gradual entrance into senior years. As this occurs it is expected the number of Canadians over the age of 65 will increase from 4.2 million in 2005 to 9.8 million in 2036 (Carstairs, 2005). There is a desperate need to have adequate palliative care services in place to tend to the needs of this aging population. In October 2013, palliative care supporters in Canada's federal government proposed a private member's bill to the House of Commons calling

for a coordinated national response to continuing care to address inadequacies and improve the quality of end-of-life care in Canada. The bill was introduced by Libby Davies, the New Democratic Party's health critic and was seconded by Charlie Angus who added a motion to specifically establish a national strategy on palliative care. They share, "We know that many, many Canadians are falling through the cracks, we know that there's not enough home care, long-term care or palliative care to meet the current demand in Canada" (*Leader Post*. November 1, 2013. Retrieved from <http://www.leaderpost.com/health/presents+bill+improve+life+care/9111548/story.html>). The hope is for the Minister of Health to establish an advisory committee to review the current conditions of end-of-life care in Canada and then work toward creating standards that would improve the quality of care across the nation.

At the provincial level, the recent debate of Bill 52 in the Quebec National Assembly regarding end-of-life care and the legalization of euthanasia has sparked a renewed interest in reviewing the delivery of palliative care as an effective means to reducing the suffering of dying persons. Advocates of palliative care claim how with the proper delivery of palliative care all people have an opportunity to die well and with dignity. Rose DeAngelis, nursing director and assistant executive director of the West Island Palliative Care Residence – a residence in Montreal caring for dying persons through hospice palliative care services, and Teresa Dellar who is executive director of the same residence, recently offered their opinions on the debate. They shared:

Our conclusion – and that of practically everyone we know in the area of palliative care – is that the best way to help the terminally ill have a better death is decidedly not to simply kill them with drugs. What is required instead is more and better specialized palliative

care, to meet the needs of these patients and their families. Palliative care affirms life, while helping ease the physical, emotional and social distress of the patient and his or her family. (*Montreal Gazette*, September 26, 2013)

They further shared how palliative care teams across Canada already possess the knowledge and expertise to alleviate practically all suffering. Where the system stumbles is in the delivery of these skills and resources: they are not always applied as they should be nor are they readily accessible to all who might need them. Recently, the head of the Canadian Medical Association, Dr. Louis Hugo Francescutti, whose mother recently died after receiving palliative care from the West Island Palliative Care Residence, shared his thoughts on the debate and the place of palliative care in helping Canadians die well (*Montreal Gazette*, November 8, 2013). He noted how palliative care is grossly under-funded and access to quality care is spotty in Canada, but still, no one should fear dying alone and in pain. Francescutti believes Canada desperately needs a national, well-funded strategy on palliative care so that dying persons and their families can benefit from expert support as early as possible. Plus, he also believes that rather than looking for quick-fix solutions in euthanasia or medically-assisted dying, policy-makers should listen to the people who deal with dying people daily.

The president of the Ontario Medical Association, Dr. Scott Wooder, shares this vision. In a recent interview he noted how improving the provision of palliative care in the province of Ontario is an item on his agenda receiving top priority during his one-year term in office. When people are dying he wants to know what can be done to help make that experience better. He shares “We want to make sure we manage pain and the patient's mental health. We need to meet their spiritual needs and help them tend to family relationships.” (*Windsor Star*, October 18,

2013). Dr. Wooder believes the key is making palliative care more accessible and consistent in its quality.

In Ontario in the mid 2000's an initiative was developed called the Palliative Care Integration Project (PCIP) to address gaps that were noted in the system of care arising from the results of studies conducted in southeastern Ontario between 1998 and 2000 (Fitzgerald, 2000; Chapman, 1998; Ostic, 1999; Rosenbaum, 2000). The deficiencies that were noted primarily concerned the unmet needs of patients and families, and a lack of coordination and communication among the various palliative care service providers. The PCIP's primary objective was to ensure high quality palliative care delivery to cancer patients through the development of service integration across the continuum of care. This model of palliative care delivery was eventually adopted as part of the Ontario Ministry of Health and Long-Term Care's End-of-Life Strategy for implementation across the province of Ontario. In 2008, Seow and colleagues conducted a follow-up qualitative study to assess if the quality of end-of-life services to clients across the province had improved under this new strategy. The researchers determined there were improvements in the delivery of palliative care. In particular, families felt more supported navigating the health care system and more of their needs were being met. Seow and colleagues (2008) cautioned, however, that barriers and challenges still remained in the delivery of high quality end-of-life care and further research was needed to achieve quality end-of-life care for dying persons in Ontario.

In 2011 a report was produced titled "Declaration of Partnership and Commitment to Action: Advancing High Quality, High Value Palliative Care in Ontario". This report was the result of a collaborative effort from over eighty stakeholders from across Ontario who shared a vested interest in the quality of palliative care in the province. The committee worked to achieve

a common consensus on a vision for palliative care in Ontario and offered suggestions to make that vision a reality. In particular, the group outlined the gaps that existed in the current delivery of palliative care and offered a new model of care to address these gaps and improve the quality of care. The deficiencies noted in the system of care include: how services were lacking in many areas, especially those in a rural setting; some dying persons and their caregivers lacked access to appropriate support and resources; dying persons and their caregivers were having challenges locating effective support; and palliative care was poorly understood by dying persons, their caregivers and in some cases service providers. The working group offered suggestions to address these concerns and two of them are particularly pertinent to the research study at hand. One of these suggestions was the need to measure the experience of palliative care by individuals and caregivers so they could then participate in the planning of services and improvement of the care offered to dying persons and their caregivers. The second goal was to measure the system's performance in the delivery of palliative care from the perspective of the individual and caregiver to measure their quality of life and quality of death. These two goals are also underlying the current research project.

Another study builds on the intentions of these goals, although it originates from outside of Canada and is now slightly dated. Still, its findings are relevant to the question under study and so it is given a brief review. In 1998, Tierney and colleagues conducted a study in Australia with 42 hospice patients who were receiving palliative care to assess the relationships between their physical and psychological symptoms, quality of life and satisfaction with the care they were receiving. The researchers comment that if palliative care programs are to improve the quality of their service it is necessary to know what makes patients satisfied with their care and what comes up short. Tierney and colleagues assert from their study's findings that

improvement in palliative care will require focusing on the lives of dying persons and especially concerns related to support at the end of their lives. They conclude that dying persons can assess their care and provide valuable information for improving palliative care.

As the voices from these various articles and reports show, there has been and continues to be a need to review the current conditions of palliative care in Canada and address gaps in the system of care. Quality palliative care is deemed a right of every dying Canadian to help address their suffering with the intent of dying well, but deficiencies in care may limit a dying person's ability to experience a good death. The literature reveals that palliative care is certainly being discussed and reviewed at many levels and in many regions throughout Canada and the province of Ontario. People are beginning to realize the importance palliative care can play in addressing the needs of dying persons and helping them to die well. Although studies show how improvements have been made in some areas, the literature also demonstrates there is still work to do and more to understand about palliative care in Canada.

Spiritual Care

The reports, studies and articles reviewed in the previous section suggest that there is room for improvement of palliative care in Canada and notably the province of Ontario, which provides the context for the current research study. We now turn our attention to the literature relevant to spiritual care as a dimension of effective palliative care in consideration of the research question's exploration of dying persons and their caregivers' experience of spiritual care. As noted in the introduction of this chapter, there are no studies related specifically to the spiritual care offered to dying persons and their caregivers in Grey and Bruce Counties. However, there is literature available that can help to shed light on the general experiences of

dying persons and the spiritual care offered to them. This section of the literature review will begin by exploring spiritual care as it relates to palliative care, followed by an exploration of spiritual care and spirituality as part of the dying process. Then the spiritual needs of dying persons will be considered and how addressing these needs can improve quality of care. Lastly, some brief consideration is given to who might offer spiritual care to the dying.

Spiritual Care and Palliative Care to the Whole Person

The World Health Organization's definition of palliative care states that spiritual care is essential to good palliative care. Professor and researcher Christina Puchalski also shares in a recent editorial:

Since the beginning of hospice and then the development of palliative care, spirituality has been recognized as an essential element of palliative care. Cecily Saunders, the founder of hospice, dedicated her life to the care of dying patients by attending to the 'total pain' of the patient, a term she described as encompassing spiritual distress as well as psychosocial and physical distress. Her model was eventually described as the Biopsychosocial spiritual model, which is the framework for palliative care. (*Progress in Palliative Care*, Vol. 20(2), 2012, p.63)

Indeed, Saunders (1996) herself understood how the initial vision of hospice care was to facilitate a spiritual journey. In order to offer palliative care effectively one must tend to the whole person – inclusive of his or her spirituality and the journey he or she is travelling as part of the dying process. Sulmasy (2002) adds to this understanding of palliative care that according to this biopsychosocial-spiritual model everyone has a spiritual history that helps shape who each person is as a whole person. When a person receives a diagnosis of a terminal illness and is

suddenly faced with a more imminent prospect of dying it affects the person as a whole including aspects of his or her spirituality. This ties in with Byock's (1997) and Emanuel and Emanuel's (1998) position regarding palliative care's need to assess and address a dying person's whole state of being. Providing a quality, comfortable death occurs when a dying person's physical needs are met as well as his or her social, psychological and spiritual and religious dimensions of care. Pronk (2005), in a review of the literature on spiritual care at the end-of-life, also supports this view. Pronk remarks how palliative care can only claim to provide care to the whole person if it is considerate of dying persons' spirituality and attending to their spiritual needs during the dying process. The hope and aim of good palliative care, therefore, is to tend to many important dimensions that encompass a dying person's life. A person's spiritual needs are an important part of the whole person and require as much attention as physical, psychological and emotional concerns.

In a report of The Parliamentary Committee on Palliative and Compassionate Care (2011, p.32) it is stated that "palliative care research is vitally needed at the psychological, social and spiritual level dealing with issues related to grief and bereavement, human dignity, and personal sense of meaning." The committee further states the importance of developing a research agenda dealing with the multifaceted aspects of good palliative care. This would include psychological, social, spiritual issues, and familial and caregiver support. The group claims that research is needed in a broad spectrum of palliative care concerns, not simply medical ones. Certainly, in reviewing the existing literature one can appreciate there has been a long-time interest to understand better the concept of spiritual care and the spirituality of people's lives, but spiritual care specifically in relation to dying has only gained prominence in research in the last couple of decades. It has only been in more recent years that a greater emphasis has been placed on studies

examining the importance spiritual care and a dying person's spirituality has as part of the dying process. Harrington (2012) in an article reviewing spirituality over the last four decades, notes that since the 1980s studies have captured the importance of spiritual well-being for the population at large. However, Harrington also explains how it has only been in more recent years that research studies have been conducted specifically regarding spirituality and health. Therefore, it would appear there is also a growing interest in studying how this phenomenon occurs in society as the population continues to see the need and importance of spiritual care to dying persons and their caregivers.

Since the early 1990s Betty Ferrell, a researcher and professor at the City of Hope Medical Center in Los Angeles, has been studying what terminal cancer patients need as they approach the end of their lives. She observes how physical, psychological and social concerns are being addressed, but spiritual care and tending to a person's spirituality are still lacking (Ferrell, 2013). While there are many studies available on clinical issues related to end-of-life, there is only a small quantity of research regarding spirituality and end-of-life. However, Nelson-Becker and colleagues (2013), after reviewing cases from clinical experiences of life-limiting illnesses, note the increasing number of pertinent studies showing how religion and spirituality in issues related to end-of-life care have become increasingly recognized.

Reviewing the literature also revealed there have been some barriers to research involving dying persons and their caregivers. Due to the sensitive and vulnerable nature of the particular population who would be under study in end-of-life research, there are those who would limit a researcher's contact and involvement with them. In a review of the literature it was discovered that a key barrier to involving dying persons and their caregivers in end-of-life research is the gate-keeping that occurs by health care professionals and ethics committees who

maintain the safeguards so no undue harm comes to this vulnerable population (Kendall et al, 2007). However, the view held by these overseers is not the same view of dying persons and their caregivers. In fact, studies show the opposite to be true. Through a number of in-depth interviews and focus groups, Kendall and colleagues (2007) investigated the desire of dying persons and caregivers to participate in end-of-life research. The findings suggest that dying persons and their caregivers want to participate in end-of-life research. The studies show how participating in end-of-life research presents an opportunity for dying persons and caregivers to give something back in return for the care they or their loved ones have received. Participating in end-of-life research also represents an opportunity to try and improve services and support for dying persons receiving care in the future. Bellamy and colleagues (2011) agree with these findings and add how participating in end-of-life research can enable a sense of personhood to be maintained and enrich the lives of those who participate. Further, Kendall and colleagues (2007) offer that the perspectives of the dying persons and their caregivers must be included in end-of-life research as a way to develop effective services and support in palliative care. In order to know what is effective and what is not it is important to elicit the opinions of those who are experiencing the care firsthand – dying persons and their caregivers. This coincides well with the claims of a Canadian researcher Stephen Workman from Dalhousie University in Nova Scotia who adds that dying persons and their caregivers should not be excluded from end-of-life research because the very research process itself can enrich the lives of the participants (Workman, 2007). Indeed, this principle reflects well the work of fellow Canadian researcher Harvey Chochinov (2010) who has developed an empirically based psychotherapeutic interview that places a person's illness within their life context and can enhance the dignity of the dying persons. As such, many potential benefits may arise from the participation of dying persons and

their caregivers in end-of-life research, both for the participants and those who will gain new understandings through the experiences of the participants. All of this, of course, while the researcher still maintains an ethical awareness and attention to the particular sensitivities and vulnerability this segment of the population may be facing as part of their dying journey.

Spiritual Care and Spirituality in the Dying Process

Several studies mention how spiritual care and a person's spirituality can serve as a resource to help them find meaning, purpose or transcendence in life during their dying journey. An interdisciplinary group of palliative care professionals gathered in 2009 in Pasadena, California at the National Consensus Conference entitled 'Improving the Spiritual Domain of Palliative Care' to develop guidelines for spiritual, religious and existential issues within the domain of palliative care. This group's definition of spirituality is supportive to the goals of a dying person's journey. Puchalski and colleagues (2009) reporting from the Conference define spirituality as "the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred" (p.887).

This corresponds with research indicating how spiritual care and dying person's spirituality often become an integral part of people's journeys as they engage in the dying process. Certainly, some earlier studies have demonstrated how this need to explore spiritual matters becomes even more relevant as dying persons journey closer to death (Smith and Maher, 1991; Anderson and MacElveen, 1988; Hinton, 1963; Leviton, 1986). In this same way Kearney and Mount (2000) claim that spiritual issues "lie at the very centre of the existential crisis that is terminal illness" (p. 361). Indeed, as dying persons address their end-of-life issues, their

mortality becomes an ever-present, increasing reality in their daily reflections. As dying persons confront their mortality in their dying journey, various studies and researchers (Nelson-Becker et al, 2013; Ferrel and Munevar, 2012; Harrington, 2006; Peck, 1997; Byock, 1997) have demonstrated how the time before a person dies can also become a time of spiritual seeking, growth and an increased awareness of the spiritual part of the self. This can occur even for dying persons who may not have previously considered or perceived themselves overly religious or spiritual. This heightened awareness of spirituality in dying persons causes them to take an inward journey to consider questions of life and death, which perhaps they had not explored earlier. McClain and colleagues (2003) demonstrated this point in a study that questioned 160 patients in a palliative care hospital to assess spiritual well-being, depression and end-of-life despair. The study revealed how dying patients struggle with questions about their mortality, the meaning and purpose of life, and whether a greater power exists, forcing them to contend with issues they perhaps had not considered before.

It appears the dying process and facing death can serve as a catalyst for dying persons to explore spiritual concerns and needs. This exploration is not limited to those who have an appreciation of religion or spirituality. Ellerhorst-Ryan (1997) encourages people to remember how spirituality applies to everyone regardless of their religious beliefs. A study by Hay (2006) indicates how there may in fact be something 'hardwired' in the human being that gives us a deepening sense of spiritual awareness when approaching death. As a result, a dying person may feel drawn to some expression of the divine, sacred or spiritual in a very natural way. This does not occur only for those who previously considered themselves spiritual or religious. In an interesting qualitative study of six dying persons, Collin (2012) explores how atheists may begin to seek a higher power or God. This study's findings reveal how dying persons who previously

had shown no interest in religion or spirituality may start searching to connect to some essence of the divine. Similarly, an earlier study by Smith and Maher (1991) revealed how over 50% of the participants in the study who were dying and identified themselves as “not involved in organized religion” had a need to talk about religious and spiritual matters. This becomes a journey all dying persons can take to explore what their experience of spirituality means to them as they open themselves up to the possibility of receiving spiritual care to help address issues they see arising as they confront death.

The earlier definition of spirituality from the National Consensus Conference (2009) described how all people seek meaning and purpose in their lives and dying persons need a connection to other people and something outside of themselves. It was also noted how other studies have revealed this spiritual search often becomes heightened when people are dying. Selman and colleagues (2011) concur reporting how spirituality refers to “those beliefs, values, and practices that relate to the search for meaning, purpose or transcendence, which may or may not include belief in a higher power.” (p. 730) Certainly this quest for meaning and purpose has been studied by others and is supported by O’Connor and colleagues (1997) who share how ‘making sense’ of what is going on in a person’s life is critical to the task of ‘making the most’ of the circumstances of living with dying. Doing this helps to promote a personal sense of quality of life. Moorhead and colleagues (2004) further claim how the search for spiritual health involves connectedness with self, other, a higher power, all life, nature, and the universe that transcends and empowers the self. Further, in a book titled *Making Health Care Whole*, Puchalski and Ferrell (2010) add how dying persons also might find meaning as expressed in nature, rationalism, humanism or the arts. Dying persons may also know spiritual well-being in

their journey as they tap into spiritual beliefs and practices, interpersonal skills, relationships with family and friends, and connections to their caregivers (Nakashima, 2002).

Needs in the Dying Journey

A review of various studies reveals how dying persons and their caregivers experience a wide range of spiritual needs as part of their end-of-life journey. Plus, what they consider to be spiritual needs do not always have a connection to religion or a sense of the divine, as one might expect. In whatever manner dying persons and their caregivers perceive their spiritual needs, it is important to tend to those needs with spiritual care. Doing so may help to alleviate any current or potential suffering in a dying person's life, aid in improving a person's quality of life and thereby increase the possibility of him or her experiencing a good death. Numerous research studies show the importance of emotional and spiritual issues for dying persons and how acknowledging these needs constitutes good, comprehensive palliative care (Post et al, 2000; Yawar, 2001; Daaleman et al, 2001; Koenig, 2001; Mueller et al, 2001; Lyon et al, 2001; Sloan et al, 1999; Levin et al, 1997; Sloan et al, 2001; Steinhauser et al, 2000; Ehman et al, 1999; Lo et al, 2002 & 2003; Hillel, 2013). It is therefore critical for spiritual care providers to take this into consideration when offering care to dying persons and their caregivers. Doing this will grant spiritual care providers a better understanding of how they might offer effective care. For spiritual care providers to assume they already know the needs of dying persons and offer care according to these assumptions runs the risk of not tending to the actual needs of the dying person and their caregivers. If this occurs, the dying person may perceive that their spiritual needs are not being met and feel discouraged, unfulfilled and possibly harmed in their dying journey. In this way Vivat (2008) asserts the importance for dying persons and their caregivers

to give their own definitions of their spiritual needs. This might mean that offering spiritual care does not involve providing answers to a person's spiritual questions, but instead listening to their concerns and taking them seriously. Spiritual care then evolves into a practice of dialoguing with dying persons and their caregivers and being attentive to their needs rather than simply making assumptions regarding the care that is needed.

Indeed, reviewing the literature reveals that many researchers have sought to listen to the concerns of dying persons and their caregivers and have taken their needs seriously as they reported their findings. We now consider in more detail those studies whose descriptions of the needs of dying persons and their caregivers are pertinent to the current research study. In a qualitative study of 19 hospice patients, Hermann (2001) hoped to identify dying persons' definitions of spirituality and their spiritual needs. Results proved fruitful as twenty-nine unique spiritual needs were identified including items such as: a desire to finish business, experience nature, have involvement and control, relate to God or an ultimate other, have gratitude and optimism, love others, receive from others, and create meaning. The themes Hermann interpreted from the list of spiritual needs included: the need for religion, need for companionship, need for involvement and control, need to finish business, need to experience nature, and the need for a positive outlook. In what may be a familiar study for those interested in end-of-life care issues, Steinhauser and colleagues (2000) examined the end-of-life factors considered to be important with 340 seriously ill participants. The study's findings compare closely with the description of results of specific spiritual needs from other studies, for example Hermann above, even though this study did not specifically describe these factors as 'needs' of dying persons, or even as 'spiritual needs'. Still, it is important to review them here because of their commonality with the results of others studies pertaining to spiritual needs. The nine factors

Steinhauser and colleagues (2000) ascertained to be most important to end-of-life patients are: freedom from pain, peace with God, presence of family, mentally aware, treatment choices followed, finances in order, feeling life was meaningful, resolving conflicts, and dying at home. Of these nine, 89% of the patients rated 'being at peace with God' as most important along with 'pain control'.

There are other studies that specifically explore the spiritual needs of persons on their dying journeys. Moadel and colleagues (1999) in their study of 242 patients with advanced cancer report that their most prominent spiritual needs were: overcoming fears, finding hope, discovering meaning in life, and a desire to talk to about death, dying and finding peace. In this same study 73% of participants expressed having at least one spiritual need. In a much larger study of 369 people with cancer, Astrow and colleagues (2007) examined if a failure to meet the spiritual needs of cancer patients was associated with their perception of quality of care. These researchers concluded that patients whose spiritual needs were not met reported lower ratings of quality and satisfaction with care. It should be noted here that this study's participants were not classified as dying from cancer. However, their understanding of spiritual needs and association with quality of life correlates with similar findings from other studies involving dying persons. As such, it is worthwhile to consider the participants' spiritual needs and their perception of quality of care. The results of the study show participants expressed the following needs: meet similar patients, relaxation, help with sadness, help to share feelings, help with family concerns, seek spiritual resources, find meaning in life, find hope, overcome fears, find peace of mind, talk about meaning of life, talk about death and dying. Many of these needs tie directly with the results of other studies examining the spiritual needs of dying persons even though the participants in this study were diagnosed with cancer, but not dying.

Bartel (2004) presents a model from earlier work summarizing the findings of five spiritual needs a dying person must address: love, faith, hope, virtue and beauty. In this article Bartel concludes that spiritual suffering arises when these needs are unfulfilled and therefore it is critical for spiritual care providers to assess accordingly and attend faithfully to these needs of dying persons. In another study, Hinshaw and Hinshaw (2000) similarly share in their findings what the spiritual needs of dying persons are, in particular, through the suffering that results when these needs are not met. This suffering arose because the spiritual care provider was not meeting the dying person's specific needs, which included: maintaining contact with the dying person, remaining emotionally present with the dying person, communicating effectively and honestly, and bearing with the dying person through struggle. More recently, Harrington (2012) conducted a study considered to be a 'beginning' exploration of caregivers' spiritual needs. From a sample of 15 participants Harrington concluded that their two most important spiritual needs consisted of maintaining a belief in God to help them through their struggles and having some form of religion or church to provide comfort. There was also an interesting study from the United Kingdom with findings pertaining to how professional caregivers perceive the needs of dying persons. It is briefly presented here as its findings contribute to the conversation of the previous studies and the current research study. Wright (2001) studied professional chaplains in England and Wales who revealed how they perceive the spiritual needs of patients at the end of life as being: someone to listen, concern for relatives, and someone to 'be there'. Although this constitutes only a short list of perceived needs, the findings associate well with results from other studies with dying persons and their caregivers.

There is another spiritual need that arose when reviewing the literature and it is worthy of mention here. The spiritual need dying persons and their caregivers may have is simply the

desire to access a spiritual care provider and not being able to do so. In a study of 343 patients with advanced cancer, Balboni and colleagues (2007) observed that 47% of participants who desired spiritual care from their faith communities were having their needs met minimally or not at all as they desired. Further, 72% of participants shared that their spiritual needs had been supported only minimally or not at all by the medical system. These are unfortunate findings since the study also reports how spiritual support is associated with a better quality of life for dying persons. Hermann (2006), in a study with 19 hospice patients, concludes the reasons spiritual care may not be provided consistently in these situations stems from a lack of education (citing Lemmer, 2002; Sellers and Haag, 1998) and confusion regarding the meaning of spirituality (citing Narayanasamy and Owens, 2001).

A few Canadian studies also explored end-of-life needs in dying persons, although not necessarily with the intent of examining spiritual needs. However, in some instances the results of their studies relate directly to the spiritual needs revealed in other studies. Other times the findings that differ in scope provide new insights into the perceived needs of dying persons. Heyland and colleagues (2006) in a Canadian study of 440 seriously ill patients and 160 family members from five hospitals across Canada, explored the end-of-life elements that mattered the most to the participants. The most important elements that emerged include: trust in the treating physician, avoidance of unwanted life support, effective communication, continuity of care, and life completion. In this study there was a variation between patients and family members in the perception of what matters most in end-of-life care. Researchers conclude that this indicates the need for customized or individualized approaches in the provision of end-of-life care. In another Canadian study Singer and colleagues (1999) explore 126 patient perspectives on what is needed to achieve quality end-of-life care. They reported the most important dimensions of end-of-life

care include: receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of spiritual peace, relieving burden, and strengthening relationships with loved ones. One other Canadian study (Jo et al, 2007) is worth mentioning as it drew its sample of participants from south-central Ontario. This study explored the perspectives of dying persons and their spousal caregivers on the end-of-life caregiving experience in home-based palliative care. In this study the participants reported that formal support providers did not listen to their needs and that questions were not clearly answered. The participants also remarked how workers were not always aware of what a previous worker had done suggesting poor communication among members of the care team.

One final study worth mentioning in this section is a recent systematic literature review by Ventura and colleagues (2013) examining the self-reported unmet needs of patients and caregivers in home-based palliative care. Although this review did not specifically examine unmet spiritual needs of patients and caregivers, the general findings of the study add to the conversation of the current research study and in some cases point to unmet spiritual needs. Plus, as Ventura and colleagues note, there have been many studies detailing the unmet needs of patients and caregivers from the perspective of the bereaved caregiver, but few studies have examined the unmet needs of current patients and their caregivers, in particular in their home setting. Ventura and colleagues employed quality assessment criteria to narrow down their review to examine nine qualitative studies, three quantitative studies, and three mix-design studies. From their review of this literature they surmised the most frequently reported unmet need was effective communication with health-care professionals and the lack of which negatively impacted on the care received by the dying persons and their caregivers. Physical needs appear to have been met, but other areas were lacking. These areas include: participants

experiencing a lack of information about their illnesses, a desire for increased support to help cope with fears of suffering and loss of autonomy, a need of respite for caregivers, consideration of future financial responsibilities, and practical support with everyday tasks such as household duties. The authors also cite in the review specific references to studies that examined the unmet spiritual needs of dying persons and their caregivers. These studies include research by Grant and colleagues (2004) who discovered dying persons with advanced cancer expressed a need for peace, freedom from the 'dark', and freedom from the fear of dying. However, in this particular study it was noted how the dying persons felt as though they had little guidance on what to expect of the dying journey and this led some participants to express a desire to end their lives. Hampton and colleagues (2007) conducted a quantitative study examining the spiritual needs of 90 advanced cancer patients based out of the United States. This study's findings revealed the most common unmet need of dying persons was to attend religious services. Other unmet needs included praying and being with family and friends. Ventura and colleagues (2013) cite one other study by Murray and colleagues (2004) that researched the spiritual needs of 40 terminally ill patients in the United Kingdom. Murray and colleagues (2004) reported spiritual issues were a source of unmet needs for the dying persons. These needs included: a desire for support to address despair, hopelessness, isolation, an altered self-image, and striving to maintain a positive outlook. It was noted how dying persons often maintained a 'brave face' so as to not upset others. As a result, their spiritual needs went unrecognized. Ventura and colleagues (2013) express the importance of tending to all these unmet needs and improving these aspects of patient care to prevent or reduce suffering in the lives of dying persons and their caregivers.

One can observe from the findings in this literature that dying persons and their caregivers perceive a plethora of end-of-life and spiritual needs they would like addressed as part

of their care. Although wide-ranging, there also appears to be some commonalities in the list of needs. These include the need to find meaning in the experience, connect with a sense of the divine or sacred, find peace, have involvement and control, connect with nature, have adequate pain control, connect with family, and tend to matters of the inner-self such as fears, hopes, sadness and gratitude. Spiritual care is an important part of helping dying persons and their caregivers tend to all of these various needs. Doing so helps to improve the quality of care they receive.

Addressing Needs to Improve Quality of Care

Puchalski (2009) comments how the needs of a dying person associated with spiritual distress or religious struggle should be treated with the same intent as treatment for pain or any other medical or social problem. Just as physical pain is screened routinely, so should spiritual issues be a part of routine care. Simmons and Clemens (2006) and Meyers (1989) concur and also remind spiritual care providers how assessing spiritual needs should occur during each encounter. The dialogue to assess spiritual needs is not a single occurrence with the dying person and their caregiver in the initial meeting, but an ongoing conversation so continuous quality of care might be ensured and quality of life be kept at optimal levels. Steinhauser and colleagues (2002) describe 'quality of life' as the gap between the expectations and the present situation of the individual. In Balboni and colleagues' previously mentioned study (2007) of 343 patients with advanced cancer, results show how spiritual care that addressed the needs of dying persons was found to be associated with better end-of-life care. As dying persons approached the end-of-life and received some form of spiritual care, their quality of life scores increased 28% on average compared to those patients who were receiving no spiritual care. Similarly,

there are numerous studies which support the association between spiritual care and the quality of life a dying person places on the end-of-life care (Tarakeshwar et al, 2006; Brady et al, 1999, Cotton et al, 1999; McClain et al, 2003; Gall and Cornblat, 2002; Koenig, 1998; Reese and Brown, 1997; Roberts et al, 1997; Balboni et al, 2010; Nelson et al, 2002; Whitford et al, 2008; Balboni et al, 2010; Fitchett et al, 1999; Fehring et al, 1997; Carson and Green, 1992; Miller, 1985; Kaczorowski, 1989; Yates et al, 1981). Some caution is required here though. Indeed, these studies have shown how spiritual care when offered effectively in response to dying persons' needs can contribute to their well-being and quality of life. However, the results of another study of advanced cancer patients also reminds us how spiritual crises at the end-of-life can arise when the spiritual needs of dying patients are not addressed effectively, or at all, through spiritual care (Phelps et al, 2009). It is therefore important to assess well the spiritual needs of dying persons and their caregivers and offer spiritual care that will help tend to those needs. Doing otherwise might lead to a deficiency in the experience of care which in turn could cause further stress and struggle in the dying person's journey.

Balboni and colleagues (2007) have also demonstrated how negative religious coping, for example perceiving an illness as divine punishment, can cause distress and a decrease in a dying person's quality of life (Balboni et al, 2007). However, the results of a study by Nelson and colleagues (2002) reminds those who offer spiritual care how spirituality-based interventions could provide important clinical benefits for dying persons who are struggling due to the very religion or spirituality that once helped them in their lives. In these instances it becomes critical to remember how a dying person's spirituality may be the very source of their spiritual struggles and emerging needs. At the same time spiritual care providers must maintain a vigilant awareness of how spiritual care and one's spirituality still might attend to the spiritual needs of

dying persons even in situations such as these. When offered effectively, spiritual care can serve as a resource to address a person's needs and assist in improving a person's quality of life even in situations where a person's spirituality may have been the initial cause of struggle in the dying person's journey.

Various researchers assert the importance of a more holistic approach to the process of dying (Koenig, 2002; Puchalski, 1998; Sinclair et al, 2006). The previously mentioned study by Hermann (2001) also concluded: to increase the quality of life of dying persons it is important that care be offered for spiritual needs as well as physical and psychological. The findings within these various studies acknowledge how a variety of inner issues like anxieties, fears, unresolved conflicts, hopes, and despair cannot be addressed simply by clinical responses alone. Research data shows that spiritual needs of dying persons are wide-ranging, encompass many aspects of a person's life, and involve more than simply religion as evidenced in the previously mentioned studies. Increasingly there is a growing awareness of how spiritual care and a dying person's spirituality can be a resource to address these many needs. How can spiritual care do this? In some cases simply by showing up, listening, providing presence and support, and asking the dying persons what has given them hope, meaning, comfort, and strength during this time in their life (Koenig, 2001). Koenig further reminds readers how spiritual needs are not confined to religious people. Spiritual needs may also exist in the lives of people who maintain no formal affiliation with religion or a faith tradition. Spiritual care should also be shared in acceptable ways with people who fall into this category to help address their needs and improve their quality of life.

Puchalski and Ferrell (2010) also note that regardless of how or where a person is dying, the goal is to die in a comfortable manner with the dying person's wishes honoured. The

importance of spiritual care and spirituality reducing end-of-life despair and improving psychological well-being so a person might die in a comfortable manner is well-supported (McClain et al, 2003; McClain-Jacobsen et al, 2004). McClain-Jacobsen and colleagues (2004) report in these studies how individuals with advanced cancer experience spirituality as improving comfort, offering protection, and increasing their quality of life. Other studies show how dying persons who approach death with less spiritual well-being were prone to having more despair, depression and anxiety (Chibnall et al, 2002; Delgado-Guay et al, 2011). Chochinov and McCann (2005) concur and share how spirituality is viewed as one important dimension to assess among biological, psychological and social considerations for maintaining quality of life and quality of dying. McClain and colleagues' study (2003) also shows the important implications of tending to dying persons' spiritual well-being as a way of keeping psychological distress to a minimum. They conclude, however, that addressing the spiritual needs and existential questions of dying persons has generally been neglected in palliative care practice, but could serve as an important aspect of a dying person's psychological functioning.

Who Can Offer Spiritual Care

The Consensus Conference Report (2009) claims there are many different people who can offer spiritual care: community clergy, religious leaders, community elders, spiritual directors, pastoral counsellors, parish nurses, lay religious professionals, culturally based healers, and other spiritual care providers of diverse backgrounds. Now, while it is important to involve such spiritual care providers in the provision of spiritual care to dying persons and their caregivers, some would argue it need not rest solely on them as this is inconsistent with the holistic approach to hospice. Rumbold (2012) acknowledges the work of such spiritual care

providers and adds how the spiritual quest of hospice palliative care ideally involves the whole community including patient, family and friends, and medical and support staff. Dudley (1995) also adds how others on the hospice team may be qualified and appropriate to provide spiritual care and indeed this could become more evident when the dying person is spiritual, but not necessarily religious. The Spiritual Care Group of the International Work Group on Death, Dying and Bereavement (1993) pushes this one step further and claims all caregivers can provide spiritual care to the dying. This may be true in some cases where a person's abilities are able to address the spiritual needs of a dying person. However, when a person's capabilities would not allow them to effectively address a dying person's spiritual needs, in fact may even cause increased suffering because the skills required fall outside of one's scope of practice, it is important to refer and seek a spiritual care provider who can attend aptly to the needs of the dying person so he or she might die well and have a good death.

Dying Well and a Good Death

The current research study examined dying persons and their caregivers' experiences of spiritual care in their home as an aid to helping them die well and have a good death. Certainly it was observed in the previous section that when spiritual care effectively attends to the needs of dying persons it can help to improve the quality of their end-of-life journey. Indeed, as Reid (2012, p.120) shares "it is important to understand how achieving a 'good death' can make a huge difference to those who are facing the end of their lives." Therefore, the following section reviews the literature's understanding of the terms 'dying well' and a 'good death' as perceived by dying persons and their caregivers.

Kehl (2006) in reviewing forty-two articles pertaining to a good death noted how terms such as ‘good death’, ‘dying well’, and ‘peaceful death’ are used interchangeably in some pieces and with different meanings in others. Kehl further notes the most widely used definition of a good death is cited from the 1997 Institute of Medicine report on end-of-life: “a decent or a good death is one that is: free from avoidable distress and suffering for patients, families, caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural and ethical standards.”(p.277) In the review of literature for this current project I observed the term ‘good death’ more frequently in the literature while the concept of ‘dying well’ was only used occasionally. Also, it was discovered how a good death sometimes referred to a single event, but also could refer to the time and activities leading up to a person’s death. Some researchers have also recognized the importance of defining a good death as a series of interactions that should begin months before a person dies rather than a single event (Emanuel and Emanuel, 1998; McNamara et al, 1994). There may be more opportunities for spiritual care to contribute to a good death when it is viewed as a series of activities over a period of time during the dying process rather than a single event at the end of one’s dying journey.

Tullis-Owen (2009) in a study examining the role of a good death in hospice care shares how in its most basic form “a good death is free of physical and spiritual pain. The ambiguity of the concept allows patients, family members, and hospice teams a great deal of flexibility to work toward this end.”(p.14) There appears to be a fairly consistent level of agreement in the literature previously examined that the role of palliative care is to help dying persons and their caregivers achieve a good death. However, describing the attributes that make up a good death may be slightly ambiguous and prove more challenging. Kehl (2006) researched the common characteristics that constitute a good death by analysing 42 journal articles that investigated the

concept of a good death. Kehl provides an excellent summary overview of the literature's understanding of a good death. According to the study's findings, the notion of a good death in the literature was described as highly individual, changeable over time, and based on perspective and experience. It is important to note the individual nature of a good death and what constitutes a good death to one person may not be the case to another. This means that spiritual care providers and other end-of-life carers must evaluate each dying person's idea of a good death to assist him or her in meeting this goal. In the same study, Kehl also provides a more detailed description of the attributes of a good death she observed in these articles. Listed in order of frequency of appearance in the literature, these include: being in control, being comfortable, a sense of closure, affirmation/value of the dying person recognized, trust in care providers, recognition of impending death, beliefs and values honoured, burden minimized, relationships optimized, appropriateness of death, leaving a legacy, and family care. Conversely, Kehl notes in the same study (2006) the description of the elements of a bad death as contained in the articles. A bad death occurs when: it is not in accord with patient and/or family wishes, including not being in the location of choice; it is prolonged; the patient is dependent; it is traumatic; the patient suffers; there is a sense of unprepared-ness; the care is disorganized; there is knowledge of impending death; the family is burdened; the person dies with no one else present; and when the patient is young.

Presenting the findings of Kehl's review provides a comprehensive overview of the literature's understanding of a good death at the time of her study. Indeed, Kehl's work is a meaningful contribution to the conversation of what constitutes a good death. Still, it would be worthwhile here to explore in more detail some of the findings of the studies Kehl referred to in her work. This, along with considering any new literature that has come forward since that time,

will help to deepen our understanding of a good death and how spiritual care might contribute to it. Steinhauer and colleagues (2000) conducted a study to gather descriptions of the elements of a good death as described by patients, families and providers. The participants in this study identified six primary elements of a good death: pain and symptom management, clear decision-making, preparation for death, completion, contributing to others, and affirmation of the whole person. Of particular interest in these elements are the participants' views of religion, spirituality and finding meaning. These participants confirmed the deep importance of spirituality or meaningfulness at the end of life in relation to a good death. Further, it is also important to understand that the primary element of a good death described as 'completion' does not only include issues related to a person's faith, but also a life review, resolving conflicts, spending time with family and friends, and saying good-bye. Also, issues pertaining to faith and spirituality were often mentioned as an important part of holistic healing for dying persons and became more important as they declined physically in their health. Emanuel and Emanuel (1998) support this assertion of the role spirituality can have in a good death. They claim spiritual and existential issues are quite relevant when considering a good death. These issues relate to how people find meaning, purpose and value in life and can be specifically religious or simply drawn from the belief systems people hold. Emanuel and Emanuel also claim that spiritual and existential issues become especially important for dying persons attending to questions they have about the purpose of their life. Why do these issues take such a prominent place in end-of-life discussions? Small (1998) explains this well by saying "it is the encounter with the deity that allows one to put oneself into the hands of something greater than oneself, without which there is a danger that reliance on oneself can fall short of what one needs at the end of life."(p.174)

Steinhauser and colleagues (2006) conducted another study with 248 dying persons to discuss with them what these participants considered to be the attributes of ‘good’ and ‘bad’ deaths. The study produced seventy attributes and participants frequently reported one of these elements was associated with coming to peace or being at peace. Often this sense of peacefulness was connected with a religious notion of being at peace with God. Other times this sense of peacefulness had no religious connotations, but instead related to a sense of tranquility that could result from deciding a clear course of medical treatment or resolving an issue with a family member, within participants themselves in relationship to God, or in spiritual reflection on the meaning of illness in their lives. Coming to this peacefulness was considered by participants to contribute to the notion of a good death.

The United Kingdom has extended considerable effort in recent years to improve palliative care and understand better dying persons’ concept of a good death. In an article discussing the findings of the final report on the “The Future of Health and Care of Older People” in England, Smith (2000) provides a list of the twelve items noted in that document that are considered necessary for a dying person to experience a good death. These include: knowing when death is coming and what can be expected, being able to retain control of what happens, being afforded dignity and privacy, having control over pain relief and other symptom control, having choice and control over where death occurs, having access to information and expertise of whatever kind is necessary, having access to any spiritual and emotional support required, having access to hospice care in any location, having control over who is present in the journey, being able to issue advance directives which ensure wishes are respected, having time to say good-bye, and not having a life prolonged pointlessly.

Finally, there is one other pertinent article to add to the conversation of a good death. In an earlier section of the literature review it was mentioned how the importance of palliative care will continue to grow in upcoming years as the Baby Boomer generation reaches its seniors years. Over the next couple of decades the size of this age group (65 and over) is projected to increase dramatically. As such, a recent article by Kadlec (2013) reviewed this particular demographic of the population to understand better their perception of a good death. The findings reveal that what makes a good death for them today coincides with findings from other research. The perception of a good death for Baby Boomers includes: having control over the process so wishes will be followed; having open and honest communication about the situation; having broad support to address end-of-life issues; maintaining a sense of spirituality that is highly personalized and creates a peaceful and comforting environment; having minimal suffering physically and psychologically; finding meaning by living with as much dignity as possible during this time; and finding closure to ensure everything has been taken care of.

There are descriptions of some of the elements of a good death that sound vaguely familiar throughout the various studies while other attributes appear to stand alone. Also, one needs to remember a good death is not necessarily a single occurrence, but can be considered a period of time leading up to the death of a dying person. In reviewing the literature one begins to understand how a good death is indeed an individual thing. Each person will have his or her own perceptions of dying well and a good death. Spiritual care providers would do well to remember this when considering how to offer care most effectively to help dying persons attain their goal of a good death.

Geographical and Rural Considerations

This final section of the review examines literature related to palliative care in rural settings. The research question seeks to explore spiritual care as it is offered to dying persons and their caregivers in Grey and Bruce Counties, Ontario. As noted in the introductory chapter of this project, these two counties are primarily rural in nature. Does living in a rural area affect the way dying persons and their caregivers experience palliative care, and in particular, spiritual care? There are no direct studies related to spiritual care offered in Grey and Bruce Counties as part of the end-of-life care received by dying persons and their caregivers. However, there is literature associated with people's experiences of palliative care in rural settings that adds to the conversation of the current study.

Research indicates there is a difference in the experience of palliative care between rural and urban residents (Lynch, 2012; Hansen et al, 2011; Menec et al, 2011; Wilson et al, 2006; Phillips et al, 2006; Evans et al, 2003; Crooks and Schuurman, 2008; Ministerial Advisory Council on Rural Health, 2002). It is also recognized that dying persons in rural areas have less access to palliative care services than people living in urban centres. Freeman and colleagues (2013) in a report titled 'Breaking Down Barriers: Hospice Palliative Care as a Human Right in Canada' state: "while the goal of hospice palliative care remains the same regardless of geographic setting, evidence suggests location is a determinant of the type and standard of care that terminally ill persons receive" (as cited from Seymour et al, 2001, p.243). This appears to fit with findings from other studies (Evans et al, 2003; Romanow, 2002) claiming how in comparison to those who live in urban settings, people in rural communities exhibit poorer health status and a greater need for health care and yet these persons are less likely to receive proper palliative care. The report further claims that dying persons who have to travel an hour or more

to an urban centre may die without having received palliative care, may be forced to commute unreasonable distances to access regional services, and may need to relocate altogether to an urban centre (as cited from Cinnamon et al, 2008). Another report titled “Advancing High Quality, High Value Palliative Care in Ontario: Declaration of Partnership and Commitment to Action” (2011) supports these findings. This report, a collaborative project of over 80 stakeholders from across Ontario with a vested interest in palliative care, notes how “care settings and services are lacking in many catchment areas, especially in rural, remote and First Nation communities and some groups have inadequate access to appropriate support and services.” (p.17) The report concludes that improvements are needed to reduce the expectation of dying persons travelling to seek appropriate care since such travel is costly, time consuming and removes dying persons from their homes, communities, and informal care supports. Indeed, polls from Statistics Canada (2007) suggest that 70% to 80% of Canadians indicate they would prefer to die at home if supports were available. Studies further indicate that dying persons in rural communities desire to remain in their home communities and do not wish to travel to urban centres for end-of-life care (Romanow, 2002; McRae et al, 2000; Magilvy and Congdon, 2000; Gilbar and Steiner, 1996). Meanwhile other studies have found that hospital deaths are more common among rural residents compared to urban residents as a result of rural dying persons having to travel to cities for health care (Grunier et al, 2007; Wilson et al, 2009; Houttekier et al, 2010). Wilson and colleagues (2009) add how a rural resident dying in a distant city hospital is not considered a ‘good death’. However, from an earlier study Wilson and colleagues (2006) offer that dying persons in a rural setting consider a good death to occur when in-community deaths are ensured through a range of home, hospital, and senior-care services. Plus, participants in Wilson’s study also believed high quality support to address the diverse interests of each

dying person was of critical importance for enabling a dying process that was in keeping with the ongoing wishes of the dying person.

The work of another government committee brings additional material to the review. In a report titled “Not to Be Forgotten: Care of Vulnerable Canadians”, the Parliamentary Committee on Palliative and Compassionate Care (2011) remarks that close to seven million Canadians live in rural areas and communities of only a few thousand people. This makes it extremely difficult to deliver care effectively to rural and remote areas with such a widely dispersed population. However, noting the strength of residents in rural settings, the report also shares how small communities have significant resources to bring about the transformation that is needed to deliver care more effectively to rural areas. Further, the Parliamentary Committee on Palliative and Compassionate Care (2011) states that people in rural areas and small communities “come together more easily in times of crisis, cooperating for the common goal. Faith communities, sporting groups, schools, and service clubs provide powerful venues for action. People know each other and can get organized more quickly than in urban centres.” (p.40).

Robinson and colleagues (2010) conducted a study with health care professionals, family members and volunteers from three rural communities in British Columbia to understand better the issues related to rural palliative care. The study revealed how participants perceived a lack of coordination in rural palliative care as the biggest problem in relation to standards of care, communication among workers, and palliative care statistics. However, it should also be noted that not all participants agreed with the problem of coordination. In fact, some participants believed palliative care was better coordinated in a rural community due to the informal networks that exist and help to ensure people are not overlooked in their time of need. Also, it

was revealed how in the closer-knit community that often exists in rural settings, neighbours tend to be more conscious of each other's needs which is a habit noticeably absent in urban centres. Participants additionally spoke of the differences between an urban community where a person knew little about his or her neighbours and a rural community where it is often considered a moral obligation to ensure there is care for one's neighbours. Other studies support such findings, noting how social solidarity, close-knit relationships and community commitments are considered a strength of rural communities (Nelson et al, 2006; McConigley et al, 2000; O'Connor and Lee-Steere, 2006; Hughes et al, 2004). These studies further contend that palliative care is seen as a way of life in rural settings rather than simply a job.

Pesut and colleagues (2013) conducted a study with 95 participants in four rural western communities in Canada to ask participants: what makes for good rural palliative care from the participants' perspectives? The findings show that families, healthcare providers and administrators in rural areas work together in fluid ways to support high quality palliative care in their communities. However, healthcare changes, particularly those that originate from outside the community, can easily disrupt the manner in which people in rural settings work together. In these cases it is important to involve local residents in the planning stages when changes are being considered in the system of care that already exists in rural settings. Doing so helps to provide meaningful input from residents who know the cultural and social norms of the rural community in which they are living. It also helps to establish programs of palliative care that better address the actual needs of dying residents and their caregivers living in rural settings. In this way Dudgeon and colleagues (2007) add how the spectrum of available supports and services becomes unique to each region and reflects the capacity and evolution of local health care. Certainly this involvement can help improve the effectiveness of the care available and

offered in rural settings. A study of rural residents from western Canada supports this notion. In a study of 32 rural palliative care providers from across seven communities in two provinces, Kelley and colleagues (2011) concluded that having local palliative care programs available in rural communities increases the access and quality of care for dying persons.

In all of the literature reviewed concerning geography and rural issues, only one was found to contain any mention of spiritual care in relation to palliative care. Although the report did not specifically cite spiritual care in relation to rural settings, the report from the Parliamentary Committee on Palliative and Compassionate Care (2011) did state that “all Canadians have a right to quality palliative care services to attend to their physical, emotional and psychological needs.”(p.38) Ensuring this right is grossly incomplete unless hospice and palliative care programs also include access to spiritual care resources. While this should not be imposed, the right to spiritual care must be easily accessible for those who desire it.

Chapter Summary

Numerous studies, reports and other forms of literature demonstrate the need for palliative care as a resource to dying persons and their caregivers in the Canadian context. At the same time several of these documents illustrate a dire need to address areas of concern where palliative care is currently lacking in its provision of end-of-life care in Canada. The literature also demonstrates how spiritual care is a critical component of palliative care to treat the whole person. Yet, it has only been in the last two to three decades that spiritual care in end-of-life care has gained prominence in research studies. Still, a review of the available literature has illustrated a desire of many dying persons and their caregivers to receive spiritual care to address a variety of needs at the end of their lives. Offering spiritual care in these circumstances can

help to address the needs of dying persons, alleviate suffering, improve quality of life, and assist them to die well and experience a good death in the way they desire. The geographical location where a person is dying may have an effect on the quality of palliative care a dying person receives. These issues need to be considered when offering spiritual care in a rural setting.

The purpose of the current research study encompasses all these various elements as it considers how dying persons and their caregivers are experiencing these resources in Grey and Bruce Counties as an aid to helping them die well and have a good death. The following chapter on Methodology will explain how the current research study was designed and structured to examine the research question.

Chapter 3: Methodology

“Hope does not lie in a way out, but a way through.”
Robert Frost

Introduction and Overview

The purpose of this research study was to explore with a sample of dying persons and their primary caregivers their experience of spiritual care in the home as an aid to dying well and having a good death in Grey and Bruce Counties, Ontario. This chapter describes the research study’s methodology and rationale for the research approach as well as providing a discussion around the following areas: the research setting, research sample and participant recruitment, the interview process, the interview format, and transcription and data analysis.

A qualitative research approach was employed for this study rather than a quantitative style. Elliot and colleagues (1999) describe quantitative research as seeking to test hypotheses, making causal connection and generalizing across examples. This was not the intent of this research study, whereas qualitative research intends to understand the meaning of people’s experiences (Sprenkle and Piercy, 2005). Flick (2002) adds how qualitative research “demonstrates the variety of perspectives (those of the patient, of his or her relatives, of professionals) on the object and starts from the subjective and social meanings related to it.”(p.6) Flick (2002) further comments how qualitative research is “oriented towards analysing concrete cases in their temporal and local particularity, and starting from people’s expressions and activities in their local contexts.”(p.13) These understandings of qualitative research combine well with my goal of exploring with dying persons and their caregivers their experience of spiritual care in their end-of-life journey in the region of Grey and Bruce Counties in Ontario.

There is a wide range of qualitative approaches one might employ for a research project. A phenomenological methodology was utilized for purposes of this study. This specific type of

qualitative method seeks to explore the lived experience of participants in relation to a phenomenon that is occurring in their contexts. Again, this method complemented well the intended goal of this research study as it was my intention to explore with participants their experiences of spiritual care within the contexts where they were residing. This also fits well in the understanding of phenomenological research, which seeks to study a phenomenon as it occurs in its natural setting. I purposefully sought to explore how dying persons experience the spiritual care offered to them in their natural home setting apart from an institutional setting such as a hospital or nursing home. This was done intentionally because I have witnessed through my work in Grey and Bruce Counties an increased possibility of dying persons and their caregivers receiving spiritual care in an institutional setting since these places often have formal spiritual care programs available as part of their holistic care structure. I learned through personal communication with workers of the various hospice palliative care services in Grey and Bruce Counties that no formal spiritual care services have been established as part of their home-based care programs. Therefore, my intention through the study was to explore how dying persons and caregivers may or may not be receiving spiritual care in their homes. However, having stated this, I will later explain in the Participant Recruitment section of this methodology chapter how it was necessary to modify my approach slightly in this regard as I engaged in the actual interview process. The reader will learn of one instance in which a research interview was conducted with one participant who was a hospital in-patient as she reflected on her experience of spiritual care in her end-of-life journey before entering the hospital setting.

A researcher also seeks to understand another person's reality, albeit through an observer's eyes, through the phenomenological method of qualitative study. One of my goals in this study was to achieve a better understanding of how dying persons in Grey and Bruce

Counties perceive their experience of the spiritual care offered to them as part of their end-of-life journey. I further wanted to understand how they thought the spiritual care they received may have been helping them to die well and have a good death, as they understood those terms. These two objectives fit well with the phenomenological research method, which seeks to construct meaning and have a researcher brought into a deeper understanding of the nature of the everyday world of a participant's experience. Therefore, through this study it was my hope to reveal the lived meaning and themes arising from the shared stories of various dying persons and their caregivers in Grey and Bruce Counties who were receiving spiritual care where they lived.

There are various ways of analysing data in a phenomenological approach to research and Sprenkle and Piercy (2005) state any method can be used in phenomenological analysis. For purposes of this phenomenological research study I employed an interpretive analysis methodology to gain a deeper understanding of the participants' lived experiences. Interpretive, or hermeneutic, methods in phenomenology focus on understanding the meaning of participant experience by searching for themes with greater interpretative engagement with the data and a move away from the search for essences than would be found in traditional descriptive phenomenology (Langdridge, 2007). In relation to the study of human experience, interpretive phenomenology goes beyond descriptions of core concepts and essences to look for meaning embedded in common life practices. Solomon (1987) adds how these meanings are not always apparent to the participants but can be gleaned through an interpretive process by the researcher from the narratives produced by participants. The focus of this form of inquiry is on what humans experience rather than what they consciously know, which is the difference between interpretive and descriptive phenomenology.

Within the branch of interpretive phenomenology I utilized in my analysis of the data a further distinction of phenomenological approach known as interpretative phenomenological analysis. This form of analysis developed in the 1990s by Jonathon Smith primarily in application to the field of psychology. However, since this method's inception its use has broadened into other fields and applications of study such as chronic illness (Osborn and Smith, 1998), quality of life (Holmes et al., 1997), the role of spirituality in bereavement therapy (Golsworthy and Coyle, 2001) and cancer patients' views on the role of palliative care teams (Jarrett et al., 1999). As is the aim in all phenomenological research studies, the goal of interpretative phenomenological analysis is the detailed exploration of a participant's view of the topic under investigation. However, the role of the researcher is recognized through the way in which he or she interprets a participant's understanding. Smith and Osborn (2003) refer to this as the use of a two-stage interpretation process, a double hermeneutic, with the researcher trying to make sense of the sense-making activities of the participant. As such, the interpretive process of the researcher depends on and is complicated by the researcher's own conceptions. Indeed, these become a required element in order to make sense of a participant's world through a process of interpretative activity. At the same time Smith and Osborn (2003) claim it should be recognized that as is generally the case with qualitative research, there is no single, definitive way to do interpretative phenomenological analysis. The application and methodology related to these philosophical assumptions fit well for the purposes of exploring this study's research question. It grants an opportunity for the researcher to enter into and engage the material forthcoming from the life-world of participants while simultaneously seeking to let participants' 'voices' be heard through verbatim excerpts presented in coding and the development of themes in the data of the participants' experiences.

The reader will note from having read the introduction of this paper that my interest in this particular research topic became more finely developed through an exploration of the existing literature. This is an acceptable practice according to Langdrige (2007) who states how phenomenological researchers frame a question based on their reading of the extant literature that seeks to explore some experience or a particular aspect of an experience. This means the researcher will enter the field with an agenda that will result in open-ended research questions designed to discover the qualities of the phenomenon being investigated. Further, Banister and colleagues (2011) state that researcher presuppositions (including knowledge of the relevant literature) that are bracketed off within the descriptive tradition are seen here in the interpretive tradition as a resource and a guide to the research process and the transformation of data.

It is my hope that a better understanding of this phenomenon will allow those who offer end-of-life care an opportunity to proceed from a more informed perspective to incorporate and offer spiritual care more effectively to dying persons and their caregivers. In this way Sprenkle and Piercy (2005) explain how the researcher and audience of any given research project share a commitment to understand a phenomenon more clearly often for a purpose such as personal, familial, institutional or community change. Banister and colleagues (2011) remind us further how people's lived experiences are often overlooked or erased as unimportant by policymakers and researchers alike in our world today that is driven by the need to achieve targets and meet satisfactory outcome measures. However, regarding phenomenology, rather than personal experiences being silenced or ignored, they are positioned centre stage by phenomenologist researchers and accepted as rich veins of understanding that are ideally used to inform practice. Langdrige (2007) adds more specifically that the aim of interpretative phenomenological analysis is on the production of empirical findings in the hope that the knowledge may contribute

to genuinely real and useful social change. This is one of my hopes in the study: the information arising from it will serve as an inspirational resource in the way spiritual care is offered to dying persons and their caregivers in their homes in Grey and Bruce Counties so that dying persons may die well and have a good death.

Research Setting

This research study was conducted in Grey and Bruce Counties in the southwestern region of Ontario, Canada. The researcher is a resident in Bruce County. The total population of this geographical area is 103,815 people representing 43,830 private households according to Statistic Canada (National Household Survey, 2011). In particular to this study, six dying persons and three caregivers resided in Grey County and four dying persons and six caregivers resided in Bruce County. Regarding religion, the population of Grey and Bruce Counties is categorized into the following affiliations: 71,805 (69.2%) describe themselves as Christian; 115 (0.11%) as Buddhist, 130 (0.13%) as Hindu, 155 (0.15%) as Jewish, 150 (0.14%) as Muslim, 80 (0.08%) as Sikh, 295 (0.28%) as Traditional (Aboriginal) Spirituality, 410 (0.39%) as Other Religions, and 30,680 (29.6%) claim no religious affiliation. These numbers are fairly evenly divided between male and female. To fit into one of these categories Statistics Canada defines religion as a person's "self-identification as having a connection or affiliation with any religious denomination, group, body, sect, cult or other religiously defined community or system of belief. Religion is not limited to formal membership in a religious organization or group." (National Household Survey, 2011, footnote 55). In regards to tending to the health care needs of dying persons, residents in this geographical area may seek care by visiting their family physician and/or one of the eleven regional hospitals in Grey and Bruce Counties. These hospitals range in

size from four patient beds in Lion's Head (in Bruce County) to 168 beds at the Owen Sound site of the Grey Bruce Health Services (in Grey County). It is not unusual for residents to travel to hospitals and physicians in larger urban centres of neighbouring counties for specialized treatment pertaining to more serious health concerns.

Research Sample and Participant Recruitment

Phenomenological research studies tend to have smaller sample sizes as a way to focus more deeply on the narratives of fewer participants (Langdridge, 2007; Creswell, 2007; Sprenkle and Percy, 2009; Saldana, 2009). Interpretative phenomenological analysis follows this guideline and seeks to employ a smaller sample size. In a review of literature, Field and colleagues (2005) described studies involving interpretative phenomenological analysis as having a mean sample size of fifteen while one study contained as many as forty-five participants. This research study was representative of eleven households in Grey and Bruce Counties comprising a sample size of ten dying persons and nine people who were primary caregivers to these dying persons.

Purposive sampling was employed in participant recruitment. Smith and Osborn (2003) share how this type of sampling is conducive to the goals of interpretative phenomenological analysis. Silverman (2000) also notes how this type of sampling allows the researcher to seek out participants because they illustrate through their particular experience some feature or process in which the researcher is interested. It further demands a researcher to think critically about the parameters of the population a researcher is interested in and choose the sample carefully on this basis. Smith (2008), commenting more generally on interpretive research adds how purposive sampling allows a researcher to find a more closely defined group of participants for whom the research question will be significant. There are also a variety of strategies a

researcher may use in purposive sampling. The purposive sampling method for this research project employed a criterion sampling strategy. According to Creswell (2007) criterion sampling is important in phenomenological studies when it is essential that all participants have experienced the same phenomenon. Therefore, for purposes of this study, participants who made up the category of dying persons were required to meet the following criteria to be included in the study: persons were diagnosed as palliative while residing in their home settings, persons knew they were palliative, persons were eighteen years of age or older and mentally competent, persons were physically capable of participating in an interview of approximately thirty to sixty minutes in length, persons had some appreciation of spirituality, and while in their homes these persons were receiving care under one of the regional hospice palliative care services.

In addition to employing purposive sampling to establish a criterion base, Denzin and Lincoln (1994) note further how many qualitative researchers employ purposive, and not random, sampling as a way to seek out groups, settings and individuals where the processes being studied are most likely to occur. For purposes of this study I sought out groups and individuals who relate regularly with dying persons and their caregivers. I partnered with the hospice organizations in the Grey-Bruce region who would have at their disposal information about potential participants who would fit the criteria of this study. These hospice services included the following: South-West Community Care Access Centre - Owen Sound (SWCCAC), Victorian Order of Nurses (VON) Grey-Bruce, Bruce Peninsula Hospice, and the regional palliative care physician. It was quickly discovered during this recruitment process that the participants often were receiving care from two or more of the aforementioned hospice services. For example, a palliative care physician in her attendant duties regularly referred dying persons to the services of the South-West Community Care Access Centre. It was not uncommon for the

South-West Community Care Access Centre to make further referrals to the other regional hospice services.

I also invited into this study any primary caregivers of participating dying persons who desired to be involved in the process. I included these primary caregivers as I believed they would serve well as a study resource from which to find further meaning and understanding to the spiritual care offered to dying persons in Grey and Bruce Counties. My additional reasoning for including primary caregivers in the study's population is because dying persons seldom face their end-of-life journey alone. Primary caregivers who may be family members or close friends are often a significant part and support in a dying person's journey. In this role they are also associate and attentive observers, participants, and recipients to the spiritual care that may be offered in the experience of a dying person. Therefore, primary caregivers were welcomed and encouraged to participate in the interview process in the presence of the dying person. In doing so primary caregivers were able to share of their experiences of the spiritual care that was offered to the dying person and how they themselves experienced that care by having an association with the dying person for whom they were caring. In this way caregiver participation could also assist in establishing validity in the experiences of the dying persons.

I worked in coordination with the aforementioned hospice services to recruit participants for the study. My work began with the Coordinator for the Supportive Care Program of the VON Grey-Bruce months before I entered into the formal recruitment and interview process. This coordinator has worked for several years in hospice service of the VON in Grey and Bruce Counties and has an excellent understanding of palliative care services to dying persons in the region. I discussed with her in great detail the intent of my proposed study to ascertain its plausibility and potential benefits for Grey and Bruce Counties. I also desired to learn whether

or not she believed I would be able to find people willing to participate in the study. She confirmed the importance and need of the study and affirmed the belief that there would be dying persons and caregivers who would be willing to participate. She further assured me I would have her assistance with the study. After confirming with her supervisor I also received the support and verbal approval of the VON Grey-Bruce.

I also sought and received approval from the Research Ethics Board of Wilfrid Laurier University before formally engaging in the recruitment and interview process for my research study. I then worked in coordination with the regional hospice groups to obtain referrals to potential participants for this research study. As part of this recruitment process I attended a timely End-of-Life Care Committee meeting that occurs quarterly and brings together representatives from the various hospice palliative care services in Grey and Bruce Counties. As a guest presenter in this setting I explained the objectives of my study, answered questions, requested their assistance in finding potential candidates for the study, and indicated how they could refer clients to me who were interested in participating in the study. They agreed to support the study's endeavours and help find participants for the study. I distributed 'Letters of Invitation' (Appendix C) to each of the representatives, which they in turn could distribute throughout their organizations as an informative resource to give to potential study participants and help them understand better the intent of the study. Following the meeting I was informed by the Client Services Manager of the SWCCAC that I would be required to submit a written request for ethics approval in relation to my work with this government affiliated organization before I could receive referrals from the SWCCAC. I completed the necessary documentation and received approval within a month's time. I met again via telephone, the Ontario Teleconference Network (OTN), and in person with the Client Services Manager and her case

managers after I received approval from the SWCCAC. In this meeting I gave an overview of my study and how they could assist me to recruit potential study participants. I checked in weekly to bi-weekly with representatives from all of the hospice palliative care organizations to keep my study on their agendas and ascertain if there might be any new referrals.

Between September and December 2012, I received referrals for eight dying persons who fit the criteria as potential participants in the study. I followed up on these referrals shortly after I received them; however, I found myself experiencing frustrations in obtaining interviews due to the timing of referrals in relation to the rapidly declining health of the study's potential participants. I soon discovered this would be a recurring theme given the sensitive physical nature of the intended study population of dying persons and their caregivers. In the brief lapse of time between receiving these eight referrals and contacting the potential participants, one person had already died and two had grown physically unable to participate in the study. In another instance, I called a home only to find myself interrupting a family's experience of a man who was actively dying at that very moment. In two other cases the dying persons had already been moved from their home into a hospital. Due to circumstances such as these I was able to interview only two dying persons out of these eight referrals I received over a four-month period. One caregiver also participated in the study during this time period. During the month of December the case managers at the various hospice service organizations shared that it was not a good time to seek potential participants due to the busier time that surrounds the Christmas season and the need for families to gather at this special time of the year with dying loved ones. I respected their reasoning and awaited the new year to begin encouraging the case managers to seek out potential participants once again.

When the recruitment process resumed after the Christmas season my frustration continued to grow as I tried to find potential participants for the study. In the first six months since beginning the recruitment process I had only completed interviews with four dying persons and three caregivers. I had not anticipated it would be so difficult to find participants for this study. In the midst of this frustration I reviewed my sampling procedures and considered if I might broaden the sampling pool as a way to obtain more referrals to potential participants. Mason (1996) affirms this practice by noting how purposive sampling is a set of procedures in which researchers manipulate their analysis, theory and sampling activities interactively during the research process. In order to increase the number of referrals I was receiving and acquire a sample in a timely manner consistent with my research goals, I considered another avenue to increase the possibility of having interviews from the referrals I was receiving. I proposed the idea to one of my advisory committee members who was filling the role of acting-advisor while my regular advisor was on sabbatical. He agreed with my proposed refinement to the recruitment process. I noted previously how I missed two potential study participants due to their admittance into hospital. Until then I had not intended to interview dying persons in a hospital setting, nor did I have approval from the ethics boards of our regional hospitals to do so. As I considered the situation I believed, if necessary, I could interview participants in the hospital setting while remaining true to the intent of my research study. I reasoned that I could interview dying persons admitted to the hospital and ask them to share of their spiritual care experience in their time apart from the hospital. It would be explained clearly to the participants to reflect on their experiences of spiritual care in their time outside of the hospital while they were in their homes. In order to conduct an interview in any of the hospitals in Grey and Bruce Counties, I needed to obtain approval from their ethics committees. Of the eleven hospitals in

Grey and Bruce Counties, six are organized under Grey Bruce Health Services (GBHS), four under South Bruce Grey Health Centre (SBGHC), and the Hanover District Hospital (HDH) is a single-site facility. I filed a 'Request to Conduct Research' application with each organization. A copy of the Research Ethics Approval from Wilfrid Laurier's Research Ethics Board was included in these applications as well as a description of the study and all required documents. I received approval from two of these ethics committees shortly after my application submission. The third ethics committee also approved my request in the latter time frame of gathering my research data.

After receiving ethics approval from the two corporations, I worked in conjunction with the Chaplaincy Coordinator who oversees the chaplains who offer spiritual care at the ten hospitals that fall under the umbrella of these two organizations. A detailed e-mail was distributed to each of these chaplains giving an overview of my study, the criteria of potential participants, and how they could assist in referring potential participants who met the criteria and were willing to participate in the study. In addition, information was distributed to all of the organizations who offer hospice palliative care services in the region to inform them I now had approval to interview people in the ten specific hospitals. I helped them understand how if any of their clients who met the study's criteria were admitted into any one of these ten hospitals, I could interview these clients in that setting if they were willing to participate in the study. I also attended a meeting of the Palliative Care Committee at the Owen Sound site of GBHS. In this meeting I presented an overview of my study, asked them to consider how they could watch for patients who met the study criteria who were willing to participate in the study, and how to make referrals. As originally intended in this study, primary caregivers to these dying persons were welcome to participate in the research interviews if they desired. I desired to learn about the

experiences of non-professional caregivers and invited into this study family and friends who filled this role. Professional health care workers were not invited to participate in the study. During the course of this research project I received referrals to three patients as potential study participants. When I followed up on these referrals two declined to participate due to failing health. I interviewed only one dying person in hospital regarding her experience of spiritual care while in her home setting. None of this participant's primary caregivers were present during the interview.

In total, between January and May 2013, I received referrals to seventeen dying persons and their caregivers primarily during the latter part of this time period. Again, I contacted these referrals as soon as I received them and eight dying persons agreed to participate in the study along with eight caregivers. The other nine dying persons did not participate for reasons of failing health, unreturned phone messages (on their part), or simply declining to participate. For those who agreed to participate, I regularly was required to have numerous telephone conversations with them prior to my visit to ascertain the best time for an interview due to their physical limitations, appointments, and caregiving services entering the home.

All participants in this study met the aforementioned criteria. Of particular interest to this study, all participants identified themselves as having an appreciation for spiritual care and spirituality. One participant (P5) who was a dying person described herself as an atheist, but still maintained an appreciation of spiritual care and an understanding that there is 'something else' in reference to a sense of the divine, she simply could not classify what that 'something else' was to her. All other eighteen participants in the study, both dying persons and caregivers, identified themselves as part of the Christian faith. Further, the participants who were dying classified their Christian faith traditions under the following denominations: Alliance (n=1), Anglican

(n=1), Baptist (n=1), Evangelical Missionary (n=1), Lutheran (n=1), Other (n=1), Roman Catholic (n=1), and United (n=2). Participant caregivers categorized themselves denominationally as follows: Anglican (n=3), Other (n=1), Presbyterian (n=1), and United (n=4). Dying participants described their activity in the representative faith traditions as ranging from actively engaged in the regular activities of a church assembly (n=6) to minimal or no involvement in church-related activities (n=4). Five caregivers who participated in the study also classified themselves as being active in the activities of a church assembly while four caregivers expressed no active involvement in church-related activities.

It is also important to note other characteristics that define this sample of participants. There were seven female and three male dying persons who took part in this study. All nine caregivers who participated in the interviews were female. These caregivers consisted of one person who was a friend and eight people who were family members to the dying persons. Of these eight familial caregivers, three were spouses, three were children, one was a grandchild, and one was a mother-in-law to the dying persons. The ages of the dying persons who participated in the research study ranged from 52 to 94 years of age, while the caregivers' ages ranged from 33 to 82 years of age. Finally, the diseases associated with the dying persons' health conditions were as follows: eight participants were diagnosed with cancer, one participant had entered into the advanced stages of Alzheimer's Disease, and one participant was suffering from recurring Transient Ischemic Attacks.

Research interviews with the study's participants began in September 2012 and concluded in May 2013.

The Interview Process

The case managers at the various hospice organizations in the region were the front-line people who first introduced the idea of the research study to dying persons and their caregivers. When they identified someone as a potential and willing participant in the study, these same case managers would ask permission of the identified persons to refer their personal contact information to me. As noted previously, given the particular health concerns and diminishing physical capabilities of some potential participants, I followed up on referrals shortly after receiving them. All of my initial contacts with potential participants occurred over the telephone. During this initial conversation I introduced myself as the researcher of the study, noted how they were referred to me, answered any questions they may have had, and established their continued willingness to participate in the study. I then established a time for the interview that was convenient to our schedules. Closer to the time of the interview, typically the morning of, I would regularly contact potential participants again to see if they believed themselves capable of being a part of the interview process we had scheduled. In total, 10 dying persons and 9 caregivers agreed to participate.

Banister and colleagues (2011) state that when gathering data, all phenomenologist researchers aim to gain the richest possible account of subjective experience from the participant in order to enable the depth and complexities of experience to be revealed and thus ultimately strengthen the authenticity of findings. To achieve this, researchers adopt an attitude of openness throughout the research. I believed it was important as part of the interview process first to spend some time connecting with study participants before asking the participants the study's formal questions. Given the sensitive nature of the research topic related to spiritual care and dying I first wanted to connect with these people who were meeting me for the first time. In a

therapeutic relationship taking time to connect with people helps to build a trusting relationship so that client and therapist can then enter into deeper and more meaningful therapy. I hoped to employ this principle as part of the interview process. Further, I was concerned how not taking time to connect with the participants may have limited the depth of their responses on the intimate subject of dying during this incredibly sensitive time of their lives. Therefore, I intentionally spent time connecting with the dying persons and their caregivers as a way to begin developing trust in the interview process. This is in line with Smith (2008) and Langdridge (2007) who share that the researcher aims to establish rapport with a participant through a semi-structured interview to enable joint exploration of the participant's world concerning the topic. In addition, this allowed me to record participant information in my field notes that would grant me a better understanding of participants' situations and experiences. This would also serve as a later resource for data triangulation and reliability. Prior to this first contact with the participants I otherwise knew only the dying person's name, their caregiver's name (if applicable), phone number, and the diagnosis that had been shared with me from the referring case managers. Five to ten minutes on average were spent connecting with the dying persons and their primary caregivers before the formal interview began. I believe I was well received during the interview process and participants were open in their conversations. I further believe their openness and honesty was accentuated through the initial time I took connecting and building trust with the participants.

Before engaging participants in the interview questions I reviewed with them the details of the Letter of Informed Consent (see Appendix B). I asked if they understood the various parts of the letter before seeking their signed permission to conduct the interview, use quotations, and audio-record our session. Three participants expressed no concern of anonymity and declared

they would welcome being identified if it fit the research's purposes. During this time five participants also wanted to know if what they shared in the interview would be useful to the study and the larger community. Participants who were dying persons also were informed they could end the interview at any time if any physical limitations related to their condition constrained their ability to continue with the interview. Primary caregivers were welcome to continue the interview in the presence of the dying person if both agreed it was a common desire. At various times throughout each interview I would ask participants of their ability to continue. During this research study only one participating dying person (P4) retired from the interview while insisting his primary caregiver continue the process. He remained within listening distance of the interview and offered input as his abilities allowed.

This research study employed a semi-structured interview format. Smith (2008) states this form of interviewing allows the researcher and participant to engage in a dialogue whereby initial questions are modified in the light of the participants' responses and the investigator is able to probe interesting and important areas which arise. A more detailed explanation as to the appropriateness of a semi-structured interview format in relation to this research project will be provided in the 'Interview Format' section of this chapter.

There was a debriefing time following each interview during which I checked in with participants to see how they experienced the interview process. I also asked if any emotional or spiritual issues had arisen during the interview that they would like to have addressed further through a spiritual care provider. In one instance a dying person (P1) noted how she would appreciate a visit from a spiritual care provider. After a brief conversation we determined what sort of spiritual care provider might help address her needs. I fulfilled her request by contacting

a competent spiritual care provider who ministered in the dying person's neighbourhood and this person in turn contacted the study participant to offer care.

Ten interviews occurred in the homes of dying persons. In three of these cases the dying persons were confined to their beds due to deteriorating physical conditions. In each of these cases a make-shift bedroom was set up in the living room of the home. One interview took place in the Owen Sound hospital site of Grey Bruce Health Services. In this instance the interview occurred in the patient's private hospital room where she was asked to make herself as comfortable as necessary to participate in the interview. This participant verbally requested the health care staff not to disturb her during the interview process unless absolutely necessary. When participants were interviewed in their homes they were encouraged to choose the place where they would like to be interviewed. In all cases the participants knew beforehand I was coming and had a general sense of what the study entailed from the Letter of Invitation that had been given to them previously by the hospice case managers (see Appendix C).

Interview Format

Langdridge (2007) shares the most common interview used in phenomenological research, and indeed all qualitative research, is the semi-structured interview. As noted in the previous section, this was the interview format employed in this research project. A semi-structured interview format was used for all interviews and they were all audio-recorded except for one. In this instance the dying person (P3) and caregiver (C3) felt uncomfortable to have the interview audio-recorded. They did, however, grant me permission to record their answers in written format. The formal questions asked during the interview are included in Appendix A. These open ended-questions sought to discover how dying persons and their caregivers were

experiencing spiritual care as an aid to help them die well in this phase of their lives. In order to gain a better understanding of their experiences in this way, participants were also asked to define what they thought spiritual care to be and how they saw themselves having received that care, if at all. Participants were also asked to describe what they thought the terms ‘dying well’ and a ‘good death’ meant to them, and again, to consider how they might have experienced these things, if at all, as part of their journey. In order to help answer the primary research question, it was important first to learn the participants’ definitions of spiritual care, dying well and good death before considering those items in view of their experiences of spiritual care in the dying process as an aid to dying well.

The interviews ranged from thirty minutes to two hours. As the researcher I regularly checked in with the participants approximately every fifteen to twenty minutes during the formal interview time to determine if they felt capable, primarily in physical consideration, to continue the interview. As noted, in one instance the dying person (P4) requested retiring from the process while his caregiver continued. In total the sample size consisted of eleven households containing nineteen participants. This may be considered a small sample size in relation to general qualitative research, but fits appropriately within the parameters of this particular interpretive phenomenological method. In this way, interpretive phenomenological analysis does not rely on the concept of data saturation, especially given its use of smaller sample sizes (Smith and Osborn, 2003; Smith, 2004, 2008; Collins & Nicholson, 2002; Reid et al, 2005, Brocki et al, 2006). Elliot and colleagues (1999, p.222) add:

Qualitative research should strive to achieve understanding represented in a way that achieves coherence and integration while preserving nuances and perhaps it is when the

researcher feels that their analysis has achieved these goals while telling a suitably persuasive story that the analysis may be considered sufficiently complete.

This description fits well with the nature of interpretative phenomenological analysis as Smith and Osborn (2003) claim there is no exact answer as to the question of sample size since it partly depends on several factors: the richness of individual cases, the degree of commitment to in-depth analysis and reporting, and the constraints under which a researcher is working. Smith and Osborn (2003, p.56) note “a distinctive feature of this interpretive analysis is its commitment to a detailed interpretative account of the participants and many researchers are recognizing this can only realistically be done on small samples.” As such, smaller sample sizes allow researchers to analyse a phenomenon with more depth granting them the ability to develop a more detailed and multifaceted account of that phenomenon. Elliot and colleagues (1999) describe this process as a form of triangulation. For purposes of the current study, research interviews were conducted until sufficient data was generated that would grant a detailed and multifaceted analysis of dying persons’ and their caregivers’ experiences of spiritual care, while also maintaining a manageable sample size as determined by the researcher that would permit an in-depth analysis of the participants’ accounts to be conducted effectively.

Transcription and Data Analysis

The audio-recordings of each interview were transcribed verbatim by the researcher into Microsoft Word documents. No form of Computer Assisted Qualitative Data Analysis Software (CAQDAS) was used as part of the research analysis. Interviews were transcribed at a semantic level. Smith and Osborn (2003) note how the level of transcription for an interpretative phenomenological analysis is generally at a semantic level, meaning it is worthwhile for a

researcher to record all the words spoken including false starts, significant pauses, laughs and other features. Each page of transcription contained a margin on the left hand side to note initial comments. A more ample margin was dedicated to the right hand side of the transcription page to note developing interpretations and themes I saw emerging from the participants' experiences.

Sprenkle and Piercy (2005) note the purpose of analysis in phenomenological research is not to tie all loose ends together, but rather to describe and understand the experiences of the participants. Sprenkle and Piercy (2005) citing Hess and Handel (1959, 1967) describe this as:

A back-and-forth movement from one kind of data to another, from one participant's stories to another's, and from one family's themes to another's – all the while looking for meanings that connect and meanings that differentiate. The only rule of analysis is to remain vitally connected to individual and family conversations and stories.(p.74)

Smith and Osborn (2003) state further how meaning is central in interpretive analysis and the aim is to try to understand the content and complexity of those meanings rather than measure their frequency. This involves a researcher engaging in an interpretative relationship with the transcript. While the researcher is attempting to capture the meanings of the participants to learn about their lived experiences, those meanings are not transparently available in the interview transcripts. Instead, this meaning must be obtained through a sustained engagement with the interview transcripts and a process of interpretation.

This sustained engagement in interpretative phenomenological analysis involves 'emic' and 'etic' interpretive positions. Reid and colleagues (2005) describe the emic position as the inductive and iterative procedures of interpretative phenomenological analysis that are intended to help the researcher develop an initial 'insider's perspective' on the topic. Here the researcher documents this in the form of an interpretative commentary. When engaging in this emic,

phenomenological, insider position, the researcher begins by hearing the participants' stories and prioritizes the participants' world view at the core of their account. During the analysis process I engaged in this emic position in two ways. First, I listened to the interview recordings in their entirety and noted in a research journal any comments that helped me understand better the participants' perspectives of their experiences. Then, as I began the more formal task of reading the interview transcripts I again took note of any reflections that I believed granted me deeper insight into the life-world of the participants. These insights were written as brief comments in the left hand margin of the transcripts and as more detailed descriptions in my research journal notes.

As noted above, taking an emic 'insider's perspective' is only one part of the interpretative phenomenological analytic process because the researcher also offers an interpretative account of what it means for these participants to have these concerns in this particular context. Reid and colleagues (2005) explain how in this etic, or interpretative, outsider position, the researcher attempts to make sense of the participants' experiences and concerns and to illuminate them in a way that answers a particular research question – in this case how dying persons and their caregivers experience spiritual care as aid to dying well. Engaging in this analytical position is underpinned by a process of coding, organising, integrating and interpreting of data. Reid and colleagues (2005) describe this process as detailed and labour-intensive, but also very rewarding as a way to find meaning in the participants' experiences. To start this process, Smith and colleagues (1995) note how it is advisable to begin by looking in detail at the transcript of one interview before moving on to examine the others, case by case. This allows a researcher to begin with a particular example and slowly come to more general categorizations of claims.

As the researcher in this project my initial etic or interpretative engagement with the voices of the research participants began when I first transcribed their interviews. I next encountered them when I began examining a single interview transcript. I ensured I had ample uninterrupted time to examine and engage meaningfully with the text. I read over the transcript to gain a general sense of its meanings and made notes of any impressions that struck me from my initial reading of the material. I continued to stay connected and immersed in the participants' material as I reviewed again the transcript and the initial notes I had written. This time I considered further interpretations of the material I saw emerging from the interview and coded these in the right hand margin as developing understandings of the participants' experiences. I spent more time with the text, moving between phrases and sentences while also considering them in the context of the interview as a whole. During this sustained engagement with the content and codes that had emerged I started to identify themes that I saw developing from my interaction with the material. These themes helped to give meaning and understanding to the participants' experiences. After analysing the first interview transcript for themes, I then analysed each of the other interviews in a similar process. During this process of analysis, these interviews were examined to discover emergent themes that may have been similar to themes from prior interviews and therefore extended the understanding of the theme. I also looked for a differentiation of themes that may have contributed to a new understanding of the participants' experiences of spiritual care in the dying journey. A meta-analysis eventually occurred between all the participants' interviews and themes were collected, organised and grouped together. The most prominent of these themes are presented in the Results chapter of this paper.

Ezzy (2002) recommends researchers check their interpretations with the participants themselves as the analysis process takes place to help ensure the findings' validity. Flick (2002)

agrees with this practice and describes it as ‘communicative validation’. This involves checking back with the interview participant during the analysis and coding to ensure what the researcher is understanding is what the participant actually meant. I had to adapt this process slightly to include it as part of my research method and analysis. Due to the rapidly declining physical conditions of several of the dying participants, it would have proven difficult to have a second meeting with them to verify results when in some cases it was a struggle even to have a first meeting. I therefore adopted a process I describe as ‘communicative validation on the go’. This involved checking back in with participants in the moment to clarify something they said that I did not understand or to verify the meaning of something they had shared. For example, a participant was asked the question: what do the phrases ‘dying well’ and a ‘good death’ mean to you? As she responded to this question I checked back in with her to confirm if what I was hearing is what she meant. The dialogue is illustrated here:

R: What do the phrases ‘dying well’ and a ‘good death’ mean to you?

P2: I think there is such a thing as a ‘good death’. I definitely don’t want to die in a nursing home and I’m doing the EDITH program. You know the EDITH program? That’s through the VON. It’s Expect Death In The Home. We learned that in our courses, classes we took with the VON. Because my last trip to the Owen Sound hospital was not a good one and I’m not putting myself through that, you know.

R: So, this is one way that you’re hoping to die well then – to die in your home and not a hospital?

P2: That’s right.

Sprenkle and Piercy (2005) also state the importance of considering an approach such as this to help validate a participant’s experiences. They write:

The significant hallmark of phenomenological analysis is that the researcher makes every effort to stay connected to the experience of the participants. This may involve checking with the participants at several points in the collection, analysis, and reporting procedures and letting them have input into the meaning being constructed by the researcher to see whether the interpretation is on target.(p.74)

By engaging in a modified version of this practice, it granted the process a partial measure for participants to validate the meaning I perceived they were trying to convey of their experiences. I employed this method realizing the participants' physical limitations and declining health would not grant another opportunity to converse with them about the research's results.

Silverman (2000) notes how the reliability of field data can be strengthened through the use of field notes. It was my practice during and after research interviews to keep field notes. These field notes included observations pertaining to personal information about the participants such as family members, disease history, interactions with others in the household, and living conditions. In this way I was also being what van Manen (1990) describes in phenomenological research as a 'participant observer'. The aim of a participant observer is to enter the life-world of the participants in order to better understand and describe it, while still maintaining a critical distance to be able to reflect on the experience. Concurring with Silverman (2000), van Manen (1997) here states that the observational researcher should keep notes of his or her experiences in the form of concrete descriptions, personal reflections and anecdotes. These field notes proved extremely valuable later in the analysis process as a resource to refresh my memory of details that aided in understanding the participants' experiences, but remained details that were not always captured in the interview transcripts themselves. Sprenkle and Piercy (2005), citing Mishler (1986) support this view, sharing how "knowledge about the culture contained in a

respondent's texts can only be expanded upon when the researcher brings into the analysis what else is known about the participant and his or her circumstances.”(p.73)

Inter-coder reliability is another method Silverman (2000) explains can strengthen a research study's findings. Inter-coder reliability occurs when two or more people code the data, looking for consistency in their coding. To ensure this reliability I enlisted the help of Donna Mann who works as a CCAC Hospice Palliative Care Team member offering spiritual care to dying persons in their homes in the region of Waterloo County, Ontario. We communicated regularly during the analysis process and were in general agreement regarding the thematic results of the study. Langdridge (2007) also notes the importance of collaborative working with colleagues and states how an opportunity arises to work critically with each member of a team in such a way that academic rigour is maximized and assured. Langdridge claims that this way of working does not mean researchers will be arriving at some truth, but they will better enable active reflection on both process and content thereby maximizing the chance that findings will be robust and persuasive. During the entire research process and especially during the analysis stage I also shared my reflections and emergent findings regularly with a colleague who offers spiritual care throughout Grey and Bruce Counties. She in turn offered reflections and insights in the process of my research study and this interaction helped to sharpen findings, affirm thought processes, challenge divergent views when necessary, and encourage new perspectives in the research material. Various scholars and researchers (Saldana, 2013; Flick, 2002; Strauss, 1987) affirm this experience noting how even if a researcher and fellow colleagues are each working on different projects, discussing dilemmas about coding and analysis generates peer support and may even help a researcher find better connections between the categories in process. They further claim that this discussion not only provides an opportunity to articulate

one's internal thinking processes, but also presents windows of opportunity for clarifying a researcher's emergent ideas and possibly making new insights about the data.

Finally, reflexivity is an important part of phenomenological research. This is a process in which researchers are conscious of and reflective about the ways in which their questions, methods and biases might impact on the knowledge produced in a research study. Langdrige (2007) notes how phenomenological research methods and analysis recognize the way in which knowledge is always co-constructed reflecting the choices and questions the researcher makes and brings to the interviews, as much as the experience of the participants being recounted. I engaged in an active process of reflexivity as part of this research project. In the introductory chapter of this paper I outlined the biases I brought with me into this study. These included items such as my position as a spiritual care provider in Grey and Bruce Counties, my belief in the importance of spiritual care as part of a dying person's journey, my desire to examine the provision of spiritual care in Grey and Bruce Counties as a way to address any perceived gaps in the system of care, and my own beliefs as a Christian who is dealing with a terminal illness. I readily admit these biases were inspirational to the study's creation as well as the specific questions that were asked of participants. It was my intention to learn of a specific knowledge base of experiences from the participants and to do so required asking the questions that were asked. Also, throughout the course of the research study and the interviews in particular, I kept a research journal as a way of reflecting upon how I was entering into the interviews, how I was experiencing the interviews, and how the participants in the interviews were experiencing me as the researcher. I was particularly conscious of the feelings and emotions I was experiencing during the interviews and reflected upon what these may have meant in relation to the participants' experiences, the research study as a whole, and my personal growth and learning as

a person on his dying journey. I further gave particular attention to occasions when I felt both comfort and discomfort in what was being shared by the participants. In moments of comfort – what was setting me at ease in my experience of the participant’s experience? In moments of discomfort – what was it in the interview that was leaving me unsettled? Keeping a journal of these reflections and maintaining an awareness of the biases and stirrings I was bringing with me helped me understand and appreciate more deeply the participants’ experiences and my encounter with their expression of those experiences.

All of these various aspects of phenomenological methodology and analysis were taken into consideration while engaging with the interview participants in this research study. Adhering to these conventional practices proved valuable in the results that began to materialise from the participants’ experiences and the emergent themes that arose during their analysis. In the next section – Chapter 4: Results - the voices of the dying persons and their caregivers will speak to the various themes that contribute most prominently to the research question’s exploration of the participants’ experiences of spiritual care in Grey and Bruce Counties.

Chapter 4: Results

“The art of living well and dying well are one.”
- Epicurus

This study explored how dying persons and their caregivers experience spiritual care in their homes as an aid to dying well and having a good death in Grey and Bruce Counties, Ontario. Themes arose from the findings by using interpretative phenomenological analysis as a way to understand the meaning of the participants’ experiences. These themes include: end-of-life spiritual care provides connection and support in the dying journey; end-of-life spiritual care helps develop personal inner-resources; end-of-life spiritual care helps to bring peace of mind in the dying process; and, the nature of rural Grey and Bruce Counties as an aid to end-of-life spiritual care. While all of these themes are important to the experiences of dying persons and their caregivers, it should be noted the participants placed great importance on the elements of end-of-life spiritual care associated with the theme of connection and support in the dying journey. The incredible details of their descriptions in the following section are evidence of this fact. It is also worthwhile for me to point out as the researcher how I observed a prideful joy in the semblance of the participants when they discussed how living in Grey and Bruce Counties was beneficial to their experience of end-of-life spiritual care.

This chapter will discuss each of these themes and use ‘thick description’ (Denzin, 2001) to review a wide range of participants’ experiences with the intention of providing the reader an opportunity to enter into and better understand the world of dying persons and their caregivers in Grey and Bruce Counties. Illustrative quotations from the participants’ interviews will be employed as a way of enabling the reader to encounter the voices of the dying persons and caregivers. It is intended these voices will provide the reader some rich insight into the participants’ lived experiences of spiritual care as part of the dying journey. The first part of this

chapter is a presentation of the prominent theme of spiritual care as connection and support for dying persons and their caregivers in Grey and Bruce Counties.

Theme: Spiritual Care as Connection and Support in the Dying Journey

Experiencing connection and support through spiritual care was a predominant theme inherent in the interview conversations with the dying persons and their caregivers. Participants regularly claimed they needed spiritual care provided to them in a way that helped them to have a connection to various people who could assist in different ways as part of the dying journey. They also mentioned how having a connection to specific non-tangible items such as traditions and practices of their churches was an important part of spiritual care. Participants further expressed how they felt supported in positive ways in the dying journey when through the provision of spiritual care they experienced a meaningful connection to the people and things they deemed as important. Conversely, participants expressed occasions of not feeling supported in the way they needed when spiritual care proved ineffective in providing these connections. Who were the people dying persons and their caregivers that needed a connection to and support from in the dying process? Likewise, what were the intangible items? This section will explore these various elements described by participants including spiritual care providing a connection and support in relation to: a Minister, Church Laity, Family and Friends, Other Care Providers, Physical Contact, God/Sense of the Divine, Spiritual Practices and Tradition, and Nature. The following section is an overview of the predominant need participants expressed for spiritual care to grant them connection and support in relation to a minister.

Minister

Dying persons and caregivers noted the importance of spiritual care providing them with a connection to the support of a spiritual care provider. It is worthwhile to point out the terminology this predominantly Christian sample of participants used to refer to the spiritual care provider included 'minister', 'clergy', 'clergyperson', 'pastor' or 'priest'. These terms were employed primarily with the understanding of this being a person who offered spiritual care in a tradition of the Christian faith. The one dying woman in the study who classified herself as an atheist also had an appreciation for these terms and used them in conversation with the same understanding and application. Regardless which of these terms was used in conversation to refer to spiritual care providers, study participants believed having a connection to them would grant the participants support in a variety of ways. This became an important and dominant sub-theme in this category and encompassed a number of variables that participants described as contributing to the effectiveness of the care offered by spiritual care providers. These variables will be reviewed in this section in the following order: Showing Up, Access to a Minister, Assessing Needs, Types of Support, and Urgency as Death Approaches.

Showing Up - A recurring theme in the interviews was how a minister first has to show up in order for spiritual care to offer a connection and support to dying persons and their caregivers. It may seem an obvious point, but participants stated how it is difficult to make a connection to ministers and feel supported by spiritual care in the dying journey if ministers do not show up. Participants recounted positive and negative examples of this connection and support. One caregiver shared of her family's positive experience with their spiritual care providers, "We have a minister and we also have a lay person who has come around and sat and talked with us, just to

keep us connected with the church during this time.”(C10) This helped the family to feel supported in their journey although they were unable to attend church and connect with the minister and lay people through Sunday morning worship. A dying woman also shared her appreciation for her minister’s visits, “My pastor has been very good. He has visited quite a bit and then he got sick so he couldn’t, but then he would phone.”(P2) Even when her minister was unable to be present with her physically it was still important to the dying woman that he connected with her and offered support through conversation over the telephone. I noted in my field notes evidence of this woman’s support when during our interview we were interrupted three times by telephone calls. One of the calls was from this woman’s minister to see how she was doing while the other two calls were from friends. She described how this had continued to be a positive experience of spiritual care that helped to meet the dying woman’s needs.

However, this same dying woman also offered another general observation regarding spiritual care she perceived in her community. She explained, “I find, unfortunately, a lot of ministers don’t visit anymore.”(P2) She did not describe her own situation in this manner, but expressed her concern for other people in her community who had shared this frustration with her. This frustration was not limited to the small community of this dying woman. A family who lived about an hour’s driving distance from this woman shared how discouraged they were with the incredible lack of spiritual care support they were experiencing from the minister not visiting in their time of need. A daughter in this family who was caring for her elderly dying mother shared of her mother’s deep-rooted connection to the church and ministers in her mother’s younger years, but now noted how they were experiencing a continual frustration because the minister was not visiting her mother. The caregiver-daughter shares:

The only thing that I would say for her right at the moment she doesn't have contact from a minister. To her the contact from the minister is sort of the thing. That's the person that gives spiritual care. You know, it's great when someone else comes to visit, but that era was the minister to come to visit. And she hasn't had that just lately because there is a new minister that doesn't know her. She knew the previous minister quite well and really appreciated her and there was a connection, but she really doesn't have a connection to a minister.(C9)

This caregiver-daughter could not emphasize enough the importance of ministers reaching out to visit the sick and dying in their time of need when they could no longer maintain an active connection to a church through attendance on Sundays and other activities. She continued to express her concern regarding the care offered by ministers as follows:

I think they need to visit more. Especially those like my mother who have been detached. I think we need more contact with the spiritual care providers, especially when I see in general what is happening is that when you can no longer attend church, they just go through the cracks.(C9)

The daughter emphasized several times during the interview how the minister of her dying mother's church had not visited once. Unfortunately, no connection had been established between the minister and the dying woman or her daughter. As a result the dying woman and her caregiver-daughter did not feel supported by spiritual care in the way they felt was needed during the dying journey. Again, the daughter articulated her concern:

The minister has never ever tried to contact her. And they know her situation and they know me and they know my daughter who has been the bulletin/secretary for years. So, there's been no visit. She's just not a good visiting minister. What happens is, I don't

feel I want to call her for a funeral...but I know we are struggling, and I guess I don't really want to call and say 'would you make a visit?' because it's very obvious that she needs a visit...But right now I don't care about the ethics of the church, I care about the connection. And that's where I'm saying our connections fall apart. I'll be honest with you, I'm not going to call a stranger that doesn't know my mom to do her funeral when it is about her life, and you never even made an effort. Not even a phone call.(C9)

The hurt of this family's unmet need for spiritual care was evident in the daughter's descriptive expression of the minister's absence. This theme was echoed in the words of another caregiver in the study who shared how she and her dying husband had both positive and negative experiences of ministers making an effort to visit. When asked to consider how spiritual care providers might help dying persons and their caregivers she exclaimed, "I think by being there for them. And I know even in _____ we had some ministers that were great to be there for people. We also had one that never showed up."(C11) A dying man who participated in the study succinctly summarized the importance of ministers offering spiritual care when he exclaimed, "they've got to make an effort to show up!"(P8)

Access to a Minister - While many participants communicated the importance of a minister showing up to offer spiritual care so that dying persons and their caregivers would experience support in their journey, some participants confessed their ignorance of not knowing how to go about connecting with a spiritual care provider who might offer them spiritual care in the first place. One dying woman who participated in the study had not fully considered her desire to connect with a spiritual care provider until the research interview stimulated her thoughts in this way. She was at one time an active church-goer, but had been inactive in the expression of her

organized faith tradition for many years. Reflecting during the research interview, this woman shared, “I fell off the map as far as organized religion went and no one contacted me. And so I don’t know how to get back to that and I don’t know if I really want to.”(P1) This dying woman repeated this refrain on four different occasions throughout the interview. As part of the debriefing time of the research interview the participant was asked if she desired a spiritual care provider to be contacted on her behalf who might visit and help address her needs. The eagerness of her reaction to this question was so dramatic I referenced it in my field notes with the comment, “mere words cannot describe the happiness and enthusiasm in the participant’s response.” Indeed, the dying woman expressed how she strongly desired this, the researcher contacted a trusted spiritual care colleague in the woman’s neighbourhood and a visit occurred.

Another household that participated in the research interviews experienced a similar gap in the delivery of spiritual care and also noted their lack of knowledge in accessing a spiritual care provider. The caregiver-wife and dying husband in this family had no active affiliation with a congregation although they both had attended Christian churches in their childhood years. Still, during the research interview they expressed how they both would appreciate the support of a spiritual care provider during their time of need. The wife commented, “There’s a disconnect between those that go to church and those that don’t. Because we don’t go to church doesn’t mean we don’t, wouldn’t like the services of a minister and I think, I don’t know how to connect between those who do and those who don’t.”(C4) She continued to note the frustration she experienced in this way since her husband’s initial diagnosis. She shared, “I think I was surprised that we weren’t visited by clergy. I was with him every waking moment when he was diagnosed and since then, I don’t remember...you’re the first clergy that we’ve talked to!”(C4) She humorously noted when the CCAC worker approached her about participating in the

research study she “kind of jumped on it. I just thought it was great that I was going to meet a minister!”(C4) This caregiver went on to explain how the CCAC worker’s referral to the research study was not the first time she and her dying husband had been asked about their desire to connect with a spiritual care provider. She recounted a story of how they were asked if they would like to see a spiritual care provider while in the midst of the many other forms they were required to fill out upon her husband’s initial consultation at the cancer clinic. She recalled, “They never ask again and no one ever came by again and I think it’s too formal a venue to be asked that question.”(C4) Later during the interview this caregiver added how it would be beneficial to be asked about the provision of spiritual care once a person’s mind has settled. She offered:

Maybe that’s a better place to have the question asked is ‘When you get home would you like to speak to a clergy?’ It’s never asked again and I think we’ve said on several occasions that it would have been nice to have someone to talk to cause again you’re left to your own devices.(C4)

The dying husband was suffering from a brain tumour and contributed minimally during the interview conversation. He did, however, agree with the comments his caregiver-wife made regarding accessing spiritual care. Again, as part of the research interview debriefing time the researcher inquired if the family would like to have a spiritual care provider contacted who might connect with them and offer support in their time of need. They declined the offer and noted how they experienced the interview process itself as a form of spiritual care that helped attend to their current needs.

Assessing Spiritual Care Needs - It is important for those who offer spiritual care to assess regularly the needs of dying persons and their caregivers. Spiritual care providers must realize this assessment is not a one-time occurrence that is carried out only during the initial meeting with the dying persons and their caregivers. The needs of this group are continuously changing and spiritual care must be dynamic to be effective. When reflecting on their lives since diagnosis, participants recognized how their needs changed over time and in some cases from day to day, or hour to hour even. Therefore, how one offers spiritual care must also adapt accordingly if it is going to address effectively the needs that are experienced by dying persons and their caregivers. Sharing the voices of some of the research participants will help to deepen this understanding. When a dying woman was asked if she felt her spiritual care needs were being provided for by her minister, she replied, "For myself right now I feel that all my needs are being met. Now maybe when I go farther into this, there may be more needs. You know, when I get sicker, but right now I feel they're being met." (P2) Although this woman felt all her needs were currently being addressed, she also realized her needs would change as her disease progressed. The spiritual care she was receiving from her minister would have to adapt accordingly if it was to continue serving the woman's needs. In another instance a caregiver expressed an understanding of how her needs changed regularly. She remarked, "If you want to test my emotional or spiritual well-being, ask me again and again because that will change daily. All of it changes with every stage of this, from a caregiver to a patient, it changes monthly, daily with what you're going through."(C4)

Some participants also noted the importance of spiritual care providers assessing the individual needs of dying persons and their caregivers because every person is different and their needs will also be different. Ministers cannot assume the type of spiritual care that supports one

person will also serve another person with the same level of effectiveness. Participants in the study expressed how it is therefore important for ministers and other spiritual care providers to assess the needs of each person they are caring for and support them accordingly. In this way a daughter providing care for her elderly mother shared how “spiritual care providers can be in touch with a patient’s needs. A spiritual care provider who is a good judge of character in this way can ‘read’ a patient well and know what the person might need and offer the best care for the person.”(C3) Other participants also remarked on the importance of paying attention to the needs of each individual and offering care to address those needs. A caregiver commenting about care to dying persons shared:

I don’t think they get asked enough ‘what do you want?’, people are assuming what they think would be best for the person...more questions need to be asked of the person who’s actually going – how do you want this done, how do you want that done, who do you want to talk to? It’s making sure the person who’s passing, their needs are being met. It’s a really individual question and I think it goes back to ‘ask them’. I think it all depends on the individual and what they want.(C4)

This sentiment was shared by others who considered spiritual care to dying persons a personal experience that needs to be catered specifically to each individual. A daughter caring for her elderly mother shared the following when asked how spiritual care might help them during the dying journey: “I think that’s a very individual question because I think for myself everybody has to come to terms with it individually.”(C10) Her daughter, also a caregiver, affirmed this position and added, “It’s very personal and I also think it’s very dependent upon the circumstances.”(C10.2)

Type of Support from Ministers - Many participants in the study expressed ways in which they hoped ministers would help to address the participants' needs when the ministers made an effort to show up. In some cases the participants also expressed what they believed would not be helpful spiritual care from a minister. Primarily, various participants thought a minister would be a good person to talk to about concerns they were having in their lives or with the dying journey. One caregiver claimed she was not 'overly religious', yet shared, "I've enjoyed when ministers have come into a home and listening to them and talking to them. I mean they're very open and they communicate very easily."(C1) It was also important to participants that a visiting minister offer care that was considerate to the dying person's situation. There was a recurring theme that ministers needed to be gentle in their approach of care to dying persons. One dying woman related the following when she talked about having a clergyperson from her faith visit, "I'm nervous about it because they can be too gung-ho and I don't really want that."(P1) This dying person's caregiver affirmed her position, stating to the woman who was dying, "Like you said you really don't want the Catholic priest because you want somebody that's easier going, you don't want somebody who comes on so strong – like, ok, 'you're ready to die', but no, 'I'm not ready to die today, so don't push it on me.'(C1) This same caregiver shared the importance of having ministers offer care who were easy to talk to and further stipulated the desire to receive care from somebody she already knew and "somebody that's more down to your own level. Like, some of them are too overbearing."(C1) She further expressed how she considered it beneficial if spiritual care providers had a previous connection to those to whom they were offering care.

In another interview a wife who had been caring for her elderly husband expressed how she desired to experience spiritual care from spiritual care providers. She said, "Well, it's

supporting. Supporting your beliefs. I don't see spiritual care as trying to say 'I'm right, you're wrong, let's change this.'(C11) Regarding her experience of ministers visiting during her husband's dying journey she relayed, "at different times they came in and supported me and I really appreciated that. And there again, they didn't preach at me, they talked with me."(C11) This turned out to be a common refrain throughout many of the interviews. Dying persons and their caregivers desired their ministers or other spiritual care providers to offer them care that provided a connection that was gentle, supportive and not 'preachy'. Participants regularly shared how they needed someone who would listen to them and the needs they were expressing, not preach at them, and who was down to their level and would meet them where they were at. In this way a dying woman who called herself an atheist expressed quite openly how she hoped a spiritual care provider would help to meet her needs. She remarked, "Like I do not find spiritual care is a minister coming in and reading scripture from the bible. So it's not that I haven't read the bible, I have. That's not what I'm looking for, not at all. That doesn't do it for me."(P5) Later in the interview this same participant shared how a spiritual care provider could support her in her time of need,

"Listening. Listening is a real big part of this. And to me that's important and if they're not listening, there's no point. If you want someone to come and speak to you, it's always a sermon, it's not somebody who just comes and listens to you or talks to you.

I'm not looking for a sermon. That's not help to me. Not at this stage of the game."(P5)

Did this woman have any positive experiences with a spiritual care provider since her diagnosis? Toward the end of the interview she recalled a positive story of a minister who had been visiting her:

She's been a little more helpful. But I did tell her, 'not really, I really am an atheist'. She said 'that's ok, if you just want to talk'. So she's been the most open of all of them and she has been helpful trying to find something out for me. So she has sort of come around that way and I appreciate that.(P5)

To this dying woman, one of the most important aspects of support that spiritual care providers could offer was to have someone listen to her needs and help her address them. She shared how she often felt disconnected from people who were trying to support her because she believed they were not hearing what she was saying and this led to her needs continuing to go unmet. After sharing of her continual frustration in this way this dying woman then shared how she found the experience of the research interview itself as something meaningful. She tearfully commented, "To think after nine years to get somebody to listen to me. Thinking all that I've been through might be of value, but no one's ever asked me."(P5) After this interview I commented in my research journal how it appeared the research interview was a form of spiritual care in itself for this woman as the researcher - a known spiritual care provider – took an interest in her dying experience and listened to what she had to say. Further still, participating in the research interview appears to have granted some meaning to the dying woman's experiences.

A woman caring for her dying husband echoed a similar desire to have ministers offer support to those who are dying through their presence and active listening. She shared, "to see a minister sometimes, no matter what your situation is, sometimes has a calming effect on whatever you have questions about or are dealing with. The sense that someone's listening. The sense that you have someone to talk to about it."(C4) This woman admitted that she and her husband had not received any kind of support from a spiritual care provider in this way even though she would have welcomed it in their time of need. A dying woman who had an active

connection to her minister also expressed the importance of a minister being available to help address questions one might have and serve as a guide to the dying journey. She commented how a spiritual care provider is “a follower of Christ and is willing to lead you through the last part. You know, if you have questions or just comfort and somebody to talk to and to pray with and to read scripture, that would be what I want.” (P2) She affirmed this comment further when she was asked how she thought spiritual care providers might help people when they are dying. She replied, “I think that goes with talking to them, praying with them, comforting them, and just making it easier for them to slip away.”(P2) This type of care she described is the very support that was received by a dying man who participated in the study. He described it in the following fashion: “When somebody came in to talk to me, read the scriptures or prayed with me, it gave me gas in my tank for one more day. I crave visitation – people, friends, ministers, chaplains, anything. I crave to have people here. It is like God with skin on.”(P6)

Another dying man related more generally to the support a minister might offer through spiritual care to the dying. He shared how a minister can be “somebody looking after you. Care for your life.”(P8) His caregiver-wife agreed that this had been their experience. Another wife caring for her dying husband emphatically summarized the role of spiritual care providers to those in their dying journey. She declared, “What can spiritual care providers do? “I would say support, support, support. Definitely.”(C4)

Urgency as Death Approaches - Some participants in the study stated how there appears to be a need to address spiritual issues and make sense out of what is going on when a person is faced with dying and death. These participants perceived how this need becomes more urgent as death draws nearer. Spiritual care, especially as offered by ministers, was considered by some

participants as an important resource that could support dying persons and their caregivers in this need. A dying man ardently stressed the importance of needing a connection to a spiritual care provider who could guide a person in that part of his or her dying journey. He articulated the following:

When you're facing death, you're faced with some serious introspection, you're faced to look inward and face the whole spiritual aspect of life that formerly maybe you never even gave some consideration to. If I was dying and didn't know anything about spirituality too much and I only had a few days to live, I would want answers. If you can't provide answers, get out of my room! The spiritual part of life is more real than physical, I think. It's got to be addressed, it's got to be part of the overall care of anyone that's sick and dying, that's for sure.(P6)

Other participants provided similar observations regarding the importance of spiritual care to dying persons. A woman dying of cancer remarked, "I think that's important because there's lots of times on the dying bed when the people are led to the Lord. And they need somebody to help them."(P2) A woman offering care to her dying husband shared, "I think a lot of people get...the closer they are to the end of their life, the more spiritual they become. And I think it's because they're looking for what's next and I think a minister can help them find that."(C4)

Another caregiver reflected on the important need for spiritual care when her father was dying years ago. She shared, "Definitely like when dad was quite ill and he knew, it was important for him to have that connection with the minister, the spiritual leader of the church. Just a kind word to reinforce your own faith because sometimes you start questioning it."(C10)

A few participants reflected upon the urgent need for spiritual care that is experienced at times by dying persons who previously did not consider themselves religious or spiritual. A

caregiver who expressed having an active faith life shared the following regarding the importance of spiritual care to dying persons: “I think it’s very important to a dying person before they die because I think even if they’ve had no spiritual care in their life, or even they don’t feel they are religious, I believe that no one wants to die alone and we all need someone to talk to, to express our feelings to.”(C9) A dying woman added the following: “An atheist can say they don’t believe. Others will say we’re gone and that’s it, there’s nothing. But I don’t believe they believe that because there’s a part of us that’s created to know there’s a God.”(P7) The sentiments shared by these participants may appear to ring true to some extent when evidenced by the comments of a dying woman who declared herself to be an atheist, yet with an appreciation for spirituality. Quite interestingly this woman claimed:

When I go I’ll be prepared because I know there’s something else there, I know that. So, I’m going to look forward to what that is, but I don’t think it’s something tangible that I can just say ‘that’s it’ or ‘that’s it’. I think it’s something I’m just going to have to wait till I die, then I’ll know better what *that* is.(P5)

The connection and support offered by spiritual care to dying persons as they approached death appeared to be appreciated by participants with deep religious backgrounds and those who were still searching to understand their spirituality. In some cases it appeared even those who had no previous affiliation with religion or spirituality could have a new appreciation for its support when experiencing their dying journey.

This is an overview of the ways in which dying persons and their caregivers experience connection and support through spiritual care in relation to a spiritual care provider and in particular to this study, spiritual care providers who are ministers in a Christian tradition. The

results continue with the other ways dying persons and their caregivers experience connection and support through spiritual care as listed in the introduction of this section.

Church Laity

Various dying persons and their caregivers expressed their desire to have a connection with the laity of churches. This desire was more apparent in the interviews in situations where participants already had an active involvement with a congregation. Those participants whose current congregational involvement was limited or non-existent did not state the same level of desire for a connection with laity, although as demonstrated in the previous section they may have desired a connection to a spiritual care provider. Again, those participants who mentioned some desire to connect with laity did so because of the support this connection would bring to the dying persons and their caregivers during the dying process.

The importance of this connection and support was expressed in different ways by dying persons and caregivers. A dying woman who remarked of her deep and meaningful relationships with fellow members of her congregation also shared of the support she was receiving: “I have a loving church family. I have friends that are there all the time. I have friends that are praying for me all the time. My family.” (P7) Indeed, this woman also noted the incredible connection she had with her immediate family and the loving support she was also receiving from them, but her connection to her church family and the support they were offering her through their prayers fulfilled a different need for her. She expressed how she felt deeply supported through the prayers of her church family. An elderly dying woman (P3) and her caregiver-daughter (C3) shared similar sentiments as they recalled how much they appreciated knowing their faith family was praying for the dying mother. These two participants added how the connection and support

from the church family toward the family was strengthened further by the church members visiting the dying mother regularly during her illness. The dying mother admitted she received so much support from her church family in this way that it sometimes appeared as though a steady stream of visitors was going through her home. Indeed, in my field notes I remarked how I was surprised to witness this shortly after the interview when I crossed paths with a church member who was coming to visit the participant as I was exiting the house. Another caregiver also expressed appreciation for prayers and visits as well as special gifts to her and her dying husband from the members of her church. She shared, “Our church, the people have come to visit, sent messages, prayer shawls made by the knitting group.”(C8) She noted how the prayer shawl was particularly special since it served as a physical reminder of the connection she shared with the congregation and a symbol of the laity’s love and support embracing her husband when it was wrapped around him. This caregiver, who also had custodial responsibilities at her church, further shared how the church people were supporting her by assuming her job duties while she was otherwise busy caring for her husband. She proudly stated, “They have done such a good job. But they do, we really support each other.”(C8)

A woman who was caring for her dying husband related how this sort of support that dying persons and their families receive by having connections to the larger community is a natural mandate of the church. She offered, “Support. I think that we’ve received from the community and people around us has been incredible. I think it kind of boosts your sense of that goodness you associate with the church.”(C4) Some participants expressed their appreciation of having church people connect with them by telephone as another avenue to support the dying persons and their caregivers. A granddaughter-caregiver voiced the following: “I feel the church itself has always been there and I think to me that is another aspect of spiritual care because we’ll

get phone calls – ‘Hi, how are things?’ At least I still feel connected to them even though we’re not able to attend.”(C10.2) The caregiver’s mother supported her experience noting how from the laity of the church they had received “...a lot of phone calls asking if they can come to visit or not.”(C10) Conversely, a dying woman expressed her concern that she felt the church people in her congregation had not made much of an effort to connect with her, even by telephone. She noted how important this connection and support would be to her during her journey. She commented, “I mean you’re still alive, you still would like to talk to somebody or someone you know.”(P2) This dying woman expressed how she had always had meaningful relationships with the people of her church family when she was able to attend. Now that the physical deterioration of her illness had essentially erased her attendance at church functions, she described how it felt as though the laity of her church had forgotten about her. She was experiencing a gap in the provision of care she needed.

In the majority of these cases the spiritual care the dying persons and caregivers received occurred when the laity reached out to the participants and not from the participants reaching out to the laity. What often occurs is the dying person is no longer being able to attend worship services and other church functions as a way to maintain former relationships with the church laity. This was the situation previously described with Participant #2 above. In cases such as this it becomes important for the laity to make an effort to come to the dying persons and their caregivers. Caregivers may also find themselves limited in their ability to attend church functions as they once did because of their caregiving duties to the dying person. One caregiver commented on her lack of connection and support from her church family because of being a full-time caregiver. She explained, “Myself, like I miss going to church on Sunday morning, that’s just because I can’t get out on Sunday morning. And I know Mom misses it. It was very

much a part of her life, as she aged she couldn't go.”(C9) This caregiver further described how she only received so many support hours a month to help take care of her mother. Therefore, in order to be able to attend the occasional worship service on Sunday, this caregiver shared how “Sometimes I even pay my home care worker to come out on Sunday so I can go. It's good for me.”(C9)

Family and Friends

Some participants in the study shared the importance of having a connection with family and friends as a form of spiritual care and support during the dying journey. The term ‘family’ encompassed a wide range of people from whom the dying persons and their caregivers experienced connection and support as the following illustrations demonstrate. A dying woman shared how delighted she was to have her children keeping contact with her and how pleasantly surprised she was by the level of support they were giving her. She remarked, “I'm quite amazed at how attentive they have been. Two of them are away. One is in _____ and one lives in _____ and the other in _____. They phone me every day, just about, and they've been really amazing. I never thought they would be like that.” (P1) Indeed, I remarked in my field notes how I was a witness to this fact when during the interview she received a call from one of her children. Another dying woman who proclaimed herself an atheist shared of the spiritual care she also experienced through her children visiting her, “I look at them as being part of the spiritual part that keeps me going too.”(P5) A woman dying of cancer expressed the incredible blessing of support her siblings had been to her during her time of need, “The family...I have four sisters, every week they're here or on the phone. They're just so close. I mean, I am so blessed.”(P7) A dying man reflecting on the care he received from his wife teared-up as he

commented, “She is my greatest caregiver, spiritually and otherwise.”(P6) This connection to family and the support it provided dying persons and their caregivers was considered an important form of spiritual care during the dying journey and was also a message repeated in many of the research interviews.

A few participants also expressed a similar need to maintain connections with friends as a source of spiritual care and support during the dying journey. A dying woman noted the importance of having friends to connect with and support a person when he or she is dying. She described spiritual care offered by friends as, “Loving someone through a hard time, and we need to know that other people care and love us and are with us during this journey.”(P7) A man dying of cancer expressively conveyed similar sentiments regarding the support he received from his friends. He commented, “And then the care of my friends and the prayers of my friends beyond the medical field was fantastic!”(P6) He continued to share how this support gave him the strength he needed for his journey. Sometimes this support and spiritual care naturally fit together when a dying person’s friends are associated through a church connection. When thinking about the spiritual care she and her dying husband had received, one caregiver commented, “I think the friendships through the church because basically all our friends in Owen Sound – we got to know our neighbours, but our basic friends came through the church. And they did, they just took us right under their wing.”(C11) When her husband fell ill this caregiver explained how their friends from the church were a great support in their time of need.

Other Care Providers

Dying persons and their caregivers shared how they experienced spiritual care from other people who were not formal spiritual care providers. Often these people included members of

the palliative care team such as nurses, health care workers and hospice workers who were providing care to the dying persons in their homes. A daughter (C3) caring for her dying mother (P3) noted how even her mother's nurse saying "we're all rooting for you" was experienced as spiritual care and helped the whole family deal with the situation they were facing. Another woman who was offering care to her terminally ill husband also shared how the home-care nursing team had helped her deal with what she was facing: "And you know you do get spiritual support from the nurses and the people that come out and look after you. That all feeds the soul as far as I'm concerned."(C4) Another wife who offered care to her dying husband shared how important it was to have visiting members of the nursing team consider offering spiritual care as part of their visits. She related:

I think being well cared for – spiritually, mentally – and I know he was very upset when they decided he was dying and I wasn't there, but the nurse that was on told me this. And she said 'we asked him if he'd like us to pray with him and he said he would and he settled down. I felt awfully good about that because lot of times nurses don't even think about that.(C11)

In some cases the connection provided by the health care workers resulted in support that went over-and-above what the participants thought was the regular call of duty. A dying man spoke of the nurses being like "God with skin on" simply by physically touching individuals and listening to them. (P6) He continued, "I am impressed with the nursing care. In some cases they would talk me down from my anxiety, but in general just sit there and talk like I'm a human being." This dying man relayed this as a positive experience that supported him in his time of need. However, during the conversation he also shared a time when he was haemorrhaging and feeling

as though he did not receive spiritual care from the health care workers in the way he had hoped or needed:

These were professionals, they were medical people, they were there to stop the bleeding but there was no spiritual component, nobody there to hold my hand. I was on my own and it was one of the loneliest, scariest things. So spiritual caregiving in my estimation is almost front and center, it's got to be foremost.(P6)

He described himself as having all the medical support he needed, but he felt no other connection to these people that would have aided him spiritually in his time of desperate need. This in turn made him feel like he was alone in his experience with no one to help address the fears he was having. He noted how simply having had someone present with him to hold his hand would have been a form of spiritual care and support for him. This is a sentiment echoed by another dying person in the study. She shared, "Ya, holding your hand and doing all that and just being there makes a difference."(P1) Both of these participants explained how small actions such as these can make a large difference in the way a dying person experiences the care he or she is receiving.

It is also worth mentioning how another participant in the study experienced positive spiritual support as she understood it from her hospice worker. This dying woman expressed how incredibly important her connection to her hospice worker was to her. She repeated several times during the interview how this hospice worker helped her address the needs she was having in her dying journey. When asked how spiritual care had helped her in her journey this dying woman shared,

My hospice worker has been most helpful in that regard. She will listen to the things that are happening to my body right now. She comes here to visit. My hospice worker has

always taken time to listen. Even when she can't get here, when she phones, she always listens to how things are going. She has a way of making me feel important and needed without even knowing it.(P5)

As all these various participants have described in this section, spiritual care can take many forms and can be offered by a wide variety of people in addition to those considered formal spiritual care providers.

Physical Contact

A small number of dying persons and caregivers in the study shared the importance of spiritual care making a connection and offering support through physical contact with the people receiving care. This need was often expressed by participants as the desire to have a spiritual caregiver offer a simple form of touch to the dying person or caregiver. A caregiver who was addressing her dying mother shared the following reflection regarding her minister offering spiritual care through his touch:

And how many times has he just taken your hand and just said 'can we say a prayer together?' That means a lot. Sat and touched. And I know I can speak for mom on that part because he has taken her hand whether it is here or in the hospital when she was sick in the hospital, and then we'll say a prayer. And he's always there, he gives me a hug, bends over gives mom a hug. Just the warmth.(C10)

This element of touch from their minister was a common experience for the caregiver and her mother. The daughter further noted the special significance associated with her minister holding her mother's hand. She offered, "Ya, like I can hold my mother's hand, but there's just something about the fact that he's a minister. Ya, I think just having that connection."(C10) The

minister's touch may have taken on further significance in this case. The mother (P10) was also suffering from Alzheimer's and had difficulty communicating verbally. As such, a simple human touch as a form of spiritual care may have connected this woman's minister to her in a manner of support that words could not have necessarily conveyed. In another research interview a dying man noted the importance of human touch in this way:

A hug or touch, human touch, just I don't know what it does, but it does something and it's huge. To not come just with words, but with genuine compassion – Jesus touched the lepers. You don't touch a leper if you don't want to become one yourself. He touched the leper. I think if we can't touch that person, then that's a huge...that would be unfortunate.(P6)

He further shared how one cannot underestimate the value of human touch as a form of spiritual care to support dying persons in their time of need.

Support Groups

Some participants expressed the need for spiritual care to help them connect with other people facing similar life circumstances as a means to finding support in their journey. One caregiver specifically noted how clergypersons could help in addressing this need. She shared, "Clergy can help connect people that are going through the same thing. It would be nice to connect with other families or other people that may be going through the same thing."(C4) A similar thought was noted by a woman caring for her dying mother. In this instance she would have appreciated seeing a support group within her home congregation. The caregiver offered this opinion, "I think I would feel better if it was in my own church community if there was a support group. I need to know that I'm not the only one in my church community that's having

this and then getting angry and frustrated.”(C10) This caregiver’s daughter clarified the point by stipulating, “not necessarily having to do with the same illness, but having to do with the same process of dealing with illness.”(C10.2) The two members of this family who were caring for the dying mother sought a connection to others in their church community as a way to support each other while their households dealt with illness in the home. When asked if their home congregation had such a support group they could attend these two caregivers responded “no.” During a different interview a dying woman shared how since she was diagnosed with cancer she had come to know of several other people in her church and larger community who were facing the same illness. When she talked about how spiritual care had helped her in her journey, she directed her thoughts to this group of people and the strength their common sharing had brought to her life. She offered, “I think it’s hearing how others are dealing with this too.”(P7) This woman felt supported in her journey by having a connection to others who were experiencing the same illness as she was. This was spiritual care to this woman.

God, Sense of Divine

The participants’ voices in the previous sections express a variety of ways spiritual care can help them feel connected and supported in the dying journey. Although they do not always state it explicitly, many times they express their experiences as a way to connect with God or some sense of the divine. For example, through prayer they hoped to connect with God. Through the reading of scripture they hoped to be connected again to God’s story. Through their attendance at worship services they hoped to connect with an expression of God in a holy place. Through the minister visiting in their time of need they hoped to have a connection with God brought into their homes when they were physically unable to attend worship services. Having a

connection to God, or a sense of the divine, is inherent in the interviews with the participants. Yet it was surprising to observe how participants shared only a few references relating directly to their desire for a connection with God or a sense of the divine. A daughter caring for her elderly mother shared the significance she placed on having a connection with God through prayer. She remarked the importance of, “Always having some sort of communication with God.”(C3) This caregiver-daughter continued to note how prayer was a regular practice for her and her mother to connect with God daily. A man dying of cancer also reflected on what it meant to connect with God through a personal relationship. He shared, “Having that personal relationship with God is possible and is the only way that a person can be ready to face death and what’s on the other side. The only way you can die well, in my opinion, is with God at the very centre. Our faith has to be central.”(P6) Lastly, a caregiver reflected upon what spiritual care can do for a dying person. She succinctly commented, “Connection. I think it helps emphasize the connection with God.”(C10.2)

Spiritual Practices and Tradition

Some dying persons and their caregivers noted how they experienced the support of spiritual care through spiritual practices such as singing hymns, reading scripture, and Holy Communion. By participating in these activities it helped participants to address their need to feel connected to their larger faith tradition, especially in those cases when some participants were no longer able to be physically present to connect with their larger faith assembly. Singing hymns or listening to faith-related music was the most common refrain from participants who expressed an appreciation for spiritual practices. A caregiver who admitted having a lapsed participation in Sunday morning worship still spoke of her appreciation for singing hymns when

her mother was dying. She shared, “The minister had us singing a hymn with my mom and she kind of came back, and when she came back she said ‘I haven’t heard you guys sing for a long time’. So that meant something, you know, that meant something. That’s a spiritual thing.”(C1) By employing something common and familiar to the family the minister was able to help them connect in a way they had not connected in a long time. This not only supported the mother in her dying journey, but it helped the family members to find support in one another. The dying woman to whom this caregiver was tending also expressed an appreciation for music as part of the spiritual care she was receiving. Regarding spiritual care she explained, “It’s your spirit, your feelings, how you see hospitality there through others as well. And _____ comes and plays music for me. She would have been here today, but she has a cold, so that’s why she’s not here.”(P1) She remarked further how experiencing the music of this other caregiver provided her with both a sense of pleasure and comfort for her dying journey.

Another dying participant relayed how her family experienced spiritual care through hymn-singing when her husband was dying twenty years earlier. She shared the following regarding her family gathering by her dying husband’s bedside: “We always sang, even as a whole family we would sing and you’d put your hand on his, or on his forehead, and sing. And he’d sing with you. And his whole body would just relax and the pain was gone.”(P7) In relation to her own dying journey this same woman added how she also experienced spiritual care in this way, “I receive it from bible study, bible reading, simple things like I have Sirius satellite radio given to me as a gift and I love that southern gospel music. That’s my thing. Just that, music, you know?”(P7) In another interview when an elderly dying woman was asked to reflect on what spiritual care meant to her, she commented, “I might have added that music adds to my spiritual care too, although I have no ability in music.”(P9) To which her caregiver-

daughter quietly added, “She used to lead our little choir in the church. She used to do a few duets with our little country church.”(C9) Older age had deafened this dying woman’s ability to hear properly. Where once she appreciated a connection to music and church hymns, declining physical health limited her ability to experience the support of this type of spiritual care.

Another participant in the study noted how churches can offer spiritual care through the spiritual practice of hymn singing. She commented how “Workers from these groups can come in, visit, sing hymns and sit by your bedside.”(P3) This woman had experienced this in her home as part of her dying journey and expressed how she found strength through these activities.

Nature

Dying persons and their caregivers expressed feeling connected and supported by spiritual care through a relationship with nature. Some of them expressed how nature carried a deep sense of spirituality for them and connecting with nature supported them on their journey. One caregiver described how some people might find a real spiritual connection through nature, “They might be a naturalist. So for them spiritual care is being connected with nature, and all of nature being connected together.”(C9) Another caregiver resided in a rural area with a house surrounded by woods. She shared, “I like having the church family, but I also know that I can walk around here and God’s creations are all surrounding me.”(C10) Similarly, in the same way connecting with nature was viewed as a form of spiritual care to some participants, not being able to connect with nature was also a cause of longing for another. A caregiver described the dying woman she was caring for as a ‘health nut’ who had always been active and involved in nature walks, canoeing and kayaking. Now, due to the dying woman’s deteriorating physical

health she was unable to enjoy these activities in the way she once did. The caregiver shared of the dying woman:

On days like today she'd love to be outside, just to walk out in the fall with all the fall leaves and enjoy the countryside. And that's a spiritual thing. You know, just enjoying the countryside, enjoying nature. So that's what we're hoping, one of these day that we'll get her out when it's a little bit warmer.(C1)

The dying woman affirmed her caregiver's thoughts and added, "I'd like to get out for a drive and that kind of thing, especially now with the leaves and the way they all are, everything is looking very nice." In this situation the caregiver not only recognized connecting with nature as a form of spiritual care that the dying woman appreciated, but the caregiver also recognized this was an unmet need in the woman's life, which if fulfilled could possibly bring the dying woman some pleasure and support for her journey.

Theme: Spiritual Care Provides Personal Inner Resources

The majority of the participants in the study expressed how the provision of meaningful spiritual care helped them to experience a variety of personal inner resources during the dying journey. This theme was prevalent in some form in all of the interviews with dying persons and their caregivers. The most dominant and recurring personal inner resources noted by the participants included the ability to experience the following: hope, comfort, self-worth, and the strength to cope. Dying persons and their caregivers noted how each of these personal inner resources was experienced as a positive attribute of the spiritual care offered during the dying journey. In many cases these personal inner resources were a desired outcome of end-of-life spiritual care. Participants expressed how experiencing any of these personal inner resources

through the delivery of spiritual care also helped them feel as though they were dying well. This section will provide an overview of the participants' experiences of each of the specific personal inner resources.

Hope

When faced with the prospect of dying several participants expressed how spiritual care can help to bring hope into what might otherwise be a dire situation. The concept of spiritual care providing dying persons and their caregivers with hope was repeated several times within some interviews. This 'hope' was evidenced in the participants' understanding of there being something more to come when an earthly life came to an end. There was hope of an afterlife even though their lives were coming to an end. An elderly dying woman shared, "Spiritual care can be a reminder to someone that there is hope of something more to come."(P3) Another elderly dying woman echoed a similar refrain of how spiritual care can help someone when he or she is dying. She commented, "Give them hope. I just don't know how to say it. I mean, something to look forward to. A future."(P9) A dying man who participated in the study voiced a strong opinion of the hope a dying person can experience through the delivery of spiritual care when he or she is part of the Christian faith. He remarked how spiritual care can, "Offer them a living hope, not a dead hope, not a false hope. Again, I don't see hope in a lot of the world religions and countries of the world that don't embrace Christianity. I don't...I see despair. As long as there's breath, there's hope."(P6) In another instance, a woman caring for her dying husband expressed how important spiritual care was to a person's dying journey. She commented, "I think there's a lot to take in when you're given a diagnosis such as these and I think spiritual care just gives you something to hope for."(C4) A participant who earlier shared

how spiritual care can help to give a dying person hope also voiced his opinion in another part of his interview how a lack of spiritual care can take away a person's hope and lead to extreme despair. He conveyed it in the following manner:

I just wouldn't have made it without it. In fact, I know now why people commit suicide because they lose all hope and the fear and punishment of terminal illness, isn't worth living another day. But with God I could face another day and still have hope.(P6)

Spiritual care helped this dying man to find the hope he needed to face the gravity of his dying journey.

Comfort

Some participants expressed how spiritual care helped them to experience a sense of comfort in the dying journey. Sometimes this comfort was experienced by a simple offering of spiritual care, "Even just having someone simply sit with a dying person can bring comfort in their time of need."(P3) In another instance a dying woman noted how spiritual care helped to bring comfort to her even though she had some difficulty articulating how it did this. She shared, "It's comforted me, whatever that means. I feel, well, you're still fearful, but not quite as fearful."(P1) Two participants related the comfort dying persons might experience when spiritual care is placed into conversation with a person's beliefs. A dying woman commented, "I think it gives them comfort and especially if they've already accepted the Lord."(P2) A dying man related the following about spiritual care to dying persons: "They no doubt have questions and need comfort...desperately need comfort, and there's no real greater comfort than to offer people hope and God is often seen played out through people."(P6) Lastly, a daughter who was caring for her elderly mother commented on the comfort one can experience when spiritual care

is offered well, “People who are good at spiritual care can really help to give comfort to someone when they’re dying.”(C3)

Self-Worth

Some participants in the study acknowledged how spiritual care helped them to feel as though their lives still had worth even in the face of dying. This was an important notion expressed in a variety of ways by dying persons and caregivers alike and is a reflection of the various ways in which dying persons can find their lives to be worthy even in the dying journey. One dying woman had been a hospice worker for several years and had trained many of the workers who were now caring for her in her dying journey. Her caregiver who participated in the interview shared the following about the dying woman: “She’s always helped us and she’s always been a great teacher. So we’ll learn everyday from her still, she’s still teaching us.”(C2) This woman was able to take her experience of dying and turn it into an opportunity to teach her caregivers how to care well for her, and in turn, other dying persons for whom they would be offering their care. A dying man also shared of his ability to share of himself and give something to the workers who were offering him care. He remarked, “We found that there was a ministry for me and people listened to it and respected what I had to say because I’m dying of a terminal illness.”(P6) In another part of the interview he explained how important it was for a person to find self-worth in the dying journey “because when you’re dying you don’t feel like a person of worth. Talk like I’m a human being, treat me not like a statistic but a person of worth.”(P6) In another interview a dying woman shared how several people were telling her she would not die yet because God still had work for her to do. Recalling when she was asked by the VON worker to participate in the research interview, the dying woman shared, “I thought ‘oh,

maybe God does have something for me to do yet.”(P2) A dying woman who once had been involved in several volunteer activities in her community had expressed her frustration that her declining health did not allow her to contribute in this way any longer. She then continued on to say how she recently had discovered a new sense of her self-worth. She shared:

The word that’s come to me lately is ‘usefulness’. I prayed to God ‘can I be useful to somebody?’ Well, then a friend of mine came in to see me this week and she’s talking about these little dresses that they make for children in Africa, they’re comfortable little slip dresses. When I can sew for an hour, an hour and a half in the morning, and that’s what I’m doing with my leftover fabric. It gives you a sense of usefulness.(P7)

A new sense of self-worth was discovered by another dying woman in the actions of her hospice care worker. The dying woman relayed how this worker made the participant feel useful and this contributed to her sense of self-worth. Regarding the hospice worker, the dying woman shared, “She’s always calling me about ‘how do you bake this?’ and ‘how do you do that?’ She has a way of making me feel important and needed without even knowing.”(P5)

Strength to Cope

Some participants shared during the interviews how their experience of spiritual care helped to bring them strength for their journey and the ability to cope more effectively with all that was happening to them. The participants of one household expressed a deep appreciation for the strength spiritual care brought to them in their journey. The dying mother commented:

Spiritual care can help a person accept what they’re going through and that helps lower frustrations. It’s something that sustains the inner ‘man’. Knowing that other people are

caring for you and when other people have the same beliefs – it can be very strengthening for the journey.(P3)

Her caregiver-daughter also emphasized the way in which spiritual care had aided the family while caring for their dying mother, “Spiritual care has given the family strength not to give up. Even seeing other people offer their care to Mom has given the family strength to keep going.”(C3) Another dying woman offered her thoughts which echo those of this daughter, “All these people who come in to see me is wonderful. I never expected it, but I feel that it is spiritually amazing. And it gives you strength to carry on.”(P1) A dying man described the strength he received from his minister visiting in this way: “I waited to see her enter the doorway because she just brought...she just breathed life into me when she came and talked with me. I’ll never forget the input she had in my life when I was at my lowest.”(P6) He noted how the spiritual care his minister offered him helped him to find strength and cope with the despair he was facing. A caregiver in a different interview offered a similar thought regarding spiritual care, “I think it helps them to cope with what might be coming. And I guess that comes from wherever you think your spiritual care comes from. But I think for me it would be coping.”(C4) Reflecting on her dying journey an elderly woman succinctly stated the strength spiritual care had provided her as follows: “It’s given me courage and something to rely on.”(P9)

Theme: Spiritual Care Provides a Sense of Peace in the Dying Journey

Several participants in this study described how they experienced a sense of peace as a result of receiving spiritual care during the dying journey. The concept of peace could have easily been included in the previous section regarding the personal inner resources participants experienced through the delivery of spiritual care. However, this ‘coming to a sense of peace’

proved to be such a prevalent theme within the research interviews it is worthwhile to review it as a category of its own. It is also important to examine this theme on its own as several of the participants remarked how coming to a sense of peace through the provision of end-of-life spiritual care helped them to believe they were dying well. Several participants offered the following brief comments about spiritual care as an aid to finding a sense of peace in the dying journey:

“Spiritual care can give them comfort, make the trip easier, more peaceful.”(P2)

“Spiritual care is food for our souls that helps to give peace through faith.”(C3)

Regarding spiritual care, “It would help them to die in peace.”(P7)

How spiritual care helps, “Well, I think just to give them peace of mind.”(C8)

“It gives you peace of mind.”(repeated several times by P4, C4 and C4.2)

Other participants offered longer descriptions of the peace that spiritual care can bring to the dying process. A dying man shared, “Dying well would be I’m at peace with my life, I’m at peace with God, I’m at peace with relationship and family and I’m ready to go and I have no regrets.”(P6) A caregiver echoed these thoughts, commenting,

I think dying well or a good death is when you are at peace with yourself, with whomever else you might need to be at peace with, and ultimately that’s how you are at peace with yourself is to be at peace with everything that surrounds you. Whether it’s God, whether it’s your family, whether it’s your friends or neighbours you’ve had conflict with. If you can find peace within yourself, I think that’s what will ultimately define a good death or a way of dying well.(C10.2)

This caregiver’s mother, who also lived as a caregiver in the same household to her dying mother, noted a similar belief. Regarding how spiritual care could help a dying person know

peace and die well, she remarked, “Yes, peace with myself, peace with what I’ve done with my life and have I been helpful to maybe somebody else?”(C10)

These and other participants in the study who discussed coming to a sense of peace also detailed a number of ways in which this could occur. These included: Peace in the Family, Dying Fears Relieved, Guidance on the Journey, and Tending to Unfinished Business. The following sub-sections will invite the participants’ voices to speak to each of these areas.

Peace in the Family

Several participants noted the importance of spiritual care granting peace to dying persons by knowing their families would be cared for and that peace might exist in their families. In an interview with a dying woman she noted repeatedly throughout the conversation how pleased she was to know her children would be taken care of after her death. All her children were now married and she appreciated the family their in-laws would provide to her children. Knowing this helped to put her mind at peace. She shared, “All three of them have married into wonderful families. So that when I’m gone, they’ll have families that they can go to and I feel much better about that...so I feel great about that!”(P1) Another dying woman shared how she would know peace in her journey if she knew her children did not have to suffer as a result of her dying. She commented, “Dying well would be that my kids don’t go through hell. And I know they’ll be upset, but I want them to be able to handle things better and that would make me very happy.”(P5) In a different interview another dying woman relayed how spiritual care had helped her to find peace knowing that God would take care of her family. She remarked, “Well, if you’re dying and you know the time is near now, and you know where you’re going, God will give you peace. And one of the things that’s happened with me is that he’s shown me I’m not

responsible for my family. The kids, grandkids. He is. I've always known it, but now I really have to know it."(P7) In another instance a caregiver commented how she believed spiritual care would help her know peace. She stated it would be important in her dying journey "To know that my family will be cared for."(C9) She continued her reflections:

You know, I would like my family around me too. And I would like them to be happy and getting along together. I don't want them to be sad either. I want them to be happy and I want them to celebrate. Celebrate the memories that we had together and celebrate the life that we're looking forward to.(C9)

Lastly, another caregiver shared how she hoped her family would be at peace by knowing she was at peace when someday in the future she entered into her dying journey. She shared it in this way: "So I feel ok if my life was taken I would be comfortable with that and I want my family to know that, that I don't have regret. I don't have regrets so I don't want them to have any. But again it ties in with that peace."(C10)

Some participants also expressed the importance of spiritual care providers helping families address unresolved issues in the family of a dying person. Participants described how the provision of spiritual care could bring a greater sense of peace to the dying journey when it helps to resolve family issues and conflicts. A woman who was caring for her dying husband remarked, "You know family can be the most difficult people in your life as well as the best people in your life, so I think a lot of times at the end of life if you've had difficulty with family or friends or whomever, the minister can act as that sort of mediator so that you can make peace."(C4) In another interview a caregiver shared how she thought dying persons sometimes try to stay alive as long as they can in the hope that family issues will be resolved. She shared:

I've been with elderly people that we thought hung on because the family couldn't get along with one another or they're fighting. Those kind of family dissensions are really hard on elderly people who are dying. They probably could have died earlier in peace, but they hung on hoping for reconciliation.(C9)

Another caregiver summarized her thoughts in this way when thinking about what would bring peace to a dying person's journey: "I think having your family around, but I also think it's having family that's very agreeable."(C11) She noted how she had witnessed dissension in families when someone was dying and it hampered the peace of mind the dying person was hoping to experience. When spiritual care helps to address the dissension in families of a dying loved one, it also has the possibility of increasing the sense of peace one may experience in their dying journey.

Fears Relieved

When a dying woman was asked how she thought spiritual care might help a dying person she plainly stated, "Well, it might relieve their fears."(P1) This view was shared by other participants in the study. A dying man reflecting on how spiritual care had helped him in his journey noted, "Without it, I don't think I'd make it. To be honest, because it's a fearful thing and a very lonely road. Yep, I couldn't do without it."(P6) It became evident during the interviews how some participants perceived that spiritual care offered during the dying journey can help to relieve a dying person's fears and help them have peace of mind in their journey. A dying woman offered a strong opinion on this, stating:

It's a peace from the Holy Spirit. It's so hard to describe because the Holy Spirit just lifts you and takes you and you're not on your own, you know you're not on your own. And

if you don't have someone if you don't know that, and if you haven't already been living in that and there's no one to tell you, how hard that must be. There must be in you a sorrow, an anger. I don't know how to describe for someone that wouldn't know that. Fear. I think fear, dreadful fear.(P7)

Two caregivers also noted how spiritual care can help relieve the fears of dying persons who have faith and help them know peace in the dying journey. The first shared, "Death should not be feared. With faith a person can trust they are going somewhere better. Spiritual care can help remind a person of that."(C3) The other caregiver similarly commented, "Dying well - I think part of it is if you have a reasonably strong faith to begin with. I think some people are terribly afraid of death."(C11) A dying woman who described herself as an atheist also commented in this regard. When asked how spiritual care might help dying persons in their journey, she shared how she was struggling to have peace of mind. This dying woman voiced the following:

I'm still trying to find it, so maybe somebody else would be able to do that much more simply than I can. And maybe it's something that might be more available because of their, maybe, religious background. So that, this wouldn't be such a turmoil for them. But for people like me, probably not.(P5)

It appears spiritual care could help relieve the fears of some participants and bring them peace of mind in the dying journey. For this dying woman who struggled to understand her spiritual beliefs, she also faced turmoil in having her fears relieved through the offering of spiritual care.

Guidance on Journey

Some participants expressed how spiritual care could grant dying persons and their caregivers peace of mind by providing guidance on the dying journey. A dying woman

explained it in this way: “I think we’re always a little bit frightened of the unknown, how it’s going to be and what’s going to happen. So, ya, I think that’s it, just to make that journey easier and peaceful.”(P2) A caregiver shared similar sentiments, “I think your minister is the teacher, the person who helps you understand or help you make peace with what might be happening or what might be coming next.”(C4) Again, another caregiver offered, “It’s like being able to let go and know that you’re going to be comfortable and the people you leave behind are going to be comfortable with your ‘going’”(C1) A dying woman spoke of the importance of someone offering spiritual care who could guide dying persons on their end-of-life journey so they specifically might come to know peace from knowing God. She stated, “There’s a part of us that’s created to know God. So, if you don’t know how to access that, I think that...how could your death be peaceful if you didn’t know that? And you had no one to tell you?”(P7)

Unfinished business

Some participants described how it is important for spiritual care to help dying persons and their caregivers come to peace by knowing there is no unfinished business in the dying person’s life. Two dying participants shared how this related specifically to their need to have the details planned for their funerals before their deaths occurred. During an interview with a dying woman, she shared for the first time with her caregiver that she had already made all the necessary arrangements for her funeral. “I’ve pre-arranged my funeral at St. _____ in _____.”(P1) Her caregiver was surprised to learn of this news while simultaneously being pleased that the dying woman had been inspired to make these arrangements to lessen her worries and have some peace of mind. While sharing in a conversation about favourite hymns with another dying woman, she offered, “The one thing I do want at my funeral, I’ve got lots of

that stuff for my funeral done, and the one I want them to play is ‘There is Room at the Cross for You.’ I’m hoping my children hear this one.”(P2) A caregiver spoke more generally how spiritual care might help a person find a peaceful death by tending to all unfinished business before one dies. She explained, “What they mean to me is dying with some peace of mind. With your life circumstances sort of tidied up. With a hope of a hereafter and a spirit life. Dying with peace, rather than anxiety. (C9) Meanwhile another woman caring for her dying husband approached the notion of having everything in order in a different way. She commented, “If a person is able at all to do something they really want to do before they die, and to have help to enable them to do it. I think if you have something you really want to do and you’re able to do it, then you’re able to say goodbye.”(C11)

Theme: Rural Setting of Grey and Bruce Counties Perceived as Aid to Spiritual Care

Another significant theme that arose from the research interviews was how the primarily rural nature of Grey and Bruce Counties contributed positively to participants’ experiences of care during the dying journey. In particular, dying persons and their caregivers noted specific aspects of rural living they believed helped a person to die well. These included the friendliness and closer-knit nature of a rural setting versus an urban centre, the increased level of concern persons have for one another, and the resources available. It is interesting to note how these various aspects of rural living relate directly and are contributing factors to the earlier theme of spiritual care providing connection and support in the dying journey. It is through these various components of rural living that dying persons and their caregivers have the opportunity to experience an increased level of support and connection in the dying journey. This section will explore in more depth the participants’ experiences in this regard.

Friendlier and Closer-Knit

“I don’t know what goes on in the city, but I would think the country is a closer-knit unit where people know each other.”(P7) This was the opinion expressed by a dying woman who had lived the majority of her life in a rural setting. It was a sentiment that also became a common refrain voiced by other participants who had lived in rural settings as well as larger urban centers. They described how they thought people were ‘closer-knit’ in a rural setting compared to a larger urban center. The term ‘closer-knit’ appeared to encompass an understanding that people in a rural setting take a greater interest in getting to know one another and make an effort to build connections with each another. Participants described how they then experienced spiritual care support differently because of the greater concern a person has for someone who is his or her neighbour. A dying woman shared, “I do know since living in _____ and moving here – a small community – everybody knows everybody, most people are willing to help do anything. Friendly, very friendly. Where in the city you don’t know anybody.”(P2) Similarly, a caregiver offered her opinion and evidenced it with an example of people caring more in a rural community. She commented,

I just think rural people are more caring. Rural people know who their neighbours are. A lot of people live in Toronto and never know who lives next door to them for 25, 30 years. My sister-in-law’s mother lived in the same place for 25 years and did not know who her next-door neighbour was. That’s pretty sad, it really is. Nobody makes an effort.(C8)

A caregiver who had lived both in an urban and rural setting noted the friendlier nature of people outside of large metropolitan areas. She remarked:

I'm much in favour of rural because that's been my experience. I was in Toronto and that was fine, but people in an elevator wouldn't bother with you. People in Owen Sound, they'll talk to you. Be in a grocery line and people before you or after you are chatting away and you'd never seen that before. It's just a different part of the world. And we used to find there were a lot of skiers from the city in the Markdale area in the winter time and you'd go into the grocery store and the people would not look in your direction at all.(C11)

A woman caring for her dying husband explained,

Most of the people who come to look after you live in your community, they're from here, it's a smaller community. So they're not just looking after a stranger, they're looking after people that well, we figured it out when you first arrived, you're connected to somebody here. Every single one of the nurses that have come in here after conversation, we've found that six degrees of separation, we're connected somehow, some way. I think it's the small town.(C4)

Indeed, the experience of this research interview was an example of the closer-knit nature of rural living. The researcher and this particular caregiver discovered they knew people in common within the region of Grey and Bruce Counties. This was an unsolicited common practice between the researcher and participants in each of the interviews to explore the 'six degrees of separation' and how they might have known people in common. I reflected on this in my research journal how this indeed appeared to be a common practice of people living in the region and how I was regularly experiencing it during the interviews. Although Grey and Bruce Counties cover a large geographical region, a common connection of this nature was established in eight of the eleven households the researcher entered during this study.

A caregiver also commented on the closeness that is shared in the rural setting. The dying woman she was caring for had worked in hospice for several years and as part of her duties had trained many of the people who were now caring for her, the present caregiver included. Her caregiver remarked, "I think we all have a bond, there's about five or six of us coming in. We've all worked with her."(C1) A dying woman also expressed the importance of knowing the people in your community who are caring for you. Reflecting on the care received by people in a larger urban center, she related, "Older people who live in Toronto who are dying probably feel much more alone because people don't even know who their neighbours are and don't talk with them. How can you get proper care that way?"(P3) This woman who lived on a farm in the country had explained in another part of the interview how she believed the spiritual care she had received had been exemplary even though she lived "in the middle of nowhere."(P3)

Meanwhile, a caregiver who had lived in both rural and urban settings offered the following detailed insight into the different geographical experiences of spiritual care:

I think there's no doubt that it's different, but that doesn't necessarily mean that it's better or worse. I think there are pluses and negatives to both situations. In a larger community for example you might have that ability to reach out on a great scale, but here the reach and return might be warmer. Bigger cities, people tend to be a little more aloof, they tend to be...they don't necessarily want to become involved in your issues. But that doesn't necessarily mean that in a church community that's not going to be the same or it could be different. I think that there are going to be obvious differences no matter where you go, whether you're in a small community or you're in a marginal community like we have here, distant though we may be from our neighbours, there's still the warmth and I

find the one thing in the big cities – and having grown up in the big city, is that distance even though you're closer to your neighbours that you can't change.(C10.2)

This caregiver noted the importance of the warmth in the care a person needed to receive in the dying journey, but also remarked how that care was less likely to occur in a big city. One might live closer in physical proximity to his or her neighbours in the city, but be more distanced from them emotionally. While conversely, people may live a greater physical distance from one another in the country, but experience more warmth in the bond they do share. Her mother who was also offering care in the household to her dying mother shared a similar opinion, “Ya, we could live beside somebody and not know who they are, and not want to. To be honest with you. You know, I lived on a street for twenty odd years and I only got close to maybe two people. I didn't want to know the rest of the people.”(C10)

Watch Out of One Another

Some participants expressed how living in a rural setting presented unique opportunities for experiences of care in a person's time of need because people watch out for another more than in an urban setting. This phrase ‘watch out for one another’ encompassed a practice of rural living that meant being more attentive to the needs of a person's neighbours in the community in which one lives and caring for them in a special way to address any needs the neighbour may be experiencing. A caregiver who grew up on a farm and was now caring for her dying mother expressed this notion in the following way:

In rural areas people sometimes complain that people ‘watch’ each other too much and know too much of their neighbour's business. People who grow up in the country often want to move away from here for that reason. When they move to a big city like Toronto

they find out that people don't 'watch' one another at all. Living in a rural area like Grey and Bruce County could be better because people actually do watch out for one another.

There is friendlier care about the way people do things.(C3)

A caregiver in a different household also relayed of a personal experience demonstrating a sense of community and the incredible care rural residents exhibit to one another. She recounted:

I think it's very different in the rural area. It's about community and I personally experienced it. I, we, used to have a farm and we lost our house to fire, and so, the community outreach was...you can't describe it! It was phenomenal. I was working in health care at the time, and I remember coming home from work and I couldn't even get to the door of our house because the porch was full of things that were donated. Food and blankets and clothing and dishes. It just made you weep. In Toronto, you hear people say that you don't even know the people who live in your apartment building, it's not that sort of community. There is tremendous community. And there was where I grew up, there was the same sense of community. I mean, when they lost the little church there it was a real loss because people all didn't go to the same church, they got spread apart. There was a good sense of community there. It is different, definitely.(C9)

Another caregiver commented how she was touched by the support her household had received from the community during her husband's illness. She remarked, "Support – spiritually, emotionally, we got a lot of that from this community that a lot of people think is dead and gone and it doesn't exist anymore, but it most certainly did for us."(C4) She continued with another example:

It's incredible, just incredible. It's still happening today. I still have people who come to the door with soup, and...or there's still an invisible person who shovels my walkway

and cuts my grass. The fact that people are still thinking of us just blows me away and if that doesn't speak to the human spirit, then I don't know what does. It's just amazing!(C4)

In another household a caregiver who was helping care for her dying grandmother commented on her experience of community support. Her grandmother who had been quite active in the community before her illness struck was well-remembered by her neighbours. The caregiver shared,

We do have a very large support network, family, church, community. My grandmother was involved with so much as a volunteer in different social groups and capacities as well. So there are people out in the community, you run into them and they still ask 'how's she doing?' or 'how's the family doing?' And it becomes something that you aren't always aware of until it happens.(C10.2)

This caregiver expressed repeatedly how important it was for her family to receive this type of care from the larger community as a way to feel supported during her grandmother's illness.

Services and Resources

Some participants talked about their experiences of resources related to hospice care and spiritual care in rural and urban settings. There tended to be a general agreement among these participants that their experience of end-of-life resources had been more positive in the rural setting of Grey and Bruce Counties compared to any actual or perceived experiences in an urban centre. A caregiver described her experiences of the care offered to her and her husband in rural Grey and Bruce Counties. She commented, "Oh, you can't compare as far as I'm concerned the difference between the services we've received here and what's available in the city. And I think

it's probably just numbers and manpower, I'm sure. But care-wise, I can't say enough about the services here."(C4) This caregiver repeated this several times during the course of the interview to emphasize the positive experience the household was having with the end-of-life care.

However, in another instance during the interview this same caregiver was talking with her elderly mother who had recently moved from Toronto where she had been caring for her husband who also had moved recently from Toronto into one of the retirement homes near the daughter's residence. The caregiver-daughter was asking of her mother's experiences of care in Toronto. The brief dialogue occurred as follows:

Caregiver-Daughter: "You haven't really been offered any spiritual care?"(C4)

Mother: "No, no. Cause I just came from Toronto a week ago."(C4.2)

Caregiver-Daughter: "They weren't even offered any nursing, I had to arrange it from up here. So very much lacking in the city."(C4)

While this caregiver's experience of end-of-life care resources had been extremely positive in Grey and Bruce Counties in relation to the care offered to her dying husband, she noted how the family's experience of these same resources had been lacking in the major urban center of Toronto in relation to her dying father. A dying woman who participated in the study shared a similar experience during her interview. Although she believed all of the end-of-life care she had received so far in her dying journey in Grey and Bruce Counties had been great, she told a story of her father dying in Toronto where a gap was experienced specifically in the delivery of spiritual care. She remarked, "My dad was in a long term care facility and he died in there and I was with him when he died and I never saw anybody. I met the chaplain after, you know, because he was going to do the service, but I don't think my dad had anybody at the time."(P2)

A dying man was at first uncertain of how services might be experienced differently by dying persons in rural and urban settings. When he considered his personal experience of services in his own journey he was able to be more specific, especially in regard to the provision of spiritual care. He shared the following observation:

I don't know if it's a rural or urban difference, I think it's just place to place. Every place is different and I don't know what would determine, or what factors are involved, but I was impressed with Owen Sound. And again I think people spoke up and offered spiritual care freely because I was receptive. If I wasn't receptive I could probably say there was a deficiency because of the Privacy laws and all this stuff.(P6)

In another interview a caregiver also spoke of the deficiency she saw occurring in the provision of spiritual care services. She offered her opinion from the interesting perspective of someone who was not only offering care to her dying mother, but also a spiritual care provider in various capacities in Grey and Bruce Counties. She presented her comments regarding the provision of end-of-life spiritual care while reflecting on the purpose of the research study: "I wanted to thank you. I think it's a great topic that you've chosen. I think it's an important topic that you've chosen. I think it's something that's being cut, rather than being improved in most places."(C9)

Another caregiver to a dying woman also had an insider-perspective of sorts as a worker with one of the regional hospice service providers. Although she was uncertain of the experience of services provided to dying persons in an urban setting, she spoke more affirmatively of the services she knew were experienced in Grey and Bruce Counties. She noted the following: "I don't know about urban because I haven't been to the city to see how their programs are set up, but I know we've dealt with London and everything's coming back up here because London doesn't know this area. So, up here, I think we're doing very well in palliative care and hospice

care and keeping people in the home.”(C1) The dying woman this caregiver was caring for had earlier remarked how she was uncertain how to go about accessing the services of her spiritual care community. Otherwise, she felt she was receiving optimal care likely due to her years of working in hospice services – she knew how to access these services. However, when reflecting on what a dying persons’ experience of such services might be like in a large city, she expressed, “I think the overall care is more individual than in the city and I’m not sure how you’d get these services in the city.”(P1)

Chapter Summary

The voices of the interview participants provided rich descriptions to help flesh out the prominent themes arising from analysis of the research material. This chapter examined these themes of spiritual care providing connection and support in the dying journey, spiritual care providing inner resources, spiritual care providing peace of mind, and the rural setting of Grey and Bruce Counties aiding in the experience of spiritual care. Indeed, all of these themes contribute to the conversation inspired by the research question’s exploration of how dying person’s and their caregiver experience spiritual care in their homes as an aid to dying well and having a good death in Grey and Bruce Counties. The next section of this research paper – Chapter 5: Discussion – will now continue to place these themes and results into conversation with the findings and theories of previous studies and literature.

Chapter 5: Discussion

“Death is one of the attributes you were created with; death is part of you. Your life’s continual task is to build your death.” – Michel de Montaigne

The intention of this research study was to explore with dying persons and their caregivers their experiences of spiritual care in the home as aid to dying well and having a good death in Grey and Bruce Counties. This specifically defined research question falls broadly under the topic of palliative care in Canada which received considerable attention in the literature review of this paper. Numerous reports and studies highlighting the historic and current state of palliative care in Canada demonstrate a desire by dying persons for palliative care services. Still, not all dying Canadians receive equal levels of care in their end-of-life journeys, nor do they always receive palliative care in a way that will help them address their dying needs. This may cause them undue stress and suffering in their dying journeys and limit them from knowing a good death in the way they hope to die. Efforts have been made over the years to address the deficiencies noted in the delivery of palliative care services in Canada, yet there is still room for improvement on national, provincial and local levels.

As the researcher in this current study it was my intention to examine the experience of palliative care in the locale where I reside and work – Grey and Bruce Counties. More specifically, the research study’s purpose was to explore with dying persons and caregivers their experiences of spiritual care as a part of palliative care within this particular rural geographical setting. Plus, numerous studies in the literature review illustrated the importance of tending to the needs of dying persons and their caregivers to reduce their perceived and real experiences of suffering in the dying journey. It was noted how addressing their needs through effective palliative and spiritual care also served as a means of improving their quality of life during their dying journey. However, when needs went unmet or gaps were experienced in the delivery of

care it was considered to hinder the dying person's ability to die well and experience a good death. Therefore, my further hope in the research interviews was to have the participants consider and express how spiritual care was helping them address their needs in the dying journey, what gaps, if any, they perceived in the delivery of care they were receiving, and how the provision of spiritual care might be improved to help them and other dying persons die well. The richness and abundance of participants' conversations demonstrates how well they helped the current research study accomplish this task.

It is worthwhile to share a reflection from my research journal regarding the dying persons and caregivers who participated in this research project. It was previously explained in the Methodology chapter the difficulty that was experienced in finding potential participants for the study. This occurred in part due to the timing of participant referrals. The hospice service providers approached clients during the final stages of patients' illnesses and found a number of people willing to participate, but were then unable to participate in the study due to rapidly declining health. The other reason for the frustration in finding people willing to participate is that this was a study examining spiritual care to *dying persons* and it is possible some potential participants did not see themselves as dying persons. This possibility is a reflection that evolved from a conversation with the spiritual care colleague with whom I collaborated to ensure inter-coder reliability in the research results. In her experience as a Community Care Access Centre (CCAC) spiritual care provider to dying persons she remarked how she occasionally encounters people who have difficulty acknowledging their dying journey. It would appear the same may be true regarding some people who could have been potential participants in the current study as well as some who actually participated in the study. In four of the eleven households in this study, I observed as the researcher how the person who clinically had been diagnosed as

‘terminal’ or ‘dying’ by a palliative care physician was not considered by the caregivers, and sometimes the dying person him or herself, to be dying - at least not yet. Although participants might admit the dying person had a terminal illness, they sometimes shared how they believed death was still in the distant future. This sentiment was also evident in what some participants did not share in their responses. For example, when a dying participant (P7) was asked what she thought might help people when they are dying and if she had experienced any of these things in her journey, she responded by referring to a story from her past and what was helpful in the journey when her husband and mother were dying. She shared nothing of her present situation or journey perhaps because she did not see herself as dying, at least not yet. Responses such as this also occurred on other occasions in different interviews. This is not to say participants did not share honestly of their experiences, they may have simply broadened the scope of their responses rather than answering them in relation to their own current journey with death and dying. Plus, as the researcher I realize the dying persons’ and their caregivers’ engagement with the interview questions may have encouraged them personally to enter uncomfortable areas and consider aspects of the dying journey they had not previously considered. In other cases it appeared some of the dying persons had considered aspects of their dying journey that they simply had not voiced previously in front of their caregivers. The space of the interview was the first time for their views to become public. I must admit I felt both surprised and privileged during some of the interviews to discover and reflect upon aspects of the dying journey that the dying persons and caregivers were formulating and voicing for the first time. Although dying persons and caregivers in these instances may have been surprised by what was voiced, the majority of the time the two parties supported each other in what they were sharing about their views on the dying journey. Even on occasions where viewpoints of dying persons and their

caregivers differed slightly, I observed how the caregivers expressed a desire to work through any differences for sake of the dying person being cared for and well-supported in his or her journey.

It is important to state that the dying persons and caregivers in this study were quite descriptive and expressive of their experiences of spiritual care as part of the dying journey in Grey and Bruce Counties, both affirmatively and in other cases with less positive regard. Indeed, the descriptions of their experiences serve as a helpful resource in answering the research question. Their stories as expressed in the interviews help to shed light on how spiritual care was tending to their needs, other times noting occasions when they felt their needs were unmet, and a variety of participant suggestions came forward regarding how spiritual care might be improved to help people die well in Grey and Bruce Counties. In particular, it was observed in Chapter 4 - Results how their responses were categorized into four themes capturing the dying persons and their caregivers' experiences of spiritual care. These themes included how spiritual care provided connection and support in the dying journey, how spiritual care provided personal inner resources, how spiritual care provided a sense of peace, and how living in the rural setting of Grey and Bruce Counties contributed positively to their experiences of end-of-life spiritual care. This discussion of the results continues with a look at the participants' prominent need to experience connection and support through spiritual care.

Connection and Support

Participants in the current study frequently expressed a need for spiritual care to connect them with people and things that would help support them in their dying journey. This included connecting with ministers, laity, family and friends, other care providers, physical contact, God

or a sense of the divine, spiritual practices and tradition, and nature. These findings appear consistent with the results of other studies examining the needs of dying persons and their caregivers. In particular, the National Consensus Conference's definition of 'spirituality' details this well as the "way individuals experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred." (cited in Puchalski et al, 2009, p.887) Similarly, Moorhead and colleagues (2004) share a list of needs involving connectedness with self, other, a high power, all life, nature, and the universe that transcends and empowers the self.

Additionally, Nakashima (2002) describes a similar list of attributes that contribute to a dying person's spiritual well-being that includes exploring spiritual beliefs and practices, interpersonal skills, relationships with family and friends, and connections to caregivers. It is revealing to compare how several of the participants in the current study expressed a desire to connect with similar groups through spiritual care: family and friends, spiritual practices and traditions, nature, God or a sense of the divine, as well as developing personal inner resources. When this occurred they also felt supported in their dying journey because they were experiencing these connections through the spiritual care that was provided. However, there were instances in which dying persons and their caregivers voiced concerns in relation to the lack of connection they were experiencing. This occurred when spiritual care was not being provided to them in the way they had hoped or needed. Both types of experiences were illustrated in the current study's results which revealed some participants feeling extremely well supported through a connection to a particular expression of spiritual care while other participants shared a noticeable gap in that same expression of care. While the positive experiences of spiritual care need to be applauded and encouraged to continue, the deficiencies that were experienced are worthy of a more detailed examination. Indeed, the research has encouraged me to say, "let's do more of what is being

done well and let's improve what is not." As such, these strengths and gaps offer deeper insight into the experience and provision of spiritual care and are placed into further conversation here.

The current study reveals how dying persons and their caregivers have a strong need to experience a connection to a spiritual care provider, in particular a minister, for the support he or she might bring in a variety of ways to the dying journey. This connection and support can add greatly to a dying person's positive experience of dying well. These results are supported by Balboni and colleagues' (2007) study of advanced cancer patients who were seeking spiritual care as part of their journeys. It was discovered from this sample that only 47% of participants reported their needs were minimally or not at all supported by a faith community. Those participants who felt spiritually supported in their dying journeys also associated this with a better quality of life. Conversely, those who did not feel spiritually supported experienced a poorer quality of life in relation to the dying journey. In the current study, many of the participants shared how they felt strongly supported by their ministers and their spiritual needs were being well-attended. The majority of these participants had previously maintained an active connection to their minister and faith group until their illnesses restricted their ability to do so. Now in their illness, the minister was making a point of reaching out to connect with them. In these instances participants shared of only a few minor occasions when spiritual care could be improved, but for the most part the participants perceived their needs were being met. They described this as a positive experience that was helping to improve their quality of life and die well. However, there was also a small group of participants who strongly voiced their discontent in the frustration they had experienced because their ministers, or any spiritual care provider for that matter, had not made an effort to show up and offer spiritual care when the dying persons and their caregivers needed them. The participants who voiced this concern consisted both of

those who up until their illnesses had maintained an active connection to a minister and faith group and those who had been inactive from these connections for considerable time. When ministers made no effort to offer care, these participants who desired a connection also commented how the lack of a minister's presence became an added source of stress and struggle in the dying journey. This relates well with Nelson and colleagues' (2002) reminder that a person's former connection to spiritual care that once served as a means to help them cope well may in other circumstances become a source of spiritual distress. Phelps and colleagues (2009) describe this as dying persons experiencing spiritual crises at the end of life when their needs are not addressed effectively through the provision of spiritual care. These participants' ministers who could have been a source of spiritual strength were instead causing participants to experience spiritual distress and crises. Indeed, an earlier description pointed out how one caregiver struggled with the thought of inviting her dying mother's minister to officiate at her mother's funeral when the minister had not once made an effort to show up and offer care during the mother's dying journey. It was evident in this caregiver's explicit narratives how she was experiencing distress and a form of spiritual suffering through lack of care from the family's minister. Further still, this caregiver expressed a projected sense of hurt and discouragement from the dying mother because no effort had been made by the minister to connect and offer care to the caregiver's dying mother who for the many years of her life had had a long and deep appreciation and connection to her ministers and congregations to which she belonged. Rather than feeling supported in this instance and similar experiences like these described by other participants, families struggled with the lack of support experienced through the minister's absence. In some cases they even questioned why the minister would not come to offer care, especially knowing that the family and dying person were facing a time of need.

This research study also revealed an interesting finding regarding dying persons and caregivers who did not have an active connection to a minister or organized expression of a faith tradition. In these cases (P1, C1, P4, C4, C4.2) they described themselves as having simply ‘fallen away’ from the church and it had been years since they had any formal connection to either a professional spiritual care provider or organized religion. Although representative of only a small number of the total participants in the study, participants of this group expressed their ignorance in knowing how to go about accessing a minister. Yet, their need to connect with a minister had become especially relevant as they now encountered a new journey in life – the dying process. The revelation of this finding may help the reader to appreciate the researcher’s specificity of the study’s criteria to examine the spiritual care experiences of people in their homes and apart from institutional settings like a hospital or nursing home. There is an increased possibility of dying persons and their caregivers accessing a spiritual care provider in these institutional settings since many of these organizations have an established chaplaincy or spiritual care program available to meet their clients’ or residents’ needs. However, what happens to the availability of spiritual care when people are in their homes? How do they access spiritual care then? If they are already active in a faith assembly they may readily know how to connect with a spiritual care provider. What happens to people in cases like these participants when they are not actively involved in a congregation or some other faith group? These questions prompt the very frustrations shared by this specific group of participants who desired a connection with a spiritual care provider, but were uncertain how to go about doing so. Admittedly, one caregiver in the study explained how she and her dying husband were offered the services of a spiritual care provider during their initial consultation at the cancer clinic, but never received any such offers after that first occasion. At the time they did not desire to connect

with a spiritual care provider, but on later occasions experienced instances when they would have appreciated the support of a minister. At that point they were already home and were uncertain how to go about accessing someone who could tend to their spiritual care needs. Regarding whether or not a person might be interested in accepting an offer of spiritual care, this caregiver emphasized, “I cannot, cannot, cannot stress enough, it’s a matter of when the question is asked.”(C4) This caregiver also shared how she remembered being asked by the CCAC case manager if they would like to talk with a social worker. She admitted this was the closest she thought they had come to receiving an offer for something similar to spiritual care, but it was not the type of spiritual care she desired. Although a social worker was a support provider, it was not an offer to connect with a spiritual care provider specifically. Notably, they experienced a gap in the delivery of spiritual care – indeed, their ability even to access it – and they felt their home-based care needs were not met in the way they had desired. However, as well as there was a perceived gap in the delivery of spiritual care, there was also a suggestion from the participants of how this gap might be remedied.

These particular participants in this one household, as well as others in the study who shared a similar concern of how to access a spiritual care provider in their time of need, offered recommendations to resolve this deficiency. It was suggested that the regional CCAC and other hospice groups caring for dying persons and their families in the area could incorporate an offer of spiritual care into their assessment and provision of care. Participants noted how pleased they were with the other palliative care services offered through the hospice service providers. In these ways they believed their needs were being met. However, spiritual care was a noticeably absent component of the care offered by these service groups. For example, in the same way that dying persons and their caregivers were asked if they would appreciate being in contact with a

social worker, dietician, or physiotherapist as part of their home-care services, the participants expressed how they would have appreciated being asked if they would also like the services of spiritual care provider. It was not expected that the CCAC, for example, would have a spiritual care provider on staff to tend their needs. Yet, in the same way the CCAC will connect a family with the services of a physiotherapy provider, participants suggested perhaps the CCAC and other hospice providers could connect families with local spiritual care providers who would offer care to dying persons and their families. In addition to this, it would be important to regularly ask dying persons and their caregivers if they would like to be connected to a spiritual care provider. In the same way case managers routinely ask dying persons and their caregivers of their physical needs, it would also be important as a part of holistic care to determine regularly if a person's spiritual needs were being met in the way they desired. Dame Cicely Saunders, founder of the modern hospice movement, would concur with this vision for hospice care in Grey and Bruce Counties as she firmly envisioned spiritually care being a part of the whole care that attended to the 'total pain' of dying persons (1996). These participants' suggestions are also founded in the views of literature by writers and researchers like Puchalski (2012), Pronk (2005), Sulmasy (2002) who describe the importance of the need for hospice palliative care to be holistically considerate to the needs of the whole person in his or her dying journey. These participants expressed and affirmed this general truth about hospice palliative care in their desire to have spiritual care offered as a regular part of it. Only when hospice palliative care considers dying persons' spirituality and tends to their spiritual needs can it claim to be providing care to the whole person.

It is worthwhile to note here an interesting phenomenon that occurred in relation to these participants who had difficulty accessing and connecting with a spiritual care provider in their

time of need. They, along with the dying atheist participant and two households who had not received visits from their ministers, noted two reasons for participating in the current research study. One, was an opportunity to connect with the researcher who had been introduced to them by the referring hospice service case managers as a 'spiritual care provider'. Where previously they may have had difficulty knowing how to access a spiritual care provider or connect with their minister, the invitation to participate in the study granted them access in their homes to a spiritual care provider. However, from the outset it was not my intention as the researcher to provide spiritual care to these dying persons and their caregivers and I held strictly to this practice. If necessary, I would connect them with a spiritual care provider if they accepted this offer during the debriefing time, but I would not intentionally offer spiritual care. Still, it appears merely through their participation in the study and having an opportunity to express their views, concerns and experiences of the dying journey, these participants also shared with me as the researcher how they experienced a form of spiritual care through the research interview process itself. As the researcher, I reflected in my research journal how I was surprised to hear these participants express how they felt they had received spiritual care by engaging in the interview process. Bellamy and colleagues (2011) would not be as surprised. They conducted a study with hospice patients that revealed how simply taking part in end-of-life research can have a therapeutic effect on participants. As the researcher I remained curious in this regard and enquired with one participant (P5) how it was she believed she had experienced spiritual care through the interview process. She responded by saying it was merely the fact that someone had taken the time to listen to her and believe what she had to say could be important to someone.

The second reason offered by the dying persons and their caregivers for participating in the study is perhaps more relevant to the goals of this research. All the participants in the study –

those who had difficulty connecting with a spiritual care provider as well as those participants who had accessed a minister - noted how participating in the study granted them an opportunity for their voices to be heard, their dying to mean something, and the possibility to contribute to a research activity that could have a positive effect on the way spiritual care is offered to dying persons and their caregivers in the future. Participants certainly had an opportunity to express how spiritual care was helping them in their dying journeys and is evidenced by their numerous narratives included in the results. Through this research study they also had an opportunity to be a part of something that is working to address the shortcomings they were experiencing as part of their end-of-life care. Although they knew their participation would not necessarily have an immediate effect on the provision of care they were receiving, it was enough to know that sharing their experiences through the research interviews might help another person die well in the future. These experiences are supported by studies that have specifically examined the experiences of dying persons participating in end-of-life research. A study by Kendall and colleagues (2007) noted how participating in end-of-life research presents an opportunity for dying persons and their caregivers to give something back in return for the care they or their loved ones have received. Their participation also represents an opportunity to improve the future services and support for dying persons. Bellamy and colleagues (2011) and Workman (2007) concur and add how participating in end-of-life research can enable a sense of personhood to be maintained and enrich the lives of those who participate. Certainly, participants in the current study shared these sentiments and expressed how participating helped to give their lives meaning as well as provide a way for them to contribute to the lives of others even in their dying journey. Through their varied expressions of these views it appears the lives of some dying persons and caregivers in the current study were enriched through their

participation. This is summarized well in one dying woman's explanation for participating in the study, "Well, I want to be able to offer something. I hope what I share helps!"(P7)

This study also reveals the importance of the type of connection and support spiritual care providers offer as part of their spiritual care to dying persons and their caregivers. Participants described how they desired to experience care from a spiritual care provider that was gentle, supportive and listened to their needs. Some participants strongly emphasized the need for spiritual care providers, in particular ministers, to listen attentively to dying persons and their caregivers. By doing so it was expected the ministers would be more attuned to the spiritual needs of these people. By listening closely to the needs of dying persons and their caregivers rather than simply assuming their needs, participants believed ministers would have a better opportunity to tend more effectively to the needs of dying persons and their caregivers and in the process offer more meaningful spiritual care as part of the dying journey. Various studies discovered similar findings and support this need as expressed by participants in the current study. The results of Vivat's (2008) study strongly encourage spiritual care providers to listen attentively to the way in which dying persons and their caregivers describe their needs and then offer care accordingly. Relatedly, a study (Jo et al, 2007) examining home-based palliative care in south-central Ontario noted how participants were greatly disappointed because they believed formal support providers did not listen to their needs and their questions were not answered clearly. Interestingly, a study of professional care providers from the United Kingdom asked them to share what they perceived were the needs of dying persons. They perceived 'needing someone to listen' as one of the most important needs of dying persons. This common refrain from these studies as well as the current study illustrate the incredible importance for spiritual care providers to listen well and tend to needs accordingly.

In a related way it is critical for spiritual caregivers to pay close attention to the particular needs of dying persons and their caregivers because end-of-life spiritual care cannot be viewed as a 'one size fits all' strategy. Indeed, the results of this study reveal quite the opposite and the needs of dying persons and their caregivers are as varied as the individuals themselves. From who offers connection and support through spiritual care, to how they go about doing it, to the personal inner resources spiritual care can help provide, the voices of the participants in this study have spoken clearly to the many needs experienced by dying persons and their caregivers as part of the dying journey. A large Canadian study (Heyland et al, 2006) involving seriously ill persons and caregivers supports this finding. This study's results revealed that not only were the needs in the dying journey highly individualized, there was also a large variation among dying persons and caregivers in the perception of what matters most in end-of-life care. The researchers concluded there is a decisive need for customized or individualized approaches in the provision of care to dying persons. Certainly some of the participants in the current research study also recognized the need for individualized care to dying persons when asked to consider the things they thought would help people the most when they are dying. While some gave specific answers such as 'contact with the minister' or 'prayers from the church', two participants (C10 and C10.2) stated they could not answer the question definitively because each person's needs are decidedly personal and dependent upon the circumstances. Various studies in the literature review complement this idea and stress the importance of assessing the specific end-of-life needs of persons facing their dying journeys. In this way several studies specifically questioned participants of their dying needs and lists were produced containing numerous items. If all the individual needs from these various studies were added together there would be dozens of needs in total. Certainly many of these needs may be shared in common across a specific

population of dying persons, but it is not possible to state that *all* dying persons will experience *all* of these different needs *all* the time. This is also representative of the current study. The participants in this study articulated a wide variety of needs they had or were experiencing in their dying journeys and certainly a number of these needs were similar enough that they could be grouped into categories with themes eventually evolving from their responses. However, not all the needs listed in this current study were experienced by all of the participants. As one considers how spiritual care might be provided to dying persons and their caregivers in Grey and Bruce Counties, this study serves as a platform from which to consider the possible needs dying persons and their caregivers may be experiencing as they have been expressed through this study. The results of the current study also advise spiritual care providers that the foremost thing to do is talk to each person individually, listen intently to the particular needs he or she is sharing, and offer spiritual care to the person that will help address those needs most effectively so the person might die well.

Although participants in this study stressed the importance of connecting and supporting people through spiritual care by listening attentively to the needs of dying persons and their caregivers, participants also voiced occasions when they felt they needed spiritual care providers to engage them in a more directive role and serve as their guide on the dying journey. Participants shared how they believed professional spiritual care providers would have an experiential and scholastic knowledge base from which they could draw to inform the dying persons and their families what to expect on the dying journey. It was also described how doing this could help them to come to a sense of peace in the face of death. This was shared both by participants who had an active faith affiliation and those whose connection to organized religion had lapsed. The need for spiritual caregivers to serve as a guide has been a recurring theme in

other studies examining the needs of dying persons and their caregivers. The dying persons and the caregivers in this study also expressed how they thought a minister serving as guide to the dying journey could be beneficial both to those who had faith in God or some other sense of the divine as well as to those who had little or no previous appreciation of spirituality or religion. This need for a guide was thought to be heightened the closer a dying person came to death. Studies by Nelson-Baker and colleagues (2013), Ferrel and Munevar (2012) and others previously cited demonstrate how the time before a person dies can become a time of spiritual seeking, growth and an increased awareness of the spiritual part of the self for all people. Certainly, in these cases the role of the spiritual care provider may take on even more significance as a guide for dying persons who may be exploring their spirituality for the first time in their lives. A study by Grant and colleagues (2004) helped to reveal the incredible significance persons dying of cancer placed on the need to have guidance of what to expect on the dying journey. When some participants did not receive this guidance it led them to express a desire to end their lives.

It was also interesting to have in the current research study a participant (P5) who described herself as an atheist with an appreciation for spirituality. This participant had explored many different religions during her lifetime, but never actively participated in any one form of religion or adhered to any formal faith practices. Although an atheist, she admitted that she did believe in something. She shared during the interview how she sensed there was “something else”, but she had not found anything in her spiritual journey that had quite captured or described what she believed that “something else” to be. Now that she was facing her dying journey she expressed how she was more open to considering what that “something else” might be and what it might mean for her life and death. This is definitely congruent with the studies mentioned in

the previous section whose results indicate that even persons who had no prior faith life or active association with religion often come to seek out a sense of spirituality the closer death comes in one's life. Collin in a recent study (2012) specifically regarding atheists determined how dying persons who previously had shown no interest in religion or spirituality may start searching to connect to some essence of the divine. Although this participant shared of some searching she had done throughout her life, this quest appeared to be heightened now as her death was imminent. In fact, another dying participant (P7) in the study who had a strong Christian faith helped to affirm these views and encapsulated these ideas by sharing, "An atheist can say they don't believe. Others will say we're gone and that's it, there's nothing. But I don't believe they believe that because there's a part of us that's created to know there's a God."(P7) This participant's opinion is supported by empirical evidence from the current study as well as other noted research studies. An earlier study by Hay (2006) revealed how there may in fact be something 'hardwired' in the human being that gives people a deepening sense of spiritual awareness when approaching death. As a result, dying persons may feel drawn in a very natural way to some sense of the divine or spiritual. The experience of this one atheist participant in the current study concurs with the sentiments of these findings.

In the current study, dying persons and caregivers also expressed a need for spiritual care to provide a connection with church laity. This is an uncommon need not readily apparent or mentioned in the other studies that were reviewed as part of this project. These other studies described how dying persons expressed a need to have a connection to religion or church, but I was unable to locate anything related specifically to church laity. For example, Harrington (2012) simply noted in a study of end-of-life caregivers how they expressed a need to have a connection to some form of religion or church to provide comfort. There was no specific

mention of the laity of the church. Meanwhile, in the current study, a connection to laity was noted both positively and negatively in the experiences of the dying person and their caregivers. In particular, participants who previously had been active in their home congregations sought the company and connection of the laity with whom they once associated and worshipped before terminal illness entered their lives. Maintaining this connection with the church family was important to them, perhaps more so now that the dying persons and caregivers were requiring extra support in their journeys. Plus, declining physical conditions limited the ability of dying persons to participate in church-related activities in the same way they once did. In addition, it also became difficult for caregivers to remain actively involved in activities with the church family when a large percentage of their time was now occupied caring for the dying person. Therefore, the laity's effort to reach out to dying persons and their caregivers could serve as a form of support in the dying journey by helping them to maintain a connection to something that once was and still is important to those who can no longer access it easily on their own. Some participants in the current study expressed the incredible connection they continued to share with members of their congregations. In these instances they described how remaining connected to the laity through visits, phone calls and knowing the church family was praying for them, helped them to find strength for their journey. However, there were occasions when participants shared how they felt forgotten by their faith groups in which they had previously been active before their illness. This surprised the dying persons because they previously had shared great connections with the laity. Now, the laity displayed no effort to maintain the former connection and the dying persons felt emotionally discouraged and unsupported in their journeys. Plus, their need to maintain a connection with their church family through the laity remained unmet. In these instances it was expressed by the participants that they did not believe they should be the

ones having to make an effort to connect with the laity since the participants believed members of faith groups should naturally be reaching out and caring for one another. These dying participants placed the onus on the laity to extend their love and care to the terminally ill in their church community and not expect dying persons to reach out and ask for help in their time of need. A dying woman expressing her frustration in this way stated, “Ya, I can still talk. I’m still here you know!”(P2), but still the presence of laity remained elusive to her dying journey.

The current study also revealed how a small portion of the participants desired a connection to a support group, whether formal or informal in structure. Although other studies noted the desire of dying persons and caregivers to connect with other people in a variety of ways for the support they would receive, the need to connect with a support group specifically was seldom mentioned in the studies reviewed for this research project (see Astrow et al, 2007). When the idea of a support group was noted, it was usually placed low on a list of needs described by dying persons and their caregivers. In the current study the desire to connect with a support group was expressed by participants in three different households. In the household where Participant #10 resided, the two caregivers shared how they would appreciate attending a support group where they know other caregiver-attendees are facing similar experiences to their own. Where at first the one caregiver (C10) remarked how she would want other attendees to be caring for someone with the same illness as her dying mother (P10), she softened on this view when her daughter (C10.2) clarified how the group would simply need to consist of other people who are caring for a dying loved one. They desired such a support group to exist in their home church, but nothing of that nature was available to them in their congregation. Similarly, the participants who resided in the home of Participant #4 also voiced a desire for ministers and churches to organize groups that could support dying persons and caregivers experiencing

similar circumstances. The primary caregiver in this household (C4) was fully aware of Privacy Laws and the difficulty they could pose in ministers and churches sharing the names of dying persons and their caregivers. However, it was also suggested that ministers could ask permission of the dying persons and caregivers if their names might be shared if in fact it was their desire to be a part of a support group. Although these participants shared knowledge of formal non-church support groups of this nature existing in Owen Sound, they noted how they were unaware of any such support groups existing in any of the churches in the community where they resided. Lastly, a dying woman (P7) shared during her interview how she had become a part of an informal support group at her church. This group had developed simply by people with cancer finding one another and agreeing to spend time together on their journeys. This participant expressed how she found incredible support through this informal church group and wished all dying persons could experience such a group. She shared, “I think there’s a reason God has shown me this wonderful, wonderful group. And I think everybody needs that, everybody. And if you don’t have that it must be extremely difficult.”(P7) Indeed, the results of the current study indicate how various participants have stated their desire for support groups, the negative experience of lacking support groups, and the positive experience by one participant who was able to be a find support in such a group. If there is a desire for support groups for dying persons and their caregivers and none currently exist in a person’s community, there may be an opportunity for ministers and churches to address this need by working together to organize such groups and offer this end-of-life support to those in the community who might appreciate receiving it.

There were also some surprises regarding the theme of connection and support in relation to the findings of other studies. As the researcher in the current study concerning *spiritual care*

to dying persons and their caregivers, it was expected participants would speak directly about their need to connect with God or some sense of the divine. Although they spoke of the importance of having God or some sense of the divine in the dying journey, statements such as “I need to connect with God in my dying journey” were uncommon. Instead, the participants spoke more often of the spiritual practices they employed as a way to feel connected to God or some sense of the divine. For example, they shared how praying, reading the bible, attending worship services, and having visits from the minister helped them feel connected to God and also feel supported by a sense of the divine in their time of need. Although this finding may have been a surprise to the researcher, it coincides with the results of other studies. In the studies reviewed for this project the desire to connect with God or a sense of the divine is seldom mentioned in the list of needs shared by dying persons and their caregivers. These other studies did note, however, how participants expressed a need to maintain and participate in sacred rituals and traditions such as prayer and worship as a way to feel connected to a sense of the divine.

Finally, the results of the current study also revealed how dying persons and their caregivers felt supported in their dying journey by connecting to spiritual practices and traditions such as singing hymns, reading scripture, and Holy Communion. These practices received minimal attention in the studies of the literature review and surprisingly the notion of singing hymns was absent in the results of other studies. Yet, a portion of the participants in the current study believed it was a significant enough practice associated with spiritual care that they described it as a helpful resource in their journey. Indeed, some participants emphasized repeatedly the positive role hymn singing, and more generally music, served in their dying journeys. It is therefore important for spiritual care providers to consider how these spiritual

practices and traditions, in particular hymn singing and music, may be an effective resource in spiritual care to help someone to die well.

Personal Inner Resources

The current study revealed how spiritual care when offered effectively can help dying persons and their caregivers experience and develop personal inner resources for the dying journey. In this particular study these items included hope, comfort, self-worth, and strength to cope. This is an interesting finding when placed into conversation with Koenig (2001) who noted the importance of asking dying persons what has given them hope, meaning, comfort and strength during their dying journey. Certainly this is a worthwhile question which may elicit responses that provide insight into the personal inner resources dying persons have available to assist them on their journey. In the current study the answer to Koenig's question would be how participants believe 'spiritual care' in its various forms of delivery can help dying persons and their caregivers experience hope, comfort, self-worth, and strength to cope in the dying journey. Expanding upon this answer, one might add how spiritual care as experienced through connection to the many people and things outlined by participants in the study contributes to the experience of these specific personal inner resources. When a dying person or caregiver shares a connection with a minister, for example, the support they receive through the spiritual care offered by that minister may in turn help them find hope and strength for the dying journey.

Many of the studies referred to in the literature review spoke of the four personal inner resources associated with the current study. More specifically, the need to experience hope through spiritual care in the dying journey is a finding supported by other studies (Astrow et al, 2007; Bartel 2004; Moadel et al, 1999). In the current study, participants expressed the way in

which spiritual care could help them experience hope specifically by exploring their spirituality and beliefs. Spiritual care providers were often considered resource people who could encourage dying persons and their caregivers to draw upon their beliefs as a way to trust in something more to come. Participants were not placing their hope in a belief that the dying person would be healed of their illness, but instead were inspired to hope in an afterlife as expressed through the beliefs of their faith. In this study's sample of primarily Christian participants, they described how they were encouraged through the provision of spiritual care to find hope in an afterlife with God in heaven. Further, some participants specifically expressed their hope of an afterlife through their saviour Jesus Christ.

Several participants in the current study also spoke of the way in which spiritual care could provide comfort to dying persons and their caregivers. The results of other studies support the experience of comfort as expressed by dying persons and their caregivers. The comfort referred to in these studies was sometimes described in a general sense as the comfort of a good death (Harrington, 2012; Kehl, 2006; McClain-Jacobsen, 2004). Meanwhile, Puchalski and Ferrell (2010) acknowledge the need for spiritual care to help make dying persons as comfortable as possible by tending to their dying wishes and needs. Still, other studies (Smith, 2000; Steinhäuser et al, 2000; Singer et al, 1999) share results pertaining to participants' need for comfort in a physical sense. In this way a dying person's comfort is achieved through effective pain management to relieve physical suffering. This sense of physical comfort was mentioned minimally by participants in the current study, again as a way to control physical pain so one might know a good death. The current study's references to comfort were related more significantly to the way in which spiritual care could contribute to a person's sense of emotional and spiritual well-being. For example, some participants described how spiritual care could offer

someone hope which in turn could provide a dying person comfort in their life. Other times participants commented about the comfort they felt when spiritual care had helped to bring a sense of peace in their dying journey by relieving their fears. This also demonstrates the interesting interconnection that can exist between the current study's personal inner resources. For example, if a person is afraid to die because they are uncertain of an afterlife, spiritual care may grant them comfort by helping to relieve that person's fears while also providing them with a sense of hope in an afterlife which in turn could lead to peace in the dying journey. Certainly spiritual care can help a person experience comfort by itself, hope by itself or any other personal inner resources by itself. However, because of the interconnection these personal inner resources can share, there may also be times when one personal inner resource serves as the stimulant to the development and experience of other personal inner resources.

The current study also reveals there is a strong need for spiritual care to help dying persons experience a sense of self-worth on their dying journey. Murray and colleagues (2004) support this finding and note how spiritual care, when offered effectively, can provide a sense of self-worth and identity to dying persons. The results of other studies also relay the notion of self-worth in the dying journey, although they express it in different ways such as having the value of the dying person recognized (Kehl, 2006), finding purpose and meaning in the dying journey (Astrow, 2004; O'Connor et al, 1997), contributing to others and affirming the whole person (Steinhauser et al, 2000), and how spirituality helps people find meaning, purpose and value in life as part of good death (Emanuel and Emanuel, 1998). These findings, along with those of the current study, point to the important task of spiritual care helping dying persons and their caregivers feel as though their lives still have worth and meaning even in the face of the dying journey. For example, this might occur by helping dying persons discover meaningful

ways in which they can still contribute something of themselves to others. The current study also demonstrates how self-worth may be something that a person can appreciate in themselves through the way in which spiritual care is offered to a person. A dying gentleman (P6) in the current study vocalized this point well when he strongly emphasized the necessity of care providers to treat him like a human being and a person of worth, not a statistic. Certainly this was a refrain echoed by other participants in the study who encouraged all end-of-life care providers to remember the ‘person’ to whom they are offering care.

The results of the current study also speak of the way in which spiritual care can give dying persons and their caregivers strength to cope with the struggles they are facing in the dying journey. Other studies have shown the importance of spiritual care and spirituality as contributing factors for finding strength and coping successfully when one is dying (Reid, 2012; Burkhart and Hogan, 2008). Conversely, the results of a study by Ventura and colleagues (2013) demonstrated how unalleviated suffering could persist when spiritual care did not help dying persons and caregivers to cope with the struggles associated with dying. It is therefore important for spiritual care providers to consider how the care they offer might give someone the strength to cope well with the struggles of their dying journeys. A common finding in these studies was spiritual care’s ability to help people find strength and cope in the face of their fears. Doing so helped to bring them peace of mind. Again, this demonstrates the aforementioned connection between the personal inner resources noted in the current study. Various participants shared how they found a sense of peace when spiritual care helped to alleviate their fears. This in turn helped them to find strength and cope more effectively with their journey. Finding strength to cope was also associated with the desire participants expressed to connect with people and things that were meaningful to them because this connection offered them support. For example, this

could occur as easily as a minister showing up and offering a prayer for the dying person and caregiver. Various participants expressed how this simple action could provide them with strength to carry on in the face of their struggles. As one dying participant (P6) described, it “gave him gas in his tank” to keep going one more day. This same participant also shared how without the experience of spiritual care he could understand the deep despair some dying persons would feel in their lives and the corresponding lack of desire to carry on. For this participant spiritual care gave him the strength to cope and this, he believed, was helping him to die well.

Lastly, another personal inner resource was mentioned in several of the studies referred to in the literature, but received only minimal direct attention from the participants in the current study. It relates to the need of dying persons having a sense of control or autonomy in the dying process (see Kadlec, 2013; Hermann, 2001; Steinhauser et al, 2006, 2000; Smith, 2000). In fact, in Kehl’s review of forty-two articles related to what constitutes a good death, ‘being in control’ was listed most frequently. This was described by participants in these studies as both a need, spiritually and generally, and as an element considered important by dying persons and their caregivers as a means to die well. Although participants in the current study may not have referred to the way in which spiritual care helped them achieve a sense of autonomy in their journey, they did mention experiences that alluded to their desire for a sense of control. Some participants shared how they had already experienced a sense of control by making their funeral arrangements. Others noted how it was their desire to die at home and the necessary steps had been taken to ensure this would happen. A few dying persons described who they wanted present when they died as well as who they did not wish to have there. Relatedly, some participants shared of their desire to have their wishes met as an aid to dying well. It appears participants in the current study also hope for spiritual care to grant them a sense of autonomy in

the dying journey even though they may not have stated it as directly as “I want to be in control.” Evidence from previous studies would suggest that personal autonomy is a need dying persons strongly desire to have fulfilled in their dying journey.

A Sense of Peace

Results of the current study demonstrate how several participants placed a strong emphasis on the need to experience a sense of peace as part of the dying journey. This sense of peace was sometimes expressed in a general way. Other times participants conveyed coming to a sense of peace through specific aspects of their dying journeys such as ensuring peace in the family, having their dying fears relieved, finding guidance on the journey, and tending to unfinished business. When the provision of spiritual care helped participants experience a sense of peace in any or all of these different ways, participants also described how it aided in improving their quality of life and experiencing a good death. Previous studies concur with these findings. The studies noted in this research project’s literature review demonstrated how coming to a sense of peace through the provision of spiritual care was also a common need expressed by participants. Further, these studies showed how working toward a sense of peace was considered an important task to help a person die well. These studies did not necessarily use the current study’s terminology ‘sense of peace’ to denote the peace that dying persons and caregivers may experience as part of the dying journey. Instead, this ‘sense of peace’ was described in various ways in the other studies. For example, Astrow and colleagues (2007) described dying persons’ need to find peace of mind. Others noted the desire for dying persons to achieve a sense of peace (Singer et al, 1999), a need for peace (Grant et al, 2000), and coming to peace or being at peace (Steinhauser et al, 2006). In another study by Steinhauser and colleagues (2000) it was stated

specifically how participants placed considerable importance on being at peace with God. These participants considered this to be the most important need of dying persons along with adequate pain control.

In the current study, the theme of coming to a sense of peace had general connotations in the lives of the dying and their caregivers. The theme also related to specific ways in which participants believed spiritual care could help them achieve this sense of peace, for example, by finding peace in the family, having their fears relieved, having guidance on the journey, and tending to unfinished business. This delineation of tasks is slightly different from the findings of other studies referred to in the literature review. Many of those studies referred to these various tasks, for example the need to relieve burden on family (Singer et al, 1999), address family concerns (Astrow et al, 2007), ensure family is cared for (Kehl, 2006), overcome fears and talk with someone about finding peace (Astrow et al, 2007; Moadel et al, 1999), find freedom from the fear of dying (Grant et al, 2000), finish business (Hermann, 2001), and have finances in order (Steinhauser, 2000). However, they were not specified as tasks that would help someone come to a sense of peace in the dying journey. These items were stated as needs of dying persons and caregivers and in some cases were desires, which if fulfilled were considered to help a person to have a good death. The participants in the current study concurred that these items were needs of dying persons and their caregivers and if tended to could help a person die well. The difference is in how the current study's participants described these tasks with an inclination toward the sense of peace they provided to their journey. It was in the experience of that peace that they further described how they might then die well and have a good death. The findings of these different studies along with those of the current study acknowledge the incredible importance participants place on the need to come to a sense of peace in their journey regardless of how it

might be phrased. Indeed, the way in which it has been described so prominently by participants illustrates how helping dying persons and caregivers find a sense of peace in the dying journey might also help a person to die well. Therefore, it is critical for spiritual care providers who offer end-of-life care to realize how important a sense of peace can be to dying persons and their caregivers. Additionally, it is important for spiritual care providers to consider ways in which they can offer care that might assist dying persons and caregivers in coming to a sense of peace. Steinhauer and colleagues (2006) suggested a simple way to do this by asking a person “are you at peace?” Their study concludes that asking people about the extent to which they are at peace offers an introductory way to assessing their spiritual concerns. This in turn allows spiritual care providers to tend more effectively to people’s needs so they might find a sense of peace in their dying journey. When one experiences this sense of peace, then they might also experience a good death.

Rural Appreciation

The reports and studies examined in the literature review commented on the inequality and deficiencies of palliative care resources in rural areas of Canada. Although spiritual care was mentioned only minimally in these reports, if at all, when it was mentioned it was deemed an important part of palliative care even in rural areas. Before undertaking the current study my bias was to agree with these reports and I believed people living in rural areas would perceive their end-of-life care experiences as limited in comparison with people living in larger urban centres. My reasoning had to do primarily with the availability of resources. I presumed there would be specialized and more resources available in a larger urban centre like Toronto, for example, and this may very well be true. However, participants in this research study surprised

me in the way they perceived their end-of-life spiritual care experiences in rural Grey and Bruce Counties in comparison to what they might receive in a larger urban centre. Some participants agreed with the sentiment that there may be more resources available in an urban setting, but the way in which those resources are experienced can make a difference in the care received by dying persons and their caregivers.

Several participants noted the difference in friendliness between rural and urban settings. They described how people are closer-knit in rural areas, know their neighbours, and watch out for one another by helping them with their needs. Whether drawing on real experiences or their perceptions, participants did not believe this would be the same experience of care that dying persons and their caregivers would receive in a place like Toronto or some other large urban centre. Instead, they believed the end-of-life care in a large urban centre would feel 'colder' because people do not even know who their neighbours are and people take little interest in one another's lives. In the rural setting of Grey and Bruce Counties the participants believed other people were more attentive to the needs of their neighbours and indeed this was the experience expressed by a majority of the dying persons and caregivers in this current study. Participants shared how they felt emotionally closer to their neighbours even though they might live a further distance from them physically when compared to neighbours living in closer proximity to one another in an urban centre. It was also stated how closeness and familiarity among people in a rural setting could aid in the accessibility of resources. It was admitted the availability of resources in a rural setting may be more limited compared to that of an urban centre. However, it was explained further how dying persons might have better access to the smaller number of resources that are available in Grey and Bruce Counties simply because of the connection and familiarity one already has to other people. In turn this may present opportunities for people to

understand better how to go about receiving hospice palliative care services. Certainly, this was the case of Participant #1 who had previously worked for a hospice service provider in Grey and Bruce Counties and still maintained an active connection to its people. She had many connections that enabled her to access the hospice services and providers to help her in her dying journey in the most effective way possible. This was a similar refrain to stories cited by other participants when asked how they had come to receive the hospice services they were receiving. Several participants shared of their associations with someone or something that granted them a previously established connection to a network that enabled easier access to hospice resources to assist them on their journey.

Indeed, it was briefly noted in the current study's results how familiarity and connection can come into play in a rural setting and occurred to some extent in the research interview process itself. I expand upon it here for illustration's sake. In an interview with a caregiver and her dying husband we quickly discovered in our initial introductions and conversation that we shared connections to common people. The caregiver described this as the "six degrees of separation" (C4). We required only exploring two degrees of separation to find people who connected us to one another. I can attest with experiential certainty this habit of searching out people who are commonly known occurs regularly within Grey and Bruce Counties. Certainly it occurred in each of the research interviews at the participants' initiation. Surprisingly, a common connection of this nature was established in eight of the eleven households the researcher visited during this study. In addition to this it appeared the participants in these specific interviews displayed a heightened level of trust with the researcher simply by taking a few brief moments at the beginning of the interviews to establish this common connection. Knowing someone in common helped to bond the researcher and participants in ways that

extended beyond merely being neighbours who lived in the same geographical region. In this way I observed at times during the interviews how participants would refer back to the person we knew in common as a way to connect me to the expanded point they desired to make in relation to the person. I believe this connection and its ensuing development of trust in the researcher-participant relationship also enabled us to delve more deeply into the sensitive areas of the research topic.

Interrelatedness of the Current Study's Themes

There is an interrelatedness between the current study's themes in regard to the provision of spiritual care to dying persons and their caregivers. The participants' voices from the research interviews demonstrate how spiritual care provides a connection to people and things that are important to dying persons and their caregivers as part of the dying journey. When these connections occur in a meaningful way it helps dying persons and their caregivers to feel supported in their time of need. In turn, this support helps to address the needs they may be experiencing in the dying journey and this aids in alleviating any suffering that dying persons and their caregivers may be experiencing. As a result, this connection and support to the people and things that dying persons and the caregivers deem as important to the dying journey also helps to bring personal inner resources to their lives. Again, these personal inner resources such as hope, comfort, a sense of peace, and strength to cope all help to contribute to a person dying well. Plus, all of these things when placed together can help dying persons and their caregivers to not only perceive a good death, but experience one as well. However, when a desired connection is not provided or experienced in the way that is needed, dying persons or their caregivers may perceive a lack of support in their dying journey. This in turn may contribute to

them not experiencing the same level of personal inner resources and feel an increased level of suffering. All of this could deter from them dying well and knowing a good death. When these thoughts are placed into the context of rural Grey and Bruce Counties a further revelation comes to light. Participants in the study shared of the special nature of living in a rural setting. People are closer-knit and friendlier, they watch out for one another, and they experience the available resources differently. Dying persons and their caregivers may therefore be able to experience more readily the connection and support they need in their dying journey as a result of the rural nature of Grey and Bruce Counties. This is not to say they would not experience a connection and support through spiritual care in an urban centre, however, the extent of that connection and support may be limited in comparison to the experience in a rural setting.

Limitations and Strengths of Current Study

The current study's sample size contained nineteen participants representing eleven households. This is a relatively small sample size and keeps with the practice associated with qualitative phenomenological studies that employ interpretive phenomenological analysis to code and theme the results. In this methodology, sample sizes generally contain fewer participants as a way to explore more richly the life-worlds of these participants. As such, the results arising in a phenomenological qualitative study with few participants are typically not generalizable across a larger population. This means in the current research study the findings arising from the interviews with these nineteen participants may not be generalized as representing the spiritual care experiences of all dying persons and their caregivers across the region of Grey and Bruce Counties. The results arising from the interpretive phenomenological analysis employed in this study are representative of the specific experiences of these particular

participants. Paradoxically, however, there is one finding in this study that may be applicable across the general population of dying persons and caregivers in Grey and Bruce Counties. It relates to the need experienced by participants in the current study for spiritual care providers to be cognizant of the specific nature of individual needs in the dying journey. One might not be able to specify exactly what dying persons or their caregivers need, although the current study gives some insight into this area, but it can be stated that each person will have desires that need to be addressed. Generally speaking, it would be good spiritual care practice to assess the needs of each dying individual or caregiver and offer care accordingly. Further, one might also generalize from this study the need to assess regularly the needs of dying persons and their caregivers because their needs are ever-changing.

It is also worthwhile to consider the nature of 'rural' as it relates to Grey and Bruce Counties. There are different categories of 'rural' according to Statistics Canada. A "predominantly rural region" is an area having more than 50% of the population living in rural communities where a "rural community" has a population density less than 150 persons per square kilometer (Statistics Canada, 2009). According to the National Household Survey (2011), from which the following data are drawn, Grey and Bruce Counties fit this definition as they maintain a population density of 12.1 persons per square kilometer. This compares lower to Ontario's population density of 14.1 persons per square kilometer and higher than Canada's 3.7 persons per square kilometer. The largest urban center in Grey and Bruce Counties – Owen Sound – has a population of 21,688 and a population density of 51.1 persons per square kilometer. Comparing this with the large urban center of Toronto referred to by participants in the current study, its population density is 4149 persons per square kilometer. Certainly, the population density of Grey and Bruce Counties is similar to that of Ontario's, yet higher than that

of Canada's population density. Meanwhile, the territory of Nunavut has a population density of only 0.015 persons per square kilometer. All of this is to say that when the earlier reports and studies in the literature review noted the inequality of palliative care service to residents in rural areas, some consideration needs to be given to the nature of the rural area. Most of these reports made no distinction between such geographic areas, but simply lumped all rural areas across Canada into one common national demographic. Yet, in the same way the current study has shown the importance of individually assessing the needs of each dying person and caregiver because their needs are different, caution must also be advised when considering how spiritual care might be offered across the different rural regions of Ontario and more broadly, Canada.

It was previously noted in the Chapter 3 - Methodology how a research study such as this must consider the limitations that might be involved in working with a physically vulnerable segment of the population. Obtaining referrals to potential participants may prove difficult because of the dying persons' declining physical health. Energy levels and the ability of dying persons to participate in a research interview may not be the same as participants who are in good physical health. These concerns must be considered when designing a research project such as the one involved in the current study. Also, validation of results and findings through follow-up with the participants may prove an impossible task given the reality of participants' deaths. This definitely was apparent in the current research study. That said, as the researcher facing these concerns and limitations, I found it beneficial to keep these items in mind as I engaged in the research project. I described in detail how I modified certain aspects of the project to accommodate these circumstances while aiming to remain true to the original intent of the research. For example, when death limited the opportunity to return to the dying participants to validate findings, I adopted a process of validating my understanding of the participants'

experiences with the participants themselves as we progressed through the interviews. The result of these considerations during the research project provided some rich descriptions of participants' experiences while keeping within the guidelines of the research methodologies and allowing the approach to remain dynamic.

Certainly a strength of this study is the very topic of the research itself. It was noted in the literature review how no studies have explored how dying persons and their caregivers experienced spiritual care in their homes as an aid to dying well and having a good death in Grey and Bruce Counties. This makes this project a ground-breaking piece of research for this particular geographical area. My hope was to have hospice service providers in this region take seriously the end results and recommendations of this project and consider how they might be incorporated into the provision of end-of-life home care in these two counties so spiritual care might help people die well. When this study began, none of the regional hospice service providers had any protocols for the provision of spiritual care in their mandates. What is surprising to me as the researcher is that we have not had to wait for the end results and recommendations to come forward for these various groups to start giving spiritual care some consideration. It appears my initial contact and continued working with them through the referral process sparked an interest in these various organizations to consider what spiritual care might mean to their programs. Indeed, in 2013 two groups invited me to present my early findings to their care providers. They also asked me to speak generally to the topic of spiritual care in the end-of-life journey. Plus, the VON Grey-Bruce has tentatively scheduled my work for presentation at a spring workshop in 2014. Further, there have been some significant developments in the programmatic structure of the South-West CCAC for the region of Grey and Bruce Counties. The Local Health Integration Network (LHIN) that oversees health care

delivery for these counties has recently (2012 and 2013) been planning, coordinating and preparing to implement a home-based end-of-life care team for this region through the CCAC. This will formally be known as an 'Outreach Team'. The LHIN has requested that the provision of spiritual care be a part of this Outreach Team. A colleague who sits as the spiritual care representative on the LHIN planning committee shared via personal communication how this current research project was introduced to the local CCAC around the same time initial work began on the Outreach Team project. This same colleague notes how if not a catalyst, the current research project at least helped to keep spiritual care to dying persons "on the CCAC's radar" while developing this home-care initiative with the LHIN. All of the regional hospice service providers have also requested a summary report of the current research project's results and recommendations. As the researcher in this project it is further expected that I will make a presentation at one of the monthly meetings of the newly named Grey-Bruce Hospice Palliative Care Collaboration (its predecessor was formerly described in the Methodology chapter as the End-Of-Life Care Committee). This committee is the group of end-of-life service representatives to whom I initially consulted and introduced the current research project as a way of seeking referrals to potential participants for the study.

Considerations for Future Research

The current research study gives voice to nineteen participant experiences of spiritual care in the home as an aid to dying well and having a good death in Grey and Bruce Counties, Ontario. The findings of this research study are now joining the early conversation of an examination into the delivery of holistic home-based hospice palliative care services in this particular region. As the researcher in this project it is my hope that the themes and

recommendations arising from this study will be granted some serious consideration in development of effective and holistic hospice palliative care services that include spiritual care to dying persons and their caregivers. While investigating this particular research topic it became evident that other areas of study would prove beneficial to the conversation of hospice palliative care services in Grey and Bruce Counties. Indeed, these recommendations could also be translated for consideration provincially and nationally. In the context of Grey and Bruce Counties it would be worthwhile to have further research conducted that examines spiritual care experiences in the home of a more religiously diverse sample of dying participants and caregivers. Simply by happenstance the current study recruited eighteen participants of a Christian faith background and one person who considered herself an atheist. Although statistics indicate Grey and Bruce Counties contain a largely Christocentric population (69.2%; see p.73 in Chapter 3 - Methodology for an overview), a more religiously diverse sample of the other faiths found in this geographical population may give voice to a broader spectrum of end-of-life spiritual care issues. Plus, a researcher may wish to distinguish between dying persons and caregivers and perform two separate studies of this nature to ascertain more specifically the spiritual care needs of dying persons apart from the spiritual care needs of their caregivers. The previously cited Canadian study by Heyland and colleagues (2006) concluded how the perceived needs vary across these two groups and need to be considered individually when offering end-of-life care. With all of this in mind, future research could explore: what do the end-of-life spiritual care needs of these two groups look like individually within the context of Grey and Bruce Counties?

In the current study it was noted how the researcher experienced some initial difficulties obtaining referrals to potential participants as a result of their admission into hospital. Various

studies (see Heyland et al, 2006; Romanow, 2002; Carstairs, 2000, 1995) expressed a deficiency and frustration to maintain proper continuity of care with patients and medical services. One might question: How does continuity of end-of-life spiritual care translate from the home into an institutional setting such as a nursing home or hospital? In this way, it would be worthwhile to have another study explore dying persons' experiences of spiritual care in institutional settings such as nursing homes and hospitals in Grey and Bruce Counties. Again, asking questions similar to those in the current study may prove revelatory: how is spiritual care being offered well in the institutional setting? Where is there room for improvement? How does spiritual care help a dying person to die well in an institutional setting in Grey and Bruce Counties?

The current research study contained one participant who described herself as an atheist who had an appreciation for spiritual care. Reflecting on her experiences of spiritual care in the dying journey revealed a deep level of insightfulness in her responses. Indeed, other studies have shown how those who previously had no appreciation for spirituality or religion may find themselves desiring such a connection as part of the dying journey. A specific study focusing on the spiritual care experiences of dying persons in Grey and Bruce Counties who previously had no active engagement or expression of a faith life may be beneficial to those people who have opportunities to offer spiritual care to this demographic of the population. What are their spiritual needs? How do they compare with those who are believers in God or some other sense of the divine? How might spiritual care providers minister to them effectively in their dying journey?

The current research study sought potential participants in collaboration with the various hospice service providers in the region of Grey and Bruce Counties. It would be worthwhile for another study in the same region to explore with the various workers and care providers of these

organizations how they envision spiritual care fitting as part of the team dynamic of holistic care to dying persons in their homes and institutional settings. Many times these workers are the first hospice-related people to interact with the dying persons and their families. What are these workers' and care providers' appreciation of spiritual care as part of the dying journey? Do they understand how spiritual care might help someone to die well? What is their view of spiritual care's place in the holistic care offered to dying persons and their families? Do they understand how they might assist dying persons and caregivers to access spiritual care if it is their desire? It appears the current study has been a catalyst to inspire these groups to consider how spiritual care might be a part of end-of-life care. In order for spiritual care to become a regular and effective part of the hospice palliative care services in this region it would be worthwhile to examine how the workers of these organizations see it fitting into the service model. Further, it is important to consider what procedures might be necessary to ensure spiritual care is a part of formal hospice palliative care services in Grey and Bruce Counties.

Recommendations Based on Current Research Study

There clearly are some recommendations that come forward from the current study regarding the provision of spiritual care in the home to dying persons and their caregivers to help a person die well and have a good death. Spiritual care providers would do well to remember dying persons and their caregivers have a variety of needs in their lives. These needs will likely be physical and will also include emotional, psychological and most definitely spiritual needs. The more effectively that hospice care can address these needs, the greater the possibility of a person's end-of-life suffering being lessened while his or her quality of life is improved during the dying journey. When this occurs studies have shown there is an increased probability of a

dying person experiencing a good death. Spiritual care is an important part of holistic palliative care to dying persons and their caregivers and can attend to spiritual needs, lessen suffering, improve quality of life, and aid in helping someone die well.

The results of the current study show how spiritual care can assist someone to experience a good death through connection and support. This theme carries a prominent role in the effectiveness of the spiritual care offered to dying persons and their caregivers. Participants in the current study expressed a critical need to connect with various persons and things as a way to experience the support they would provide to the dying journey. First and foremost, spiritual care providers need to make an effort to connect with those who desire care. Spiritual care providers need to make an effort to show up. Results of the current study recommend this is especially true for ministers of a congregation, but any leader of a faith group would benefit from the urgency of this recommendation. Showing up and making oneself available presents enormous opportunities for a spiritual care provider to engage with dying persons and their caregivers, listen to their needs, and consider how they might best offer care to help them fulfill their dying needs. When spiritual care providers make an effort to do this they are taking steps to help dying persons and their caregivers know a good death.

It is also important for those offering spiritual care to remember that every person they care for has unique spiritual needs. In fact, it was observed how some of these spiritual needs may not appear 'spiritual' or 'religious' in a traditional sense, yet according to the person's spirituality they were indeed spiritual to the person receiving care. Therefore, it is vital to listen and assess the spiritual needs of each dying person and caregiver in each home a spiritual care provider visits. Certainly the current study and numerous other studies have produced lists from empirical data of what these needs might be. It would be worthwhile for spiritual care providers

to consider these lists to gain a better understanding of the needs dying persons and their caregivers may be experiencing as part of the dying journey.

It is further recommended spiritual care providers regularly assess the needs of those in their care. It is presumptuous to assume the spiritual needs of dying person and their caregivers will remain the same from one encounter to another. Participants in the current study described how it is important to check in with them routinely because their needs are dynamic and change according to the circumstances of the day. Indeed, it would be necessary to assess a person's needs in each encounter one may have with the same dying person or caregiver within the same day. A person's spiritual needs can change that quickly and that often.

The results of the current study also encourage us to consider the need for spiritual care to help dying persons and their caregivers connect with people who are not traditionally considered formal spiritual care providers. This was illustrated in the current study in the way that participants described their desire to connect with church laity, family and friends, and hospice workers. These groups can provide spiritual care in the way a dying person or caregiver needs to experience their definition of spiritual care. In particular, it was noted how participants who already had a strong connection to their church family expressed a deep desire to maintain such connections with the church laity. The results of this study recommend the laity make an effort to maintain this connection toward the dying person or caregiver. It was observed how dying persons often were limited in their physical abilities to remain actively connected to their church families. Caregivers were also too busy caring for the dying person to have time or energy to reach out to the church family. Therefore, it is important for the laity of the church to reach out to dying persons and caregivers in their time of need. It was observed in the current study how a simple phone call from laity can help maintain this connection. An in-person visit, if possible, is

also often appreciated by dying persons and caregivers. Participants who were active in their churches expressed a deep desire to be remembered by the laity of their churches. Again, it would be worthwhile for ministers of churches and leaders of other faith groups to encourage laity to consider how they might remain connected and offer their support to people in their dying journeys.

Another recommendation arising from this study involves spiritual care as a form of community support. This involves three distinct possibilities. One is for faith leaders and groups to consider how they might use support groups to offer spiritual care to dying persons and caregivers in the congregation and larger community. The second action is for faith leaders who serve as spiritual care providers in organized religions to consider how they might make themselves available to those in the community who do not have an active affiliation with a faith group, yet desire a connection to a spiritual care provider in their community. Ministerial groups may be a good starting place to consider how this might develop and could tie in well with the third part of this recommendation. It is recommended that spiritual care providers work with their regional hospice service providers to incorporate some form of spiritual care into the end-of-life services offered to dying persons and their caregivers. This may be as simple as one participant recommended: providing a list to these hospice service providers of spiritual care providers who would be willing to offer care to any dying person or caregiver in their locale who desires it, but currently is not receiving it or is unaware how to access it.

This relates to another recommendation arising from the current study. It is important for hospice service providers to consider how they might incorporate spiritual care into their provision of end-of-life care. In particular, they are encouraged to ask clients about the provision of spiritual care in the same manner as they would assess other service needs. Some of these

organizations may be limited in their abilities to do anything depending upon the formal mandates of the organization. However, it was documented how the current study has served as a catalyst for the hospice service providers in the region of Grey and Bruce Counties to at least start a conversation of what spiritual care might look like as part of their services. Two years since the initial presentation of this project to these groups and the conversation has grown to the point of them inviting the researcher to share findings, offer presentations and guest speak at workshops hosted by the various regional hospice service providers.

It is also recommended spiritual care providers consider how their work may help dying persons and their caregivers experience and develop personal inner resources through the delivery of spiritual care. The participants in the current study have shared how spiritual care can help one find hope in an afterlife even in the face of death, comfort amid worries, a sense of self-worth and that life still has meaning, and strength to cope with the problematic experience of dying. The results of the current study also encourage one to consider how spiritual care can provide a sense of peace to the dying journey by helping people to address family issues, relieving fears, offering guidance on the dying journey, and tending to unfinished business. When spiritual care helps dying persons and their caregivers tend to these items it also helps to relieve potential suffering in the dying journey which in turn aids in a person experiencing a good death.

The current study also raises a recommendation regarding dying in a rural area. While living in a rural setting like Grey and Bruce Counties may be perceived by some to hinder a person's ability to experience a good death due to fewer resources, limited specialties, and travelling greater distances to receive services compared to people living in a larger urban centre, participants in the current study presented alternative viewpoints for consideration. They

described the closer-knit, friendlier, neighbour-watching-out-for-neighbour nature of this rural area as a positive aspect of the end-of-life care and spiritual care one might receive. It is recommended spiritual care providers consider how they might draw upon these strengths of rural living as a way to increase the effectiveness of the spiritual care they offer. Drawing upon the informal network of connections many people share in rural regions may help to increase the support experienced by dying persons and their caregivers and help them to know a good death as part of the dying journey. Knowing how to tap into these connections may also prove useful in more easily accessing the smaller number of resources available in this rural setting. Plus, participants shared repeatedly how the friendliness associated with people living in this rural region offered an emotional warmth and spiritual support that were very unlikely to be experienced among strangers in a large urban setting.

Finally, it is recommended that anyone who has an interest in or offers spiritual care in Grey and Bruce Counties considers seriously the results and recommendations of this study. What could these results mean to their delivery of spiritual care? How might they apply these recommendations to their provision of spiritual care? The results of this study may not be easily generalizable across the nation-wide population of Canada, but they certainly do convey the voices and experiences of nineteen dying persons and their caregivers in Grey and Bruce Counties. The nature of their experiences of spiritual care and dying is likely similar in some way to the experiences of others. Taking into consideration what these participants' voices shared through this study will hopefully give spiritual care providers courage to consider the spiritual care they are offering to dying persons and their caregivers, what they are doing well and what they might consider doing a little better – all for sake of those who are dying and those who care for them to know the experience of a good death.

Chapter 6: Theological Reflection

“Death is not the opposite of life, but a part of it.”
- Haruki Murakami

The purpose of this research project is to explore how dying persons and their caregivers experience spiritual care in their homes as an aid to dying well and having a good death in Grey and Bruce Counties, Ontario. In the introduction of this paper I shared how I am a spiritual care provider who lives and works in the region of Grey and Bruce Counties and received a diagnosis of a rare terminal illness in 2005. Over the years since my diagnosis I have reflected deeply to discover where God might be present in my experiences and how God might be working to give my life new meaning even in the presence of a terminal illness. Indeed, I believe through the experience of having a terminal illness God has inspired me to be more pro-active and engage in activities which previously I had not considered doing as part of my life’s journey. This research project is one of those activities. Over the last several years since my diagnosis I believe God has guided me through a variety of life experiences that have inspired and led me to undertake this research project both for the betterment of my life and the lives of those receiving spiritual care in their dying journeys.

In this chapter it is important to continue reflecting theologically as a way to consider how God’s abiding presence and inspiration are part of the experience of this research project. Indeed, O’Connor and Meakes (2013) in a Canadian qualitative study on spiritual care and psychotherapy state how one of the goals of theological reflection is to help people “understand the presence of the sacred” in an experience. (p.101) Pastoral theologian Robert L. Kinast (1996) adds how theological reflection “tries to help a person discover God’s presence in that person’s experience and lead one more directly to encounter God.”(p.x) To do this theological reflection encourages a person to ask the questions: what difference does God’s presence make

in an experience? What does God expect as a result of reflecting on this experience? The answers to these questions are the goal of this chapter. In order to answer these questions I will employ a spiritual wisdom model of theological reflection as outlined in the book *The Art of Theological Reflection* (1994) by Patricia O'Connell Killen and John de Beer.

The spiritual wisdom model of theological reflection is rooted in the everyday life experiences of people. Killen and de Beer (1994) pattern their model of theological reflection on the way people naturally think about their life experiences which they describe as "movement toward insight." (p.21) This movement toward insight then facilitates an exploration of the ways God is revealed in the experiences of people's lives. Killen and de Beer's method consists of four steps involving two sources for theological reflection. The first step involves thinking about an experience as honestly and non-judgmentally as possible. An experience is anything that happens to a person and has inner dimensions such as feelings and thoughts that people carry into and out of any situation. An experience also has an outer dimension involving people, places and things with which we interact. In this spiritual wisdom model the experience also serves as the first source for theological reflection.

The next step in the process is to be attentive to any feelings that may become apparent when one thinks about an experience. Killen and de Beer (1994) share how feelings exemplify the human drive for meaning and are clues to the meaning of our experiences. As these feelings come forward it is important to let them occur naturally without trying to limit their expression. This may result in uncomfortable feelings arising at this stage as one reflects upon an experience. Indeed, a person may be tempted to stop the process at this point due to unsettling feelings. Killen and de Beer (1994) encourage the reflector to persevere through the process because this is when a person is truly coming to a central issue and the heart of what matters in the reflection

process. When a person allows him or herself to engage in these feelings it is expected an image will emerge that begins to capture the meaning of the experience upon which a person is reflecting.

Step Three involves putting the image that has emerged into conversation with a reflector's faith tradition to see what new insights will develop through the reflection process. Faith traditions such as scripture, rituals and practices are the second source for theological reflection in this method. Killen and de Beer (1994) describe how an image has the ability to transport us or a situation to a new standpoint from which we can view the original experience differently when it is placed into conversation with faith traditions. When reflectors enter the space of the emergent image in this way they then open themselves up to the possibility of gaining insight about an experience. This insight may deepen what a person already believes, grant a different perspective to a person's beliefs, or provide a whole new perspective and direction for living. The purpose of the fourth and final step in this process is to put into action the insights and learnings gained through the previous step. It is here a person needs to be willing to implement the insights that have evolved through the reflection process. Killen and de Beer (1994) comment, "the Christian way of life is not primarily a matter of increased knowledge or understanding, but of incarnating the truth we receive so that we come to embody the love of God in the world."(p.43) How can we ensure we 'incarnate the truth' we receive through the insights and learnings of this reflection process? Killen and de Beer (1994) answer we can follow through on what we have learned "through prayer, planning, and other people."(p.44)

In this research project the experience upon which I am reflecting theologically is the way in which spiritual care helps dying persons and their caregivers find connection and support

in the dying journey. This is an incredibly prominent theme in this research's findings. It has caused me to reflect deeply on its significance to the provision of spiritual care in the dying journey of the participants I interviewed for this study. I became aware of a feeling as I reflected upon the research, the participants' voices and their expression of the need for spiritual care to help them experience connection and support. The feeling is described as 'compassion'. When I note the word 'compassion' I am considering its Latin roots which define it in this way: "to suffer together with" (Retrieved from website <http://www.merriam-webster.com/dictionary/compassion>). I prefer to consider this definition in a more pastoral sense to mean "coming alongside another person in his or her suffering." As I reflected upon the participants' repetitive desire to have spiritual care help them experience connection and support in their dying journey I felt this overwhelming expression and emotion of compassion – they desired someone to come alongside them in their suffering. Most notably they described their desire to experience a feeling of compassion with their minister, but also from their families, hospice workers, nurses and the laity of the church. They did not want to be alone in their suffering. Not once did I hear a participant express such a desire. They wanted people to walk alongside of them in their journey and if possible help to relieve their suffering. They did not want someone who would preach at them or not listen to their needs. They wanted compassionate companions for their journey who truly wanted to help them in their time of need. They wanted spiritual care providers who were not afraid to come alongside them in their suffering and lovingly hold their hands as they walked a road they had never before journeyed. As I reflected upon this feeling of compassion in the participants' experiences, an image came to mind in the form of a story found in the New Testament of the Christian bible.

There is a story in the gospel of Luke (24:13-35, NRSV) that tells of two companions journeying together along a road that leads out of the city of Jerusalem to a village seven miles away called Emmaus. These two companions are followers of Jesus of Nazareth who just days before had been crucified. Now in the wake of Jesus' death these two people were walking along the road to Emmaus. As they walked along they conversed with one another, trying to console each other and make sense of the suffering that had touched their lives through the tragic death of Jesus. While they were conversing in this way Jesus appears to them, although unrecognizable to them at first. As Jesus travels with these two companions he asks them what they are talking about and converses with them about their experiences. He also helps them understand their recent experience of death by drawing references from the Hebrew Scriptures. As they approach the village of Emmaus these two companions ask Jesus to stay with them longer because night is falling. He stays and joins them for a meal. Then as Jesus breaks bread with them during the meal the two people recognize that it is the resurrected Jesus in their midst just before Jesus vanishes from their sight. Suddenly they come to new understandings about what is going on around them and what Jesus' appearance means to them. Through their encounter with the resurrected Christ they know their lives have been touched in a special way with love, understanding and compassion when they needed it the most.

People who provide spiritual care to dying persons and their caregivers are like the companions travelling the Emmaus road together. I realize there is a difference in the timing of death between the two people in the Emmaus story (post-mortem) and people who are in the palliative stages of an illness (pre-mortem). However, what I appreciate in this story in relation to end-of-life spiritual care is that in both situations people are figuring out meaningful and caring ways to journey together through the suffering that comes to their lives in the shadow of

dying or death. They are not having to face their struggles or journey alone. One can only imagine how different the walk to Emmaus would have been if either of the companions had to make the journey alone. Having a companion on the journey in the midst of their struggles gave them both someone in whom they could find comfort, strength and support for their lives. Their companionship also granted them someone with whom they could try to make sense out of all the stuff that was going on around them. How reminiscent this sounds of the participants' voices in this study! Dying persons and caregivers alike expressed their desire to have a spiritual care provider with them on their journeys. One of the most important aspects of spiritual care as expressed repeatedly by the participants was the need for the spiritual care provider to show up. An absentee spiritual care provider does not make for a supportive travelling companion in someone's dying journey. Yet, to have a spiritual care provider present to travel that road together can make all the difference in the world to dying persons and their caregivers. This is not to say that all of a dying person's suffering will be alleviated through spiritual care, but at least there is an increased opportunity for comfort and support to be experienced when a spiritual care provider makes an effort to companion someone on their dying journey. When a spiritual care provider makes an effort to come alongside a dying person in their suffering, the spiritual care that is offered can provide the connection and support that is needed to help that person experience his or her dying journey well.

I also find it insightful how the resurrected Jesus came alongside the Emmaus road companions in their time of need even though they did not recognize it was Jesus travelling with them. It challenges me to wonder how often this has been part of my experience – Jesus coming alongside of me while I was serving as a spiritual care companion to a dying person in his or her journey? With faith, I trust this is true that Jesus is with me as I companion someone with

spiritual care. Further, I trust this can be true in the experiences of all spiritual care providers offering care in a whole variety of circumstances. In this way pastoral theologian Charles Gerkin believes there is always more to the case or event than our interpretation can explain and this ‘more’ is the mystery of God’s presence (O’Connor, 1998). It would be worthwhile for spiritual care providers to consider that they are not simply offering care on their own. God, or some sense of the divine, is present alongside them and helping the situation to be experienced by dying persons and their caregivers as something more than spiritual care providers could ever make it on their own. Also, as the two Emmaus road companions realized after Jesus had revealed himself to them, “Were not our hearts burning within us while he was talking to us on the road...?” (Luke 24:32, NRSV), so too spiritual care providers would do well to remember that God can be at work in them as they offer spiritual care in the midst of struggle. In the research study, a dying participant’s description of spiritual care providers takes on new meaning when considered in this light. He shared, they are like “God with skin on.”(P6) This may be truer than anyone who humbly offers spiritual care wishes to realize. Again, Gerkin agrees with these sentiments and claims how in the practice of ministry, spiritual care must incarnate the presence of Christ in the spiritual care provider in relation to those receiving care. In this, spiritual care providers embody the love of God in their ministry. (O’Connor, 1998).

It is also fascinating to consider in the Emmaus story how Jesus indirectly asks the two companions about their needs in the midst of their suffering. Jesus appeared to them along the road while they were in deep conversation about all the events that had occurred surrounding Jesus’ death. Jesus inquired, “What are you discussing with each other while you walk along?” (Luke 24:17, NRSV) At first they stood still, looking sad. Then one of the companions describes in great detail the woes they were trying to sort through regarding Jesus’ recent death.

After asking them of their needs, Jesus then goes about addressing their needs by opening up their understanding of the Hebrew Scriptures in relation to his life so that they might know peace in the midst of their suffering. Then in his revelation to them as Jesus the Christ just a short while later he proved the scriptures to be true and granted them ultimate and eternal peace. The insight granted here is twofold. One, spiritual care providers must remember to assess the situations they encounter to understand the needs of the people with whom they are hoping to offer care. Once their needs are known, it is also important to tend to those needs in the way that best fulfills them. This insight affirms the findings in this study. The second insight relates to Jesus' use of the very scriptures the two companions were struggling to understand. Spiritual care providers would do well to consider the faith and religious traditions of dying persons and their caregivers which might serve as a resource to address their needs and alleviate suffering. Also, the Emmaus companions found incredible peace and joy learning the message of the resurrected Christ was true. Could this same knowledge bring peace and joy to those specifically of the Christian faith as they approach death? Certainly, one could broaden this insight to apply to other faiths and religions with which dying persons and their caregivers might associate. In these cases spiritual care providers could also explore how the resources of other faith traditions might serve as a strength and comfort to bring peace to persons facing their dying journeys.

I described earlier how the final step of Killen and de Beer's model of theological reflection involves putting one's insights into action. I can say with great certainty my involvement and reflections in this research study have already changed me and continue to transform me both as a person facing a terminal illness and as a spiritual care provider offering care to dying persons and their caregivers in Grey and Bruce Counties. This reflection process has encouraged me to recall an encounter with spiritual care in my post-diagnosis journey. In

2005 I was admitted to the Southampton hospital (where I serve as the day-chaplain) due to some side-effects related to my terminal illness. I was bed-bound in a private hospital room with strict orders to remain in a horizontal position and refrain as much as possible from moving my body. My condition required minimal nursing care and I was visited only occasionally by my tending nurse. My wife was working during the day and would visit in the evening as time allowed. Otherwise, most of the day I was alone with the side-effects of my disease and wondering what would happen with me. I admit I was afraid as the possibilities bounced back and forth in my mind. A knock came at my door and I was surprised to see the Roman Catholic priest from the community parish enter my room. He said he was in the hospital making his rounds and noticed my name on the hospital census list. He decided to drop in for a visit and see if there was anything he could do for me. Before he left he offered to say a prayer for me in my condition and I accepted his invitation. After he left I thought about the visit we shared. I appreciated that in his busy schedule he had made an effort to show up in my time of need and offer care, even if only for a couple of minutes. I may have been alone physically once again when he left my hospital room, but I no longer felt alone in the way I did before. God had remembered me. Through this priest's visit and care I was reminded that God was with me in my journey both in spirit and the people who made an effort to show up and offer support. Although I still had wonderings about my future, I was not as fearful as before. I had been reminded of what having a companion can mean for one's journey with illness and facing death. Although I did not consider it at the time, years later my reflections also encouraged me to consider how often I am the 'priest' entering into someone's journey and how important my showing up and offering care can be to the person.

Making an effort to show up is vitally important to the effectiveness of offering spiritual care. This belief has been a growing realization over the last few years of my life. This study and my reflections have encouraged and reminded me to consider again the crucial importance of showing up to offer care in someone's time of need. This becomes even more important during a person's dying journey because it is a new road all people will travel only once. Having a spiritual care companion come alongside people in their dying journey may be the very care they need to find the connection and support that will help to alleviate some of their suffering and know a good death. The care offered by spiritual care providers might be the reminder dying persons and their caregivers need to be encouraged that God or some personal sense of the divine has not forgotten them in their journey, but is very much with them. When spiritual care is offered well to dying persons and their caregivers, no one needs to feel alone in his or her dying journey. However, as obvious as it sounds to state it, a spiritual care provider first has to show up to be able to offer care. I have always believed in the importance of showing up to offer spiritual care to dying persons and their caregivers. Not only has this study heightened my awareness of its importance, but it has also heightened my sense of empathy in terms of what the experience of spiritual care can mean to those who receive it. I think I will forever carry with me the voices of this study's participants as I offer care, both those who were touched positively through the care of their spiritual care providers and those whose needs remained unmet as they wondered why their minister never made an effort to show up. These participants' voices will serve as reminders of the need to show up and meaningfully consider the care that is offered to dying persons and their caregivers.

This insight is a reminder and revelation I intend to share with spiritual care providers in Grey and Bruce Counties. When the two Emmaus companions came to new understandings of

their faith after their encounter with the risen Christ they journeyed back to Jerusalem to share it with their fellow believers. As they shared with their colleagues they all were inspired to work more effectively together for sake of Jesus' ministry not only continuing in the world, but growing in new and exciting ways. I hope the findings and reflections of this study will help spiritual care to dying persons and their caregivers grow in new and exciting ways so that end-of-life suffering is lessened and more people know what it means to die well. This study has affirmed many of the existing end-of-life spiritual care practices in Grey and Bruce Counties that are helping people to die well. Certainly there have also arisen from these reflections many new understandings that are also important to share with my spiritual care colleagues. I hope and pray these findings and new understandings will encourage my colleagues to consider the importance of coming alongside people and offering them meaningful spiritual care in their dying journey. The voices of some participants in this study shared of their frustration and disappointment when spiritual care providers did not make an effort to connect and provide support to persons on their dying journeys. Unfortunately in my travels around Grey and Bruce Counties I have personally heard other stories about spiritual care colleagues who made little or no effort to offer care to dying persons and their caregivers in their time of need. In these instances families commented on the great discouragement they experienced with their spiritual care providers. I have also heard stories of colleagues who made an effort to show up, but then offered spiritual care in a manner that essentially missed addressing the needs of the dying persons and their caregivers. The sharing of insights and findings from this study therefore becomes an important step to improve the provision of spiritual care to dying persons and their caregivers in this region. At the same time it is important to celebrate the strengths of spiritual care as experienced by dying persons and their caregivers in Grey and Bruce Counties. These

strengths need to be highlighted and encouraged to occur more regularly in the provision of spiritual care that is offered to persons in their dying journeys. Also, for those spiritual care providers who are already offering effective spiritual care to dying persons and their caregivers, they need to be encouraged to do more of the same.

It is my desire to implement these insights with one further action. Just as the Emmaus companions went back to share their new understandings with the people where their journey began, I plan to do the same in my journey. It is my intention to return to the various hospice service providers in Grey and Bruce Counties who originally granted me the privilege of introducing my research project to them when I was in search of study participants. They took a vested interest in what I proposed to do through my study. They agreed to support me in my research endeavour and they followed through on their promises. They were companions to me on this journey and shared a part of themselves as they utilized portions of their already limited work hours to help me achieve the goals of my study. One can only assume they made such an effort because they believed the topic of my research project was important enough that they would give a part of themselves to it. Also, their questions to me regarding my project appeared to indicate a curiosity and interest in how spiritual care might be a part of the end-of-life hospice services they offer. Perhaps they too reflected, “Could spiritual care be a part of our services to help people die well?” The voices of this study indicate “yes”. Indeed, I have heard through various contacts in the region how the work of this research study has kept the idea of end-of-life spiritual care on the radars of these hospice services providers. Therefore I will return to encourage them with the voices of this study to consider further how spiritual care might be implemented more formally into their holistic programs of care. Then as they come alongside people in their dying journeys one can hope and pray the inclusion of spiritual care will move

dying persons and their caregivers a little further along the road to dying well and having a good death in Grey and Bruce Counties.

Concluding Thoughts

“Every ending is a new beginning. Through the grace of God we can always start again.”
- Marianne Williamson in *Everyday Grace*

A research project involving end-of-life spiritual care compels a researcher to engage in a journey of discovery that ironically can lead to as many new understandings about life as it does about death. This observation is appropriate for this study because a good death is much more than a single event that occurs when a person breathes their last breath. A good death consists of the journey a dying person takes while still living and is filled with all kinds of activities and experiences that help a person to die well. A good death also involves a dying journey that is often full of people from all walks of life who enter into the life of the dying person. These people are the family, friends, loved ones, doctors, healthcare workers, hospice volunteers, and spiritual care providers who share their love and care as they travel with a person in the face of dying and death. These are the people who also tend to the many emotional, physical, psychological, mental and spiritual needs a person may have when dying. Their care, when offered effectively, not only has the ability to address a dying person’s needs, but can also help them to know a good death.

Spiritual care providers can be a significant part of dying persons and their caregivers experiencing a good death. When faced with the prospect of dying, many people experience a heightened need for spiritual care to help them address serious end-of-life issues and needs of the dying journey. In these cases, the importance of spiritual care providers showing up to offer care cannot be stated strongly enough because it is then that dying persons can feel connected and supported in the ways they need during their journey. When this occurs, these dying persons may then also experience a plethora of personal inner resources such as strength, comfort, hope and peace of mind that will help them on their dying journey. When spiritual care providers are

able to reach out and touch the lives of dying persons and their caregivers with gentle compassion, lives will be affected in positive and meaningful ways. It is also important for spiritual care providers to remember they will be touched in the process too as they walk on the sacred ground of a dying person's journey. As spiritual care providers, it is difficult for us to embrace a life and hold the hand of another person without being touched ourselves.

In this way I am reminded of a story I will offer as a final thought. I once received a call in the middle of the night from a family member of a ninety-four year old parishioner named Margaret (name changed to ensure confidentiality). She had not been feeling well and earlier in the week was taken into the hospital. I had visited with her and some family members a couple times in the hospital throughout the week. The phone call now was to inform me that Margaret had taken a turn for the worse and was wondering if I could visit. I made my way to the hospital and visited with Margaret and her family. When it appeared as though there was nothing more to say, I sat down beside Margaret's bedside and simply held her hand. Frail and feeble, it looked as though Margaret used what little bit of energy she had left to say, "Thank you, Pastor, for being here. It means a lot to me and my family." As I continued to hold Margaret's aged hand she shared a few more words with her family who was gathered there. It was not long after that Margaret died.

Margaret's words "it means a lot to me and my family" have stuck with me all these years. Whenever I wonder if the spiritual care I offer people in their dying journey is making a difference, I recall Margaret's words. The spiritual care I offered her and her family meant something to her. Indeed, a few days later at Margaret's funeral her son approached me to thank me for the care I offered Margaret and the family during her dying journey. He commented that what I did indeed helped and touched them in a special way. I too was touched that they had

invited me into that incredibly intimate and sensitive time of their lives to help them along in their journey.

Can end-of-life spiritual care help people to die well? The answer is a definite “yes!” Margaret and her family’s voice attest to this and more significantly the nineteen voices of the participants in this research study also strongly affirm it. When offered well, spiritual care can have an incredibly positive impact on the experiences of dying persons and their caregivers and it is a truly sacred road spiritual care providers travel with them on their dying journey. We can be encouraged that effective spiritual care is an aid to dying persons and their caregivers experiencing a good death.

Appendix A – Research Interview Questions

1. How did you come to know about the hospice palliative care services you are receiving?
2. Please describe what you understand spiritual care to be.
3. How have you experienced this spiritual care?
4. How has the spiritual care you have received helped you in your journey?
5. Has the spiritual care you have received been lacking in any way? Please describe.
6. When thinking about spiritual care, what else might be done or improved to help you at this time in your life?
7. How do you think spiritual care might help a dying person in the time before they die?
8. How do you think spiritual care providers (e.g. ministers, churches, etc.) in our area might help people when they are dying?
9. Do you think the care you are receiving is different because you live in Grey and Bruce Counties compared to someone living in a big city like Toronto, for example? Please describe.
10. What do the phrases ‘dying well’ and ‘a good death’ mean to you?
11. What are the things you think would help people the most when they are dying?
12. Is there anything else you would like to share?

Appendix B – Informed Consent Statement

WILFRID LAURIER UNIVERSITY **INFORMED CONSENT STATEMENT**

“Comfort, O Comfort My People”: A Qualitative Study Examining Dying Persons’ and their Caregivers’ Experience of Spiritual Care as an Aid to Having a Good Death in Grey and Bruce Counties, Ontario.

Researcher/Investigator: Dwight Biggs - Doctor of Ministry Candidate at Waterloo Lutheran Seminary, Wilfrid Laurier University

Advisor: Dr. Kristine Lund, Waterloo Lutheran Seminary, Wilfrid Laurier University, 519-884-0710 x2246, klund@wlu.ca

You are invited to participate in a research study. The purpose of this study is to ask you about the spiritual care you have received in relation to the hospice palliative care program from which you are receiving care in Grey and Bruce Counties.

INFORMATION

Persons are invited into this study because they have a current association with a hospice program in Grey or Bruce Counties and are approaching the end stages of their illness. Other participants are the primary caregivers to persons in the end stages of their illnesses. As a study participant you will participate in a one-time interview with the researcher in which you will be asked open-ended questions. These questions will cover topics related to the spiritual care you have received in relation to the hospice palliative care program, what you see as strengths in this care, where there are weaknesses, and how this care might be improved in areas where there are concerns. It is anticipated the interview will take approximately 1 hour, depending upon the amount of conversation shared during the process, to a maximum of two hours. A maximum of 10 participants who are in the end-stages of life will participate in this study and a maximum of 15 primary caregivers to these persons will make up the other portion of study participants.

The researcher wishes to audio-record interviews to transcribe them personally at a later time for research purposes only. All audio-recordings will be deleted permanently following transcription. If you do not wish to have the interview audio-recorded you may still participate in the interview process. At the end of this form the researcher will ask if you would like to give your written permission to have the interview audio-recorded. In cases where audio-recording and transcription have occurred, a spiritual palliative care provider named Donna Mann in a neighboring county will review these transcriptions to validate themes noted in the interview by the researcher. All identifying information will be removed to protect participants’ identities. At the conclusion of the researcher’s study project all transcribed reports of the interviews will be securely stored in a locked cabinet at the researcher’s office. These transcriptions will not be used for any additional purposes without your permission.

RISKS

Dying can be an extremely emotional, sensitive and intimate time in the life of those who are terminally ill as well as their primary caregivers. With this in mind the interview process of this study may elicit conversation regarding spiritual concerns that need to be addressed further following the interview. The researcher will not engage you in areas of conversation in which you do not wish to participate and you are welcome to decline answering a question if you wish to do so. If personal concerns arise during the interview that need further care, the researcher will contact for you a competent spiritual care provider to help you with your needs. If you have a personal spiritual care provider with whom you already have a connection and who you would like to assist you, the researcher would be willing to contact that person for you. Further, physical considerations of your illness may limit your ability to continue or finish an interview. If this occurs, you are welcome to conclude the interview at any time. If a primary caregiver is present, he or she may continue the interview in your presence if desired.

BENEFITS

This study is hoping to explore the spiritual care offered to dying persons and their primary caregivers and consider ways in which this current system of care might be improved. By participating in this study and sharing of your current experience, you will help to affirm any strengths of the system that are already in place and offer encouragement to areas of concern that you believe could be improved. As the results of these findings are translated into recommendations to the hospice palliative care programs and providers in Grey and Bruce Counties, your participation in this study could benefit dying persons, their families and caregivers in the future by providing more effective spiritual care to others in their journeys. What is more, as we consider and improve the spiritual care that is offered in relation to hospice palliative care in Grey and Bruce Counties, the whole system of care will be better through this process.

CONFIDENTIALITY

During this study process the researcher will keep strict confidences of all data pertaining to the participants. Participants' names will be audio recorded with the data, but participants' names will not be included on the interview transcriptions that are being kept indefinitely. Once audio recordings have been transcribed, these recordings will be deleted permanently. As previously noted, all transcriptions will be stored in a secure locked cabinet at the researcher's office at the conclusion of this research project. A spiritual palliative care provider named Donna Mann in a neighboring county will review the transcriptions to assess the validity of any themes the researcher notes in the data, however, these transcriptions will have been made anonymous of any identifying markers of personal data from participants. Results from this research will be used in the researcher's doctoral thesis project at Wilfrid Laurier University and a summary article in *The Canada Lutheran* magazine at the request of the researcher's affiliated faith organization. Articles may also be submitted to academic journals for publication. Quotations of your material may be used in reference to these, however, if you wish for this not to occur, you may still participate in the study. In all these cases, your identity will remain anonymous unless requested otherwise.

CONTACT

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study) you may contact the researcher, Dwight Biggs, at 525 Ivings Dr. Port Elgin, ON, N0H 2C1, and 519-832-6811. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Robert Basso, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-1970, extension 5225 or rbasso@wlu.ca

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study, every attempt will be made to remove your data from the study, and have it destroyed. You have the right to omit any question(s)/procedure(s) you choose.

FEEDBACK AND PUBLICATION

The results of this research project will be written up in a doctoral thesis for defense at Waterloo Lutheran Seminary, Wilfrid Laurier University. As previously noted, a summary article will also be written for *The Canada Lutheran* magazine; articles may also be submitted to other academic journals for publication. A written summary of the research findings and recommendations will also be provided to the hospice palliative care organizations with whom the researcher has been communicating to organize this study. These organizations include: VON Hospice Grey-Bruce, Grey-Bruce Hospice, CCAC Grey-Bruce, Bruce Peninsula Hospice, and Dr. Hillary Huff - palliative care physician Grey-Bruce. This research may also be used for future teaching purposes.

Would you like to receive a summary report of the research findings at the conclusion of the study? _____ If 'yes', please provide the researcher with the necessary information to get this report to you.

AUDIO RECORDING

Please sign below if you would like to give the researcher permission to audio-record your interview.

Participant's signature _____ Date _____

QUOTATIONS

Please sign below if you would like to give the researcher permission to use quotations from your interview.

Participant's signature _____ Date _____

CONSENT

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature _____ Date _____

Investigator's signature _____ Date _____

Appendix C – Letter of Introduction

Re: Research Study - “Comfort, O Comfort My People”: A Qualitative Study Examining Dying Persons’ and their Caregivers’ Experience of Spiritual Care as an Aid to Having a Good Death in Grey and Bruce Counties, Ontario.

Dear Sir or Madame,

Greetings. My name is Dwight Biggs and I am a doctoral student at Wilfrid Laurier University, residing near Port Elgin in Bruce County. I have received ethics approval from the CCAC, the university, and the GBHS and SBGHC hospitals to conduct a study in Grey and Bruce Counties that explores the spiritual care dying persons and their primary caregivers receive in connection with the hospice palliative care programs in our region. I have been working with various hospice organizations and hospitals to find potential participants for my research study. You have been identified as a potential participant.

In particular, the study hopes to explore the experiences of participants in relation to the spiritual care they have received during this important time in their lives. This study would like to dig a little further into themes that consider how spiritual care has helped participants at this time in their lives, what do participants see as the strengths of the spiritual care that has been offered, where have there been weaknesses or gaps in the system, and what might we do to improve the spiritual care that is offered to help people at this time in their journeys? The sharing of your experiences in this regard may assist and prove beneficial to the effectiveness of the spiritual care that is offered to dying persons in our area.

I would meet with you to have an interview that would last about ½ hour, depending upon how much conversation we share during that time, to a maximum of two hours. At that meeting, before the interview occurs, I would explain to you how all information you share will be held confidentially, how the information would be used in my research, where it might be published, how it might be used to improve end-of-life care in Grey and Bruce Counties, and answer any other questions you might have related to the process.

Thank you for your consideration of participating in this research study. I will contact you shortly as your name has been referred to me. In the meantime, if you have questions you would like answered please contact me at 519-832-6811 or by e-mail mndbiggs@hotmail.com

Sincerely,

Dwight Biggs

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