

**Family caregiver experiences: A case study of caregiving for an advanced cancer
patient enrolled in a palliative rehabilitation program**

Shauna Daly

A thesis submitted to the Faculty of Graduate and Postdoctoral Studies
in partial fulfillment of the requirements for the degree of
Master's of Arts in Education, Counselling Psychology

Faculty of Education

University of Ottawa

Abstract

This study employed a case study research design to explore how family caregivers experience caring for an advanced cancer patient enrolled in a palliative rehabilitation program. Demographic, case note, pre-post quality of life scores, and interview data sets were collected from four family caregivers throughout patient enrollment in the 8-week Ottawa Palliative Rehabilitation Program. Thematic analysis of the interview data revealed caregivers' perceived caregiving as: 1) Being a Witness of the Patient's Struggles, 2) A Duty Paired with a Desire to Support Patients - Regardless of the Challenges, and 3) A Role Which Requires Tailored Knowledge, Support, and Resources to Aid in Improving Patient Functioning and in Managing Caregiving Tasks. Involving family caregivers in palliative rehabilitation programs provides them an opportunity to engage with the patient and health care professionals in order to develop a shared understanding of the illness implications, learn tailored caregiving approaches, and gain social support.

Keywords: family caregivers, quality of life, palliative rehabilitation, cancer rehabilitation

Acknowledgements

This study would not have been possible without the unique insight, support, and encouragement of many individuals. First, I would like to thank the incredible family caregivers who took the time to share their inspiring experiences with me. Their keenness to contribute to this research so that other caregivers may benefit is a truly selfless act which I can only repay by ensuring this knowledge is shared.

Thank you also, to Dr. Martin Chasen and the Palliative Rehabilitation Team, for welcoming my research with open arms. To my interprofessional Palliative Care Research Team at the Bruyère Research Institute, thank you for teaching me the delicate combination of academic research and compassionate care which provided me the skill and courage to take on this Master's thesis.

I am grateful as well to my outstanding thesis committee members, Drs. Nick Gazzola, Katherine Moreau, and Tara Tucker for their specialized insight and guidance throughout this academic journey. Thank you to my supervisor, Dr. Andre Samson, for the many evening meetings and encouragement to achieve this accomplishment.

Especially, I would like to thank my family. All of you make me who I am. Your unconditional love and support throughout this project and throughout my life is something I will always have and cherish. Finally, to Tyler, my Fiancé, thank you for still wanting to marry me even after the ups and downs throughout this academic adventure and for the late night brainstorming, reviewing, and presentation practice sessions. Without this thesis, I may never have known just how far you would go to help me reach my goals, so here is to us and the many more challenges we choose to face together!

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Chapter 1: Introduction

Palliative Care Rehabilitation and Past Studies

Palliative care is defined as an approach to caring for individuals with a life threatening, incurable illness, by focusing on their quality of life and quality of death through addressing their mental, physical, social and spiritual wellbeing (Pallium Canada, 2011). For over 50 years, palliative care services have spread into the health care system from hospitals, to hospices, to home care (Buck, 2011). The rapid growth of curative and palliative cancer treatment programs have contributed to the palliative care movement (Clark, 1998).

With cancer being the leading cause of death in Canada (Public Health Agency of Canada, 2012), and its treatments having a large impact on patient functioning (Chasen & Bhargava, 2009; Metri, Bhargav, Chowdhury, & Koka, 2014), the need to support the functioning and wellbeing of terminal cancer patients while they live with the illness has arose. Recently, specialized rehabilitation programs have been designed to support these terminally ill patients, and research findings have shown positive improvements in various aspects of patient functioning and wellbeing (Chasen, Feldstain, Gravelle, MacDonald, & Pereira, 2013; Jensen, Baumann, Stein, Bloch, et al., 2014; Jones, Fitzgerald, Leurent, Round, et al., 2013). Such interventions are able to support patients in regaining aspects of their functioning abilities which had been effected by treatment, in turn improving patient quality of life, in line with the philosophy of palliative care. The philosophy of palliative care not only aims to support patient wellbeing, but also the wellbeing of the family members (Saunders, 2000), through treating the patient and family as the unit of care via a family centered care approach (Kuo, Houtrow, Arango, Kuhlthau, Simmons, & Neff, 2012).

Family Caregivers within the Terminal Cancer Context

Over the course of an individual's illness, a relative, partner, friend or any other individual who has a close relationship with a patient, often assumes the role of a family caregiver, providing daily support for the patient (Blum & Sherman, 2010). More and more, family caregivers are supporting patients within the home. Research has highlighted that it is common for individuals to have a desire to be cared for and die at home (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013). Further research has identified that family caregivers would like to meet patient desires to be cared for at home, but may feel pressured and unprepared to do so (Woodman, Baillie, & Sivell, 2015). Not only may caregivers feel pressured to care for the patient at home, in line with patients' desires, but recent transitions in health care policies encourage home care due to large cost differences between home and hospital care (Ministry of Health and Long Term Care, 2014).

In accepting and taking on a primary caregiver role, research has found that family caregivers often experience negative implications on their quality of life (Weitzner, McMillan, & Jacobsen, 1999). Interventions aimed to educate caregivers on both patient care and self-care techniques have been found to improve various aspects of caregivers' wellbeing (Harding, List, Epiphaniou, & Jones, 2012). As supporting both patient and caregiver quality of life needs is the objective of palliative care (World Health Organization, 2013), it was the aim of this current study to add family caregiver perspectives to the literature examining palliative rehabilitation programs. Specifically, the Ottawa Palliative Rehabilitation Program has found positive improvements in patient functioning as a result of enrollment in the program; thus this study focused on exploring the perceived experiences of family caregivers caring for an advanced cancer patient enrolled in the palliative rehabilitation program.

Current Study

The aim of the present study was two-fold. First, it aimed to develop an understanding of the experiences of family caregivers who are caring for a palliative cancer patient. Second, it explored caregiver quality of life and any changes that may have occurred in their Caregiver Quality of Life – Cancer (CQOL-C) Index (Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999) scores while their loved one was enrolled in a palliative rehabilitation program.

The context of this current study is the Ottawa Palliative Rehabilitation Program which is an out-patient program personalized for palliative, advanced cancer patients, to assist them in improving their functioning, symptom management and quality of life with the support of an interprofessional healthcare team over an 8-week enrollment period (Chasen, Feldstain, Gravelle, MacDonald, & Pereira, 2013). Thus far, the Palliative Rehabilitation Program has focused its research endeavours on patient functioning and wellbeing as a result of participating in the program, finding significant improvements (Chasen, Feldstain, Gravelle, MacDonald, & Pereira, 2013). Throughout patient enrollment in the program, the care team invites patients' family caregivers to be involved in the meetings and engage in the session as much as desired. The Ottawa Palliative Rehabilitation Program's team has not yet explored the experiences of family caregivers caring for patients enrolled in the program, thus the present study may offer some insight into caregiver perceptions of caring for a patient enrolled in a palliative rehabilitation program.

The presentation of this study has been divided into five chapters. The current chapter introduces the topic of palliative care, cancer, and rehabilitation, as well as the area of family caregiving, briefly highlighting the importance of family caregiver experiences throughout patient care, and situates the current study in relation to the literature. The second chapter, is

designated to the literature review, which contains several sections that (a) explore the literature on palliative care and cancer, (b) review research regarding rehabilitation programs in cancer and terminal care, (c) highlight the role of family caregivers in patient care and the implications of caregiving, (d) emphasize successful methods of supporting caregiver needs, (g) summarize the area of research focus, and finally, (h) present the current study's research questions. The third chapter is focused on the methodology of the study. Specifically, describing the case study research design, the various data sources, data collection methods, and data analysis approaches. The study context, participants and procedures, as well as the credibility, dependability, and transferability of results are also presented within this chapter. The fourth chapter lists the results of the study and displays verbatim examples from the participants within case reports which depict the unique caregiver contexts, followed by cross case comparisons. Finally, the fifth chapter presents a brief summary of the study's main results and provides a discussion of the results as related to family caregiver literature. The chapter concludes with the study's implications, limitations and recommendations for future research, followed by an overall conclusion of the study.

Chapter 2: Review of the Literature

This review will present various approaches aimed to improve patient and family caregiver quality of life within the contexts of palliative cancer. Family caregivers, referred to throughout this thesis, are defined as a relative, partner, friend or any other individual who has a close relationship with a patient whom they provide a variety of support for (Blum & Sherman, 2010). Within this chapter I will first describe the field of palliative care and the connections cancer has within the palliative care realm. This section will further highlight the need for interdisciplinary care approaches, which are rooted deeply in the palliative care philosophy of providing

individualized care to support the quality of life needs of both terminally ill patients and their families. The role of rehabilitation care in improving palliative patients' comfort and functioning abilities impacted from their illnesses and treatments will also be reviewed. Second, I will review the applicability of cancer survivorship rehabilitation programs and their alignment with the quality of life needs of palliative cancer patients. The development of an interdisciplinary palliative cancer rehabilitation program will be highlighted. Third, I will situate family caregivers in the palliative and advanced cancer context, identifying the need for their involvement in patient care. Transitional models regarding taking on the caregiving role and the implications caregiving can have on family caregivers will also be identified throughout this chapter. I will also review interventions which have successfully improved caregiver quality of life. Finally, within this literature review I will highlight the importance of including both the patient and family caregiver as the unit of care to address both patients' and caregivers' experiences.

What is Palliative Care?

Palliative care is an approach to caring for individuals with a life threatening, incurable illness, and their families, through focusing on their quality of life and quality of death by addressing their psychological, physical, social and spiritual needs (Pallium Canada, 2011). Since its rise in the 1960s, palliative care services have continuously spread into hospitals, community hospice settings, and in-home palliative specialist visits (Buck, 2011).

Cicely Saunders began the hospice palliative care movement through working with patients diagnosed with terminal cancer, and thus cancer contributed to the growth of the palliative care movement (Clark, 1998). As cancer diagnosis and treatment approaches can differ for patients, the implications on their wellbeing can vary, which may require the support of different

professionals. As such, hospice palliative care models were designed using an interdisciplinary team approach in order to support the varying and holistic needs of patients and their families in order to improve their quality of life experiences (WHO, 2013). Such holistic approaches require the involvement of interdisciplinary professionals to support the unique needs that each patient and family may experience. Interprofessional teams often include medical professionals such as physicians and nurses, in collaboration with physical and nutritional rehabilitation specialists, as well as psychosocial specialists (Krouse, 2008). Research has found that the efforts of palliative care teams contribute to significant improvements of cancer patient symptom control as well as improvements in patient and family caregiver quality of life (Higginson & Evans, 2010). Saunders (2000) highlights in her approach to palliative care that it is necessary to view both the patients and their families as the unit of care as both parties have unique and important experiences throughout end-of-life care that interprofessional teams have the capacity to support.

Recent practice theories have overlapped the domains of curative care, palliative care and rehabilitation care, in order to implement interdisciplinary supports to address the implications and discomforts resulting from illness and treatment (Barawid, Covarrubias, Tribuzio, & Liao, 2015). Early research regarding the integration of rehabilitation care to cancer care began within the curative cancer care realm in an effort to address the functioning challenges patients experienced as a result of their illnesses and treatments (Kjaer, Johansen, Ibfelt, Christensen, Rottmann, et al., 2011; Korstjens, Mesters, van der Peet, Gijzen and van den Borne, 2006). In the next section of the review I will delve into the research on cancer rehabilitation programs and the effectiveness for this curative cancer population, which we will later see is also necessary for cancer patients who are diagnosis as terminally ill.

Cancer Survivorship Rehabilitation Programs

The integration of rehabilitation programs into cancer care first began with efforts to improve the functioning and quality of life of cancer survivors who were cured of the disease but were experiencing implications from the illness and treatments. Within this section of the chapter, I will first identify the need for such cancer rehabilitation programs for cancer survivors. Second, I will review sample rehabilitation programs, describing both the program and the research results regarding the impact of such programs. Third and finally, within this section I will highlight the relevance of such rehabilitation programs for all individuals who battle cancer, even in advanced terminal cancer cases.

It is estimated that almost half of Canadians will develop cancer in their lives and that there is an estimated 63% chance of surviving at least 5 years after recipient of a cancer diagnosis (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015). For those who have battled cancer, there are often many side effects of cancer treatment such as fatigue, nutrition challenges and decreased functioning abilities (Chasen & Bhargava, 2009; Metri, Bhargav, Chowdhury, & Koka, 2014). Research has found that cancer rehabilitation programs can be an effective approach to reducing post treatment side effects and improving the quality of life of cancer patients (Kjaer, et al., 2011; Korstjens, et al., 2006).

In particular, research has found that physical rehabilitation approaches can support patients in improving their physical functioning abilities, which had been impacted from the illness and treatments. For instance, a high intensity resistance training program which involved, physical exercises for various muscles in the arm, leg, and chest areas, along with interval training for the heart and lungs, was utilized as a rehabilitation intervention for cancer patients. Research on this program included 22 cancer patients who participated in the 18 week

intervention at least 6 weeks after completing their chemotherapy treatment (De Backer, Vreugdenhil, Nijziel, Kester, van Breda, & Schep, 2008). The researchers collected data at the beginning and end of the program as well as 68 weeks after the intervention. Significant improvements (<0.01) were found not only at the end of the 18 week program but also at the 68 week follow-up in areas of patients' muscle strength, cardiopulmonary assessments, fatigue levels, and overall health related quality of life scores. The researchers concluded that these results suggest such physical rehabilitation may be a key component in supporting the improved functioning and quality of life of individuals who have completed their cancer treatment.

Similarly, Korstjens and colleagues (2006) examined the QoL of cancer survivors at three points throughout a 12 week cancer rehabilitation program focused on physical and psychosocial rehabilitation. The program provided physical training and psychoeducation for patients and close family members. All sessions were led by an interprofessional health care team that included a rehabilitation specialist, nurse, dietary advisor, social worker, and psychologist. The participants were invited to complete the 30 item European Organization for Research and Treatment of Cancer Quality of Life (EORTC QoL) questionnaire at intake, half way through the program and at the completion of the program. The EORTC QoL has been identified as a reliable and valid tool which measures global quality of life, as well as physical, emotional, cognitive, social, and life role (i.e. family member) functioning. Baseline measures from intake included 658 participants, halfway (6 week) measures included 634 participants and program completion measures included 579 participants. Multiple linear regression analysis results identified that at the six week assessment, participants experienced significant changes which continued to progress at the 12 week follow-up (<0.001). Specifically, quality of life scores improved (63.0 to 71.9), as well as emotional (66.2 to 74.4), role (<0.001), physical (67.3 to 80.4), and cognitive

(70.5 to 74.4) functioning, while fatigue scores decreased (49.8 to 41.8). This study identified that such a cancer rehabilitation program may have the capacity to significantly change and improve the quality of life of its patients.

These research studies have shed light on the important role rehabilitation programs may play in lives of patients after cancer treatment has ended. In recognizing the negative implications of cancer and its treatments can have on all cancer patients' functioning abilities, whether curative or palliative, the terminal advanced cancer care areas have been called to explore how such rehabilitation programs can impact terminal advanced cancer patients' functioning, comfort, and quality of life (Santiago-Palma & Payne, 2001). A review by Okamura (2011) highlighted the importance of including rehabilitation care in cancer treatment and palliative medicine to support patient and family hopes around improving and maintaining patient functioning, independence, and quality of life, again in line with the curative cancer philosophies. Recent work has been initiated to implement such cancer survivorship rehabilitation programs into the palliative cancer context. It has also been have found that these approaches align with the palliative care philosophy.

Palliative Cancer Rehabilitation

Within this section of the literature review, I will first identify how rehabilitation programs align with the goals of palliative care and how they can effectively be implemented. Second, I will examine various forms of rehabilitation approaches which have been implemented into advanced, terminal cancer contexts and the impact that patients experienced as a result of them. Finally, this section will identify the important role of providing individualized, holistic care in order to support the variety of needs that advanced terminal patients may experience. More

specifically I will highlight the Ottawa Palliative Rehabilitation Program, which is central to the current study.

Rehabilitation within the terminal care context can be described as a secondary prevention approach, which focuses on preventing further functional decline (Kanach, Brown, & Campbell, 2014). Often these rehabilitation programs incorporate interprofessional team members who meet with patients one-on-one for initial assessment, identify therapeutic activities to support the individual, and set goals. Further, the programs then incorporate the necessary supports and interventions to move towards meeting the outcome goals. Then once the program is complete, they provide ongoing supportive resources, whether internal or community based, to support the patient in maintaining the life style changes for as long as possible (Kanach, et al., 2014). The individualized approach of these rehabilitation programs aligns with the palliative care philosophy in providing patients and their family members with support to improve their quality of life in end-of-life experiences (Saunders, 2000). As each individual patient and family member may have differing experiences and needs during their care, it is necessary for rehabilitation programs to take a holist approach in order to assess and address the varying needs.

It is important to keep in mind that cancer is the leading cause of death in Canada (Public Health Agency of Canada, 2012). Further, it is expected that 1 in 4 Canadians will die of cancer (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015). Often medical professionals attempt to predict the amount of time terminal cancer patients may have to life, despite the challenges that can arise in doing so, in order to attempt to effectively assess how palliative care resources can support the quality of life of patients and their families (Llobera, Esteva, Rifa, Benito, Terrasa, et al., 2000). As cancer patients as a whole often experience physical functioning and quality of life limitations as a result of their illness and treatment, many

physical rehabilitation specialist see their physical rehabilitation role as an important aspect of providing quality end-of-life care when patients have a desire to maintain or regain some of these functioning abilities (Wilson, Stiller, Doherty, & Thompson, 2015). Similarly, meeting these desires and hopes of patients, and their families, aligns with the overarching philosophy of palliative care to bringing patients to a place of comfort and improved quality of life experiences (Saunders, 2000). Some of the recent rehabilitation work which has been implemented into palliative cancer care have primarily focused on the impact of physical rehabilitation supports.

As a starting point, a 2010 single sample case study was conducted to examine the impact rehabilitation in end-of-life cancer care may have on patient experiences of quality of life (Kasven-Gonzalez, Souverain, & Miale, 2010). The advanced cancer diagnosis and treatment for this patient resulted in significant implications in her physical functioning abilities. The rehabilitation intervention included an assessment of patient functioning abilities and discussions around patient goals of functioning. Over four weeks, an occupational therapist and physical therapist focused the intervention on moving the patient towards regaining some physical functioning abilities that she expressed she wanted to regain, including sitting up and standing up. The team was able to achieve these goals with the patient and both she and her family expressed gratitude towards the team for their work with her prior to her discharge from the program based on her end-of-life functioning declines just a few days before she died. This case highlighted that it was important to the patient to try to regain some of her functioning abilities within her last few months of life, and perhaps that it may be important to others (Kasven-Gonzalez, Souverain, & Miale, 2010).

A quantitative study took the research in this area further by conducting a randomized control trial to examine the difference between advanced cancer patients who were treated with

the usual care and advanced cancer patients who enrolled in a hospice day-care rehabilitation intervention (Jones, Fitzgerald, Leurent, Round, et al., 2013). Usual care included check-ins with oncologists and access to community health services. The rehabilitation intervention incorporated individualized clinical assessments, goal setting, and tailored rehabilitation support from an interprofessional health team made up of nutritional, physical, energy/spiritual, and psychosocial supports. Baseline and three month follow-up data was collected from 20 participants in the intervention group and 16 in the control group. The researchers utilized a variety of measures to explore the varying experiences of these group, including the level of need patients experienced in the last month, psychological experiences, feelings of continuity of care, and their health related quality of life. Results identified a significant reduction in patient experiences of unmet needs within the psychological domain ($P=0.006$), physical and daily living ($P=0.022$), and patient care and support ($P=0.022$). A significant increase was also found in patient reports of the EuroQoL-Visual Analogue Scale which asks patients to rate their health status from 0-100 with 100 being the best possible health state ($P=0.010$).

Another recent study examined the quality of life, daily living physical functioning, and physical performance of advanced, terminal cancer patients randomly assigned to either a resistance exercise training or an aerobic exercise training (Jensen, Baumann, Stein, Bloch, et al., 2014). While undergoing palliative chemotherapy treatment, 11 patients participated in the aerobic training while 10 participated in the resistance training for a 12 week duration. The researchers utilized the European Organization for Research and Treatment of Cancer (EORTC-QLQC30-version 3) to measure the various physical, psychological, and social aspects of patient quality of life, and patients wore a SenseWear® Wristband to assess physical activity day-to-day. Significant improvements occurred for both test groups in scores of fatigue ($P=0.003$) and

sleeping duration ($P=0.028$). Muscular strength increased in the RET group, while experiences of functioning in their day-to-day role significantly increased ($P=0.045$) for AET as well as patient's over all feeling of their health status ($P=0.039$). Further, the research identified that a higher number of steps taken in day-to-day living was associated with higher levels of physical ($r=0.51$) and social ($r=0.56$) functioning, along with lower pain ($r=-0.53$) and fatigue ($r=-0.54$) scores. These results suggest that interventions which include a physical therapy aspect may improve daily patient functioning. Another research team had taken a holistic approach to developing their advancer cancer rehabilitation program (Chasen, Feldstain, Gravelle, MacDonald, & Pereira, 2013).

With these studies showing positive results of such rehabilitation programs in the palliative cancer care field, further research has been encouraged in order to continue to inform oncology practitioners of the important role they play for patients as research has found that very few oncologists tend to refer palliative cancer patients for rehabilitation support. To elaborate, a 2012 study found that of 395 oncologists and rehabilitation physicians surveyed, only 8% of oncologists stated that they would refer an advanced terminal cancer patient for rehabilitation support, while 35% of rehabilitation physicians identified they would accept these terminal cancer patients into a rehabilitation service (Spill, Hlubocky, & Daugherty, 2012). The interprofessional collaboration of various medical professions is deeply rooted in palliative care in order to create the capacity to support the holistic, and individualized care needs of palliative patients and their families (Saunders, 2000). Thus it is necessary to build collaboration between the oncology clinicians and rehabilitation supports in order to facilitate the holistic palliative rehabilitation care to support then unique needs of this terminal cancer population. An Ottawa

based palliative cancer rehabilitation program, was developed to do just this, with its lead clinician being an oncologist and palliative care specialist (Chasen, et al., 2013).

The Ottawa Palliative Rehabilitation Program. This Ottawa Palliative Rehabilitation Program (Chasen, et al., 2013) is the context in which the current study takes place. The program was designed specifically for individuals who have completed cancer treatment, have been diagnosed as palliative, and are experiencing symptoms that impeded their everyday functioning, such as fatigue, weight loss, anxiety, weakness or pain due to their illness or treatments. In order to address these holistic needs of patients, the rehabilitation program is made up of an interprofessional team. This team includes a physician, nurse, nutritionist, occupational therapists, physiotherapist, and social worker. When a patient is enrolled in the program, they first attend a one-on-one assessment session with each individual health care professional to explore his/her experiences and needs within the given area. It is at this point that the patient and the provider develop and set goals to address his/her individual needs. Over 8-weeks, patients engage in weekly one-on-one appointments with members of the interprofessional care team based on the needs presented. Participants are invited to attend sessions either once a week or twice a week. As the form of cancer diagnosis, treatment type and implications, and experience of each patient can differ, each patient's participation in the program is unique. Throughout patient participation in the program, family caregivers are invited to observe the rehabilitation sessions, partake in the educational and experiential conversations that take place with the patient and providers, and hold individual meetings with the care providers for any personal needs they may have.

Preliminary Research regarding the Ottawa Palliative Rehabilitation Program has taken place (Chasen, et al., 2013). The program received 173 referrals of which 67 motivated and

medically stable patients were eligible, consented to participate in the program as well as the study components. Eligibility criteria also included an age of over 18, a score of 3 or more on the Eastern Cooperative Oncology Group Performance Status (ECOGPS) or more than 50% on a Palliative Performance Scale. As part of the program, all participants completed an initial 3 hour assessment, spending 30 minutes with each of the health care providers including, a physician, physiotherapist, dietitian, occupational therapist, social worker and nurse who collected baseline data (Chasen, et al., 2013).

A number of self-report questionnaires regarding patient symptoms, fatigue and nutrition, along with clinical, physiotherapy and laboratory assessments were examined pre- and post-program using SPSS software (Chasen, et al., 2013). Numerous assessments were found to have moderate to large effect sizes showing positive increases in physical performance ($p < 0.000$), symptom interference with functioning ($p = 0.003$ to 0.001), nutrition ($p = 0.001$), fatigue ($p = 0.001$), anxiety ($p=0.004$) and depression ($p=0.005$). Small to moderate effect sizes were also identified in appetite, nausea, shortness of breath, decreased motivation, pain, and walking. Patient assessments of the program resulted in 70%-100% satisfaction and complaints revolved around parking concerns and desire for follow-up at the program site although follow-ups in the community were referred (Chasen, et al., 2013).

Taken together, this quantitative study provided a large amount of data that highlighted the positive effects patients enrolled in the Ottawa Palliative Rehabilitation Program (Chasen, et al., 2013) experienced. Specifically, significant changes on measures of physical and mental health functioning pre and post their involvement in the program. An aspect this study did not take into account was the perspective of the family caregivers who may have been able to provide further detail and feedback regarding the potential functioning changes that occurred for patients in day-

to-day life. Further, as the program was designed within a palliative care philosophy – to attend to the quality of life of both patients and family members – it was important for the team to invite family caregivers to participate in patient appointments. The next section of this review will examine the importance of family caregiver involvement in palliative patient care.

Family Caregiver Role in Palliative Patient Care

The palliative care philosophy places great importance on improving the quality of life of both patients diagnosed with a terminal illness, and their families (WHO, 2015). Dating back to the early development of hospice palliative care, Cicely Saunders, recognized a need for both patient physical and emotional care, as well as family support (Saunders, 2000). In order to meet the needs of both patients and family members, palliative care places high importance on a Family-Centered Care approach.

Family Centered Care has been described as a collaborative approach to care delivery, with a partnership in decision-making between the health care provider and the patient and family (Kuo, Houtrow, Arango, Kuhlthau, Simmons, & Neff, 2012). The philosophy of family centered care includes: providing patients emotional and physical comfort care and opportunities to control medical and daily decision making, as well as educating family members in caring for the patient and providing emotional and decision making support (Teno, Casey, Welch, & Edgman-Levitan., 2001). Not only has great importance been placed on this family centered philosophy in palliative care (Kissane, 1999) but also in cancer care (Lederberg, 1998), and more recently, rehabilitation care (Bamm & Rosenbaum, 2008) to ensure there is a collaborative effort in care and that both patient and family member needs are cared for. More and more, there is a need for collaborative efforts of family members in patient care and thus, an there is an important need to support family caregivers throughout this role.

In this section of the literature review I will examine the role of family caregivers within palliative patient care. First, the increasing need for family caregiver involvement based on health care policies shifting from professional/ institutionalized care to informal/ in home care will be highlighted. Second, research regarding patient desires to live at home during end-of-life care will be reviewed. Finally, family caregiver perceptions of taking on this caregiver role will be identified – including their rationale for taking on the role and their level of felt preparedness to take on the various responsibilities entailed in caregiving.

As it is estimated that there is a 63% chance of surviving at least 5 years after cancer diagnosis (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015), the length of necessary care has transitioned from short-term fatality to potentially requiring more long-term palliative treatment. Based on cost effectiveness, it may not be possible to keep a patient in hospital, long-term and thus, discharge from hospital to homes occurs. This transition to home care is cost effective for the health care system as keeping patients in hospital is extremely expensive in comparison to home care as displayed in a 2014 report from Ontario's Ministry of Health and Long Term Care.

This report estimated that providing care to terminally ill patients in an acute-care hospital setting costs approximately \$1,100 per day which is over 40% more than the \$630 to \$770 per day when in a hospital based palliative care unit. Further, this number is more than double the approximate \$460 per day in hospice care, and over 10 times more than providing care at home which costs approximately under \$100 per day (Ministry of Health and Long Term Care, 2014). Other Canadian research has assessed the costs associated with home-based palliative care from a societal perspective. This work examined publicly and privately financed resources for 136 primary caregivers who had a loved one who was enrolled in a palliative care program.

Results identified an average monthly cost of \$24, 549 per patient. The research further identified that of this monthly cost, 71% represented the time costs incurred by family caregivers which included time lost from the labor market, leisure, and household work (Guerriere, Zagorski, Fassbender, Masucci, Librach, et al., 2010). These researchers noted that the estimated amount of caregiver time costs from the perspective of caregivers was infrequently identified in previous cost based reports but that it is an important aspect to learning about caregiver involvement.

This health care transition to home care aligns with individuals' preferences to die at home. Recent research found that two-thirds of individuals from various European countries (N=9344) stated that if diagnosed with advanced terminal cancer, they would prefer to die at home and family involvement was an important factor associated with their preference (Gomes, Higginson, Calanzani, Cohen, Deliens, et al., 2012). Further, a systematic review was conducted to examine past research regarding adult preferences for place of care in end of life or place of death, including preferences from patients, caregivers, and members of the general public (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013). This review found that of 210 studies reviewed, 75% of the studies found moderate evidence that most people prefer a home death. Of these studies the preferences for home based deaths ranged from an estimated 31% to 87% for patients, and 25% to 64% for caregivers. These results highlight that many patients may have a preference to die at home and many caregivers may also have a preference for their loved one to die at home.

In recognizing that health care policies are transitioning to information caregiving based on cost efficiency needs, and that patients have a desire to stay at home during end-of-life care, a third and very important aspect that must be taken into account is the perception of family

caregivers. Early research explored caregivers' rational behind taking on the caregiver role through conducting interviews with 11 family caregivers (Wennman-Larsen & Tishelman, 2002). Research results found a split between family caregivers who felt they were not given an option and family caregivers who took on the caregiving role to meet the patient's desire to be cared for at home. Despite the difference in reasons for taking on the caregiver role in a home based setting, many of the family caregivers felt it would be beneficial for the patient to be cared for at home. Similarly, qualitative research was conducted with 13 family caregiver participants to further examine caregiver preferences for caring for a palliative patient at home, (Linderholm & Friedrichsen, 2010). The results of this study highlighted that although family caregivers took on their caregiving role voluntarily, they described these responsibilities as a moral duty to their loved one.

Other research has examined family member perceptions of what matters most in end-of-life care (Heyland, Dodek, Rocker, Groll, et al., 2006). This research collected data from 160 family members and found that 76.3% of the family members rated "To be able to have your family member die in his or her location of choice (home or hospital)" as very important and extremely important. Further, 95.5% of these participants identified that it was very or extremely important for them to "To have an adequate plan of care and health services available to look after him or her at home, after discharge from hospital". Together these family member ratings provided further insight into understanding the level of importance family members place on meeting patient desires for place of death and to feel prepared with a health care plan and supports available to care for the patient after hospital discharge (Heyland, et al., 2006).

A systematic review narrowed down a search to 18 qualitative studies to develop a further understanding of the themes across studies which relate to family caregiver preferences and

perspectives regarding place of care at the end-of-life (Woodman, Baillie, & Sivell, 2015).

Results identified that the majority of family caregivers expressing a preference for home based patient care while at times caregivers felt obligated to take on the caregiving role. Sixteen of these 18 studies also identified that caregivers recognized both facilitators and barriers to caregiving. Facilitators were identified as support around emotional and practical needs of caring for a palliative patient, from both formal health care teams and informal networks. Barriers included feeling unprepared to take on the caregiving role.

More specifically, research identified this experience of unpreparedness through interviewing 13 family members whom were providing care to a palliative patient at home and 47 bereaved family members (Stajduhar & Davis, 2005). Of these 60 family members, 37% of participants felt they made uninformed decisions without considering the various implications a caregiving role may entail. Specifically, they felt unprepared and unaware of the realities of taking on a caregiver role within a palliative home care situation. Further, 48% of the family members felt they were indifferent regarding their decision to take on the caregiving role. The limited decision making that did take place was impacted by three aspects. First was that some of the caregivers had promised the patient they would be cared for at home and thus the caregiver felt they needed to keep this promise. Second was a desire to maintain a 'normal family life' by keeping the patient within the home. A third, and final, influential factor in family caregiver decisions to commit to home care was having experienced negative encounters with institutionalized care in the past. None of these aspects considered in the decision making process related to the challenging realities and potential hardships that can arise when taking on a caregiving role (Stajduhar & Davis, 2005).

These hopes to feel prepared and gain support throughout the caregiving role, were again identified in a qualitative study which explored the hopes and expectations of 11 family caregivers whom were caring for an advanced, end-of-life, cancer patient at home (Wennman-Larsen & Tishelman, 2002). This study highlighted themes regarding the transition into the family caregiver role and the life situation transition as a caregiver. The results also touched on the idea that caregivers hope to have support throughout their transitions but that they had low expectations of such support being available. Specifically, the family caregivers presented expectations that the professional supports available to them would be primarily to assist them with care-related tasks, despite the hopes for support in other areas. In recognizing that the transition of taking on a caregiver role may be a key aspect of the overall caregiver experience, researchers have developed theories in order to better prepare health care teams in understanding these transitions and the importance of supporting caregivers throughout the transitions.

Transitions for Family Caregivers - Conceptual Frameworks

Taking on a caregiving role is a life transition for family caregivers - going from a friend, family member or spouse, to care provider for daily needs and activities. Research has begun to explore this transition for caregivers and the needs of those within the caregiving role. In this section of the literature review will I review theories which help us to develop an understanding of the transitional process family caregivers may experience when they become a family caregiver.

Early theories on the caregiving transition process outlined a conceptual framework which aligned with the cognitive stress theory (Nijboer, Tempelaar, Sanderman, Triemstra, Spruijt, et al., 1998). This framework identified that family caregivers first encounter the stressor that is their family members' illness diagnosis. Second, caregivers experience outcomes related to this

stressor, which includes taking on new caregiving tasks and experiencing impacts on their health and quality of life. Third, and finally, are the potential mediators that include sociodemographics, social support and any other factors that can impact the caregivers' abilities. The key aspects of this conceptual framework include the idea that caregiver experiences are central to their ability to progress through the transition, and that support systems are an important aspect of assisting with the transition and managing the stressors associated with caregiving. The important role of these moderators presented itself again in research from 2000 that examined the transitional process that can occur for individuals who experience changes in their health and illness, and the role nurses can take on to assist in moderating the transitions (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000).

A more recent conceptual model built off of these older models lead to the development of a transitional model that looks at both cancer patient and caregiver transitions throughout the patient's illness process (Blum & Sherman, 2010). In developing this model the researchers hoped to have a resource to support health care teams in identifying appropriate opportunities to intervene and support this vulnerable caregiver population. This model was then applied to a case study of a family caregivers and patients to assess where they were in the transition process after being informed of the progression of the illness and that there were no further treatments. Through the use of this model the authors were able to identify where in the transition process the patients and caregivers were and how nursing staff could assist them in identifying their personal, societal and community resources and how these resources could be utilized in order to assist them to transition.

Another more recent model further expanded on these past conceptual models based on the growing body of research in the caregiver wellbeing field and determined that caregiving has

three main elements (Fletcher, Miaskowski, Given, & Schumacher, 2012). First, caregivers transition through a stress process which includes both the caregiving demands and personal wellbeing. Second their lived context such as personal, sociocultural and economic, as well as health care, are important elements in this model. The third and final element of this model is the illness trajectory, which revolves around the patients' illness from diagnosis throughout treatments, remissions or recurrence, survivorship or end-of-life and bereavement. This model highlights the importance of taking into consideration these varying aspects which can impact caregiver experiences and wellbeing. The need to understand when and how to support family caregivers in transitioning into their caregiving roles is highlighted when reviewing the literature regarding the extensive implications family caregivers may experience in their quality of life as a result of their caregiving role (Stajduhar, 2013).

Impact of Caregiving on Family Caregivers

The palliative care philosophy places great importance on improving the quality of life of not only patients but also the family caregiver of dying patients (World Health Organization, 2013). Quality of life is comprised of psychological, physical, social and spiritual experience in which individuals characterize their life (Fujinami, Otis-Green, Klein, Sidhu, & Ferrell, 2012; Grant, Padilla, Ferrell, & Rhiner, 1990). Despite a small body of research which has identified that palliative family caregivers have experienced their caregiving role as a rewarding experience resulting in high levels of life satisfaction (Haley, LaMonde, Han, Burton, & Schonwetter, 2003), the large majority of the family caregiver literature is centered around the negative implications caregivers may experience as a result of their caregiving role (Blum, et al., 2010). This section of the literature review will first highlight research which identified some of the implications caregiving can have on family caregivers' overall quality of life. Various aspects of

quality of life will then be reviewed. First, mental health implications will be identified, including experiences of anxiety, depression, and overall psychological distress. Second, concerns regarding caregivers' physical health experiences will be presented. Finally, implications of caregiving on family caregivers' perception of social support, including social burdens, time to partake in activities for themselves, and

Quality of Life

Quality of life is comprised of psychological, physical, social and spiritual experiences in which an individual characterizes their life (Fujinami, et al., 2012; Grant, et al., 1990). Research has found that family caregivers of terminal cancer patients experience more frequent depression episodes than normative samples (Song, Shin, Choi, Kang, et al., 2011). These findings were based on a study which compared the quality of life and mental health of 160 family caregiver's who were caring for cancer patients receiving palliative care services in Korea, to a control group selected from the fourth Korea National Health and Nutrition Examination Survey (a general population). Using comparative analysis, the researchers found caregiver health-related quality of life scores on the European QoL-5 Dimension questionnaire were significantly lower than the control group ($P=0.0018$). When asked to identify levels of stress and depression experienced over the last year, caregivers identified more frequent depression episodes than did controls ($P<0.0001$). The researchers conclude their results identify that family caregivers of terminal cancer patients experience mental health difficulties and lowered health-related QOL significantly more than a general population sample (Song, et al., 2011).

Not only are the quality of life levels of family caregivers' of palliative cancer patient lower than those of a normative sample but they are also lower than family caregiver's caring for a curative cancer patient (Weitzner, McMillan, & Jacobsen, 1999). The findings were identified

through assessing the quality of life of 134 family caregivers for palliative cancer patients and 267 family caregivers for patients receiving curative cancer treatments all completed the Caregiver Quality of Life-Cancer (CQoL-C) Index. Using analysis of variance (ANOVA) to compare the caregivers CQoL-C scores of curative and palliative family caregivers, it was found that family caregivers for palliative cancer patients experienced significantly lower CQoL-C scores than those caring for curative cancer patients. Further, family caregivers also completed the Medical Outcomes Study Short Form to assess perceived health and functioning of the patient and the ECOGPS Rating Scale to rate patient functioning and performance. In comparing the CQoL-C scores to the patient performance scores, it was found that the poorer the patient performance scores were, the lower the caregiver CQoL-C scores.

In line with the idea that family caregiver quality of life worsens as patient performance worsens, more recent research has identified similar findings. Wadhwa, Burman, Swami, Lo and Zimmermann (2013) examined the QoL and mental health of 191 caregivers of individuals diagnosed with advanced cancer whom were receiving care from ambulatory oncology services. The patients were diagnosed with advanced breast, gastrointestinal, genitourinary, gynaecologic or lung cancers. Caregivers completed the CQoL-C, the Medical Outcomes Study Short Form, and a care-related questionnaire addressing areas such as amount of time spent providing care and work place changes. Spouses/partners represented 84% of the caregiver population and 90% of the caregivers lived with the patient. Simple regression analysis showed better caregiver quality of life was associated with better patient physical well-being ($P=0.001$) and better caregiver mental health ($P<0.001$). Further, as the CQoL-C includes mental health components, the researchers removed the mental health components from the CQoL-C and reanalyzed the data finding the mental health scores on the Medical Outcomes Study Short Form

where still significantly associated with caregiver QoL ($P=<0.0001$) (Wadhwa, et al., 2013). Taking mental health on its own into account, there is a large body of research which has identified how the mental health of caregivers can be impacted by caring for a patient whom progressively declines.

Mental Health. In this section I will highlight the mental health implications family caregivers may experience in light of taking on the caregiver role. Specifically, I will review research which has identified anxiety, depression, and overall psychological distress as challenges which have arose for family caregivers. Further, this section of the review will also identify aspects of being a caregiver which may correlate with these mental health concerns, such as patient illness status, living arrangements, and relationship to the patient.

The percentage of family caregivers who experience high levels psychological distress has been found to range between 41% to 62%, based on a sample of 212 caregivers, while the estimated percentage of the general population is estimated at 19.2% in general population (Dumont, Turgeon, Allard, Gagnon, Charbonneau, & Vezina, 2006). This study examined caregiver levels of psychological distress in relation to the patients' functional abilities as scored on the ECOGPS. Patient functioning categories included patients confined to chair or bed for less than 50% of waking hours (Grade 2), more than 50% of waking hours (Grade 3), 100% of waking hours (Grade 4). The family caregivers' psychological distress was assessed using the Indice de détresse psychologique de Santé Québec tool which measures anxiety, depression, aggressiveness and cognitive disorders. Analysis of data found that the psychological distress experiences of caregivers is strongly associated with decreased patient performance ($P=0.0008$).

In line with these findings, other research has examined the impact of perceived cancer stage on caregivers' anxiety and depression levels. Using the Hospital Anxiety and Depression

Scale the researchers examined the anxiety and depression levels of 98 caregiver participants in comparison to their perception of patient cancer stage (Burridge, Barnett, & Clavarino, 2009). Results identified that anxiety scores increased over the one year time frame while depression scores increased within the final 6 months of the year. Further, females were found to be significantly more anxious than males at both six months away from perceived patient death ($P = 0.049$) and three months away from perceived patient death ($P = 0.009$).

Further research has identified that the anxiety and depression experiences of family caregivers whom are caring for advanced cancer patients have been found to be worse in comparison to that of normative samples (Grov, Dahl, Moum, & Fossa, 2005; Song, et al., 2011). Specifically, research has compared 49 male primary caregivers and 47 female primary caregivers, to a normative sample taken from the Nord-Trøndelag Health Study. This research found that anxiety levels were significantly higher in comparison to the normative sample for both males ($P < 0.001$) and females ($P < 0.001$). The depression scores were not significantly different from the norm sample for males but were significantly higher for females ($P < 0.001$). This research further identified that demographic factors significantly influenced the caregiver scores, for females where their relationship to the patient ($P = 0.013$) and their residence being the same as the patient ($P = 0.049$) (Grov, et al., 2005).

Together, this research highlights some of the mental health implications that can occur for family caregivers caring for an advanced, terminal, cancer patient. Although mental health implications have been more prominent in the literature and are identified as more detrimental to family caregivers, physical health is a second aspect of quality life that has similarly been found to be negatively impacted by taking on a caregiving role (Schulz & Sherwood, 2008).

Physical health. Beyond the impact caregiving for an advanced, terminal cancer patient can have on family caregiver mental health, research also shows similar difficulties for family caregivers in regards to the physical health implications they may experience as a result of their caregiving (Kurtz, Kurtz, Given, & Given, 2004; Mosher, et al., 2013). Specifically, research examined health related subscale of a quality of life measure which identified that physical functioning and general health of caregiver's of palliative cancer patient (n=134) were significantly lower compared to the family caregivers of curative patients (n=267) ($P<0.0001$) (Weitzner, et al., 1999).

Kurtz and colleagues (2004) examined the physical health of 491 family caregivers caring for geriatric cancer patients over the span of one year. Demographic information identifying that 76% of family caregivers were female, 77% of the relationship to patient were spousal and 88% of family caregivers live with the patient. Physical health of caregivers was measured using the Medical Outcomes Study 36-Item Short Form Health Survey and compared with patient health and demographic data. Results suggest two or more comorbid conditions reported by the patients correlated with significantly worse caregiver physical health ($P=0.013$). Further, significantly lower physical health of the caregiver was also found for those living with the patient (Time 2 $P=0.05$, Time 3 $P=0.04$). Taken together, Kurtz and colleagues (2004) were able to identify that the physical health of family caregivers can be significantly impacted by caregiving for a cancer patient.

The Medical Outcomes Study Short Form-36 was more recently utilized to assess the physical health of 91 family caregivers of lung cancer patients (Mosher, et al., 2013). More than one-third of family caregivers reported negative changes in physical health (35%) and physical functioning (37%) as a result of caregiving. Further, the researchers found that employed family

caregivers showed better physical functioning ($p < 0.01$) and general health ($p < 0.01$) than retired or unemployed caregivers and that income positively correlated with physical functioning ($p < 0.01$), general health ($p < 0.001$), and vitality ($p < 0.05$). These physical difficulties associated family caregiver income and occupational status begin to speak a the third aspect of quality of life which has been found to be negatively impacted by taking on a caregiving role – social experiences (Kurtz, et al. 2004, Mosher, et al, 2013).

Social Support. The social aspects of an individual's life can be greatly impacted by taking on a caregiving role, especially regarding the amount of time required to care for the patient, resulting in family caregivers feeling the need to take time off of work and self-care activities (Stajduhar, 2013). This section of the review will examine research which identified implications family caregivers may experience on their perception of social support. Research has highlighted that such social experiences can include perceived social burdens and time for personal activities, as well as involvement in patient care and having open discussions with health care providers.

According to research, caregiving can negatively affect various family caregiver experiences of social support. Specifically, Mosher and colleagues (2013) asked 91 family caregivers to identify if they felt specific life aspects changed for the worse, for the better, or not at all. Regarding social aspects, it was found that a large percentage of family caregivers experienced a change for the worse in: time for family activities (47%), relationships with friends (26%), and time for social activities with friends (57%) (Mosher, et al., 2013). Further, research with a family caregiver population of 491 has suggested that a caregiver depression and physical health can significantly correlate with social experiences of caregivers (Kurtz, et al., 2004). Such specific aspects include, caregiver sense of control over their daily schedules

(depression $P=0.000$, physical health $P= 0.032$), caregiver social functioning (depression $P=0.021$, physical health $P= 0.027$), and caregiver sense of abandonment (depression $P=0.000$, physical health $P= 0.012$)

To build on these quantitative studies, a mixed method study was conducted with 65 caregivers of palliative cancer patients in order to develop an understanding of their needs (Jansma, Schure, & Meyboom de Jong, 2005). The researchers noted that all participants were eager to share their experiences. Results highlighted many social aspects within the caregivers desires, including that caregivers had a desire to: be heard, discuss their difficulties, discuss cancer freely, stand up for themselves, and participate in the decision making process. Further, they wanted to be able to discuss practical information around: nursing skills, medical aid information, combining employment and caregiving, social support and how to attain cancer information. The caregivers also highlighted a need for: discussions around coping and grief, support during palliative phase and after the death of the patient, a confidante for the caregiver, physical and mental care, and the maintenance of personal/private space. This mixed methods study greatly informed research of the needs family caregivers may experience when caring for a palliative cancer family members. In particular, around their feelings of needing to be heard and involved in the decision making and patient care in order to feel support by health care providers. These aspects were also highlighted in a Swedish research study which explored the experiences of 13 family caregivers whom were caregiving for a palliative family member at home (Linderholm & Friedrichsen, 2010). Results identified that caregivers felt powerless in their caregiving role if they did not establish a relationship with the healthcare professionals. Further, the researchers identified that in order for the carers to feel seen, they wanted to share their experiences regarding their supporting role (Linderholm & Friedrichsen, 2010).

In summary, research has shown that family caregiving is becoming more and more important based on patients' desires to die at home (Gomes, et al., 2012) and health care policy transitions to more home-based care (Stajduhar & Davis, 2005). However, there are many issues family caregivers may experience related to their mental health, physical health, and social experiences as a result of their caregiving roles (Blum, et al., 2010). These three aspects of mental health, physical health and social experiences are included in the concept of quality of life which is currently a growing area in family caregiver research (Fujinami, et al., 2012). Further, within the social support aspect for family caregivers, research has identified that caregivers expressed that it is important for them to feel involved in patient care and to be able to have open discussions with the health care teams regarding patient and personal needs. In recognizing the role social support from health care professionals plays for family caregiver wellbeing, interventions have been developed in order to improve caregiver experiences and overall quality of life throughout their caregiving role.

Improving Caregiver Experiences and Quality of Life – Interventions

The body of research examining interventions aimed at improving the various difficulties family caregivers may experience as a result of caring for a cancer or palliative patient has more than quadrupled within the 2001 to 2011 decade (Harding, List, Epiphaniou, & Jones, 2012). Since then, interventions have narrowed into mainly psychoeducational interventions as they have consistently shown improvements in the various aspects of family caregivers' quality of life (Northouse, Williams, Given, & McCorkle, 2012). A meta-analysis was completed to look at intervention studies and their impact on family caregivers. They found three main forms of interventions were used: 1) psychoeducational sessions aimed at educating and discussing care and emotional experiences with caregivers (57% of interventions); 2) skill training aimed at

educating family caregivers on coping, problem-solving and communication (26% of interventions); 3) therapeutic counselling aimed at improving patient-caregiver relationships, conflict management and addressing and dealing with loss (17% of interventions). For all of the intervention studies reviewed, caregivers experienced significantly less burden, depression and distress while also reporting improved knowledge, coping skills, self-efficacy, psychological wellbeing and quality of life. Taken together, this article identifies such educational and supportive based interventions may have a positive impact of caregiver health and wellbeing.

A systematic review examined six studies of psychosocial interventions which aimed to improve cancer family caregivers' quality of life: all were classified as skills-training with cognitive-behavioral and psychoeducation components and had small to significant changes in CQOL-C scores (Waldron, Janke, Bechtel, Ramirez, et al., 2013). These studies suggest that such educational interventions have an impact on improving family caregiver quality of life and these changes can be examined using the CQOL-C tool. Further, providing caregivers education to assist them in caring for the patient, as well as providing them psychosocial support, is included in the description of the collaborative family-centered care approach highlighted within palliative care (Teno, et al., 2001), cancer care (Lederberg, 1998), and rehabilitation care (Bamm & Rosenbaum, 2008). The next, and final section of this review will highlight the importance to both patients and family members that the other is cared for.

The Need to Ensure Patients and Families are Viewed as the Unit of Care

This review has highlighted research suggesting that family caregivers may often make their decision to take on the caregiver role in order to support the desires of patients to be cared for at home (Woodman, Baillie, & Sivell, 2015). Further, many expressed a sense of moral duty to support their loved on in this way, and acceptance of the unpredicted challenges that arose in

taking on this role (Linderholm & Friedrichsen, 2010). However, what we had not touched on was the importance patients place on the wellbeing of their loved ones whom care for them in end-of-life. This section of the review will first highlight research which identifies patient hope to not place a burden on their family. Second, the concept and prevalence of self-perceived burden will be identified. Finally, the concept of reciprocal suffering between patient and family experiences will be explained in relation to the importance of caring for both patient and family caregiver needs.

Heyland and colleagues (2006) asked 434 patients to rate the importance of 28 elements of quality end-of-life care, results found that within the top five most important elements, patients selected “To not be a physical or emotional burden on your family”. This research suggests that the well-being of family caregivers is not only important for the quality of life of the caregivers themselves but is also important for patients during end-of-life.

Although there is minimal research exploring patient concerns regarding the burden they feel they place on family caregivers, McPherson, Wilson, and Murray (2007) completed a systematic review of this research between 1995 and 2005. Specifically, this review examined patient self-perceived burden, defined as the burden patients feel they place onto the caregiver, and its effects on patients. The review revealed that 65% of palliative patients experience self-perceived burden as a significant problem. Further patient self-perceived burden was found to correlate with suffering, patient thoughts of a ‘bad death’, and patient experiences of loss of dignity. Self-perceived burden was also identified as a relevant factor in acts of hastening death and patient decision making regarding care (McPherson, et al. 2007).

This fear of burdening their loved ones, on top of any of the discomfort and fear that may arise independently as a result of a palliative illness diagnosis, may impact patient’s end-of-life

experiences, which in turn may impact the experiences of family caregivers as Witt Sherman's review explored (1998). This review identified that as patients suffer, family caregivers suffer and vice versa, an experience defined as reciprocal suffering. Witt Sherman (1998) further suggests that this reciprocal suffering is a common patient-caregiver experience during palliative care and that the quality of life of both parties is negatively affected. In turn, the review article aligns with the copious amount of current research identifying the quality of life struggles caregivers of palliative cancer patients experience and the need to ensure the patient and family remain the unit of care as identified in the definition of palliative care (WHO, 2015). Further, viewing the family as the unit of care was always intended to be a key component of the interdisciplinary, palliative care model as identified by the founder of hospice and palliative care, in order to support the holistic needs of patients and their family members during end-of-life (Saunders, 2000).

Summary and Research Questions

Family caregivers play a significant role in the care of palliative cancer patients. The transition of taking on the caregiving role of a palliative patient can be examined through various models, which all identify the exploration of caregiver experiences as necessary in order to understand their needs. Furthermore, it is apparent in the literature that family caregivers experience significant implications on their quality of life in taking on the caregiver role, similar to their patient counterparts as a result of the illness, treatments, and end-of-life experiences.

Many interventions and health care approaches focus on and successfully address patient quality of life through the use of rehabilitation approaches. These holistic rehabilitation approaches are common in the cancer survivorship realm, however are new to the advanced terminal cancer setting. The Ottawa Palliative Rehabilitation Program was developed to build on

the limited research in this area, in order to address the gap in care for individuals who were diagnosed with advanced terminal cancer but still experienced negative implications on their quality of life as a result of the cancer treatment. Research on this program found significant improvements in patient functioning.

A unique aspect of this specific palliative cancer rehabilitation program that has not been explored further by the researches is the high level of involvement of family caregivers for patients enrolled in the program, providing caregivers the opportunity to learn new techniques and strategies to support the patients and themselves. As family caregiver research has found such educational and psychosocial intervention support can improve family caregiver experiences and quality of life. As such, in this study I aim to explore the experiences and quality of life levels of family caregivers who actively participate in the Ottawa Palliative Rehabilitation Program with their family members.

Research Question

The aim of this study was to develop an understanding of family caregivers' experiences within the context of their loved ones participating in a palliative cancer rehabilitation program. The following research question served as a guide to answer the research question:

How do family caregivers perceive their experiences of caring for a loved one diagnosed with advanced cancer and who is enrolled in a palliative rehabilitation program?

In order to do so, the study:

- 1) Aimed to develop an understanding of the experiences of family caregivers who are caring for a palliative cancer patient who is enrolled in a palliative rehabilitation program through qualitative interviews.

- 2) Examined caregivers' quality of life and any changes that may occur through quantitative measures on the Caregiver Quality of Life – Cancer (CQOL-C) index (Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999) scores pre and post their loved ones' enrollment in a palliative rehabilitation program.

Chapter 3: Methodology

This chapter will provide an account of the methodology for the current study. First, I will highlight the rationale for a case study approach. Second, I will describe the research context and the various data sources and corresponding data analysis techniques. Third, I will identify the data collection approach, then finally I will highlight the research quality and rigor.

Rationale for a Case Study Approach

In order to develop an understanding of how family caregivers experience caring for a palliative cancer patient who is enrolled in a palliative rehabilitation program, this study was designed using a case study research approach. More specifically, a multiple case study was utilized to examine this phenomenon through collecting a series of data from multiple perspectives (Stake, 2006).

Case studies are an ideal research approach when the researcher has minimal control over the area of study and specifically when the aim of the study is to examine a phenomenon in a real-life context (Yin, 2003). Such case studies have been identified as appropriate research methods within palliative care research, particularly in situations where context is central to the study and when multiple perspectives need to be recognized (Walshe, Caress, Chew-Graham, Todd, 2004). Case study research tries to preserve the multiple realities of the context (Stake, 1995).

A multiple-case study allows for the examination of numerous cases in order to develop an understanding of the context of study. Further, an embedded data approach provides the opportunity to collect and analyse multiple units of data within each given case to gain a more in-depth understanding of the individual cases (Yin, 2003). Both of these aspects of the research design are applicable to this study as: 1) the central focus is to explore family caregiver experiences within the context of caring for a cancer patient enrolled in a palliative rehabilitation program, and 2) multiple perspectives are expected to arise since the criteria for patients to enroll in the Palliative Rehabilitation Program are quite broad and thus collecting various data from each case.

Case studies often blend data collection approaches such as interviews, observations, and questionnaires, and data forms can be qualitative and/or quantitative (Eisenhardt, 1989). The current study was designed in such a way as to combine these various approaches in order to develop an understanding of how family caregivers experience care giving for a palliative cancer patient, within the context of a palliative rehabilitation program.

Setting and Participants

The Élisabeth Bruyère Hospital in Ottawa Ontario, provides rehabilitation, palliative care, long-term care, and community services – including the Ottawa Palliative Rehabilitation Program. The patients who were eligible to enroll in this outpatient palliative rehabilitation program were required to meet the following criteria: 18 year of age or older, in the advanced stages of cancer, have completed any other treatments, are medically stable, scored moderate or higher on palliative performance scales, and are self-motivated to participate in the program (Chasen, et al., 2013). These broad program criteria open the doors to an abundance of unique family caregiver perspectives based on such aspects as the patients' cancer diagnosis, level of

functioning, relationship and living arrangement with family caregivers. Family caregivers may also have different quality of life experiences and personal demographics such as having a family of their own, employment status, income, education level, etc.

Participants. The participants of the study were four self-identified primary family caregivers of patients enrolled in the Ottawa Palliative Rehabilitation Program (3 female, 1 male). The cancer diagnosis of the patients being cared for by these family caregivers were all different (brain, neck, lung, and pancreas). All family caregivers attended all of the 8 weeks with the patient. Three of the family caregivers were the wives of the patient enrolled in the Ottawa Palliative Rehabilitation Program, while the fourth caregiver was the brother of the patient whom now lived with he and his wife.

All participants were between the ages of 61 and 68 years old. Two family caregivers identified their occupational status as employed and also identified that they had not personally accessed any supports for themselves, expect arranging to have flexible work schedule as one of these family caregivers identified. The other two family caregivers identified their occupational status as retired and both identified that they have personally accessed metal health support and one of these caregivers had accessed friends for support. Further demographic details are displayed in Table 1 below.

Table 1

Descriptive Participant Demographic Information

Demographics	Participants
Age	61 (n=2) 63 (n=1) 68 (n=1)
Relationship to Patient	Brother of Patient (n=1) Wife of Patient (n=3)
Patient Cancer Type	Brain Cancer (n=1) Neck Cancer (n=1) Lung Cancer (n=1) Pancreatic Cancer (n=1)
Living Distance from Patient	All lived in a shared residence with the patient (n=4)
Ethnicity	All Caucasian (n=4) None (n=1)
Religion	Protestant (n=2) Catholic (n=1)
Education	University (n=2) Secondary/High school (n=2)
Occupation	Employed (n=2) Retired (n=2)
Income	>100k (n=1) 61-80k (n=2) <10k (n=2) None (n=2)
Supports caregiver has personally accessed	Mental Health Support (n=2) Friends (n=1) Flexible Work Arrangements (n=1)

Data Sources

This study, which was approved by the Bruyère Continuing Care Research Ethics Board, collected a variety of data sources from a small number of participants to develop a detailed understanding of the varying experiences of primary family caregivers who are caring for a patient enrolled in the Ottawa Palliative Rehabilitation Program. Each family caregiver participant and the data collected from them made up their individual case. Thus, an embedded case study approach was utilized throughout this study as it allows for numerous data sources (units of analysis) to be examined within each individual case (Yin, 2003). The multiple units of analysis that make up each family caregiver case (displayed in Figure 1) include: demographic information (Appendix A), Caregiver Quality of Life - Cancer scores (Appendix B), case notes (Appendix C), and interviews (Appendix D). This variety of data was collected over the span of each patient's enrollment in the eight-week Palliative Rehabilitation Program (Figure 2). Purposeful sampling, selecting cases (in this study cases are the family caregiver participants) which are "information-rich" and examining them (their experiences) in depth, will be invoked using a "maximum variation strategy" (Patton, 1990) in order to ensure a variety of family caregiver experiences are explored.

Demographic Data. Basic demographic data were collected from the family caregiver participant as a means to provide a context of their personal caregiving context (Appendix A). Six of the questions were regarding the caregiver participant specifically, including there are, ethnicity, religion, education, occupation, and income. Three of the questions were in relation to the patient, including their relationship with the patient, the patient's cancer diagnosis type, the distance they live from the patient. Finally, one question asked caregivers if there were any supports they have personally accessed for their own needs.

Caregiver Quality of Life – Cancer Index. Caregiver quality of life was examined using the validated Caregiver Quality of Life- Cancer (CQOL-C) (Appendix B). Measures were collected pre- and post-eight-week program. These scores were used as means to identify commonalities or differences between participant quality of life as well as explore any changes that may occur pre-post for the individual participants. The aim of this data set was to enrich the understanding of the individual participants' caregiving experiences and their quality of life, thus any changes that may arise are an important factor to include.

The CQOL-C Index (Weitzner, et al., 1999) is a frequently utilized tool to measure the quality of life of cancer family caregivers (Waldron, et al., 2013). Reviews have examined the psychometric properties, including validity and reliability, of many psychosocial self-assessment tools developed to examine the variety of difficulties family caregivers may face (Deeken, Taylor, Mangan, Yabroff, et al., 2003; Hudson & Hayman-White, 2006). The CQOL-C (Weitzner, et al., 1999) is the only scale developed specifically to measure the quality of life of family caregivers caring for patients diagnosed with cancer. Since this tool includes measures of mental health, physical health and social experience, it has been deemed a valid and reliable tool to examine the overall quality of life of cancer family caregivers as well as any changes that may occur as a result of an intervention (Deeken, et al., 2003). Further, this tool continues to be widely used over a decade later in both practice and in research and has recently been translated and validated in a number of different languages (Bektas & Ozer, 2009; Lafaye, De Chalvron, Houédé, Eghbali, & Cousson-Gélie, 2013).

The CQOL-C was developed by Weitzner and colleagues (1999) based on interviews with caregivers and health care staff who then tested and evaluated the 35 item tool. Their validation processes invited 263 caregivers, to complete the CQOL-C along with numerous tools to validate

the CQOL-C including the: Medical Outcomes Study Short Form-36, Beck Depression Inventory, State-Trait Anxiety Inventory, Caregiver Burden Scale, ECOGPS, Multidimensional Scale of Perceived Social Support and Marlowe-Crowne Social Desirability Scale. All caregivers completed the questionnaires and 83 were invited at initial consent to complete the CQOL-C again days later for test-retest purposes. Analysis identified the CQOL-C as moderately correlating with caregiver over all mental health, emotional distress, burden and patient performance status. Strong test-retest reliability and internal consistency were identified (Weitzner, et al.,1999).

The CQOL-C index results were examined individually for each caregiver to assess any changes that may have occurred in each case. Specifically, as only four participants were enrolled in this study, neither statistical significance of pre-post comparisons nor statistical comparisons to demographic data were conducted. The maximum total score for the CQOL-C index is 140 – higher scores reflect a better quality of life.

The CQOL-C index also includes four quality of life factor measures within it. The maximum score for each factor, as well as the questions which make up the factors are as follows: Burden has a maximum score of 40 (questions 9, 11, 14, 17, 18, 19, 20, 25, 31, 33), Disruptiveness has a maximum score of 28 (questions 1, 3, 5, 21, 24, 26, 29). Positive Adaptation has a maximum score of 28 (questions 10, 12, 16, 22, 27, 28, 34), and Financial Concerns has a maximum score of 12, (questions 6, 7, 8).

Case Notes. The case notes were collected throughout the eight-weeks the patient of the family caregiver was enrolled in the Palliative Rehabilitation Program. These case notes documented the involvement and attendance of the family caregiver in the patient's rehabilitation program, as well as their use of the program resources for their own wellbeing, i.e. scheduling

time with the social worker. These check-ins took place in the forms of observations, discussions with the family caregiver, and conversations with members of the health care team.

The weekly check-ins with the participant also provided an opportunity for rapport to develop between the researcher and participant which played an important role in ensuring the caregiver felt comfortable with sharing their experiences. As these discussions were anticipated to potentially provide insight into the participants' experiences, all participants were informed that any conversations pertinent to goals of this study would be documented, i.e. discussions around their experiences. These case notes were made directly following encounters to allow full attention to the conversation as well as to have the notes included in one file.

Interviews. In depth, one-on-one interviews were conducted with the family caregiver participants at the end of the patient's eight-week enrollment in the Ottawa Palliative Rehabilitation Program. The goal of this qualitative data was to explore family caregiver's detailed accounts of their caregiving experiences. More specifically, the open-ended, semi-structured interview questions were designed to elicit narrative responses relating to participants' lived experiences and perceptions of the patient's illness, their caregiving experiences, and their experiences of the Ottawa Palliative Rehabilitation Program.

The interview guide (Appendix D) was developed based on a review of literature as well as expert opinions from members of the Bruyère Palliative Care Research Team. Questions one through five were based on the literature exploring the experiences of family caregivers of palliative cancer patient to gain a better understanding of their personal experiences (Hudson, 2006; Linderholm & Friedrichsen, 2010). Questions six, seven and nine were developed based on the caregiver needs literature (Fridriksdottir, Sigurdardottir, & Gunnarsdottir, 2006; Hudson, Aranda, & Kristjanson, 2004) to learn how the program may have addressed their personal needs

while questions seven and eight looked into their perception of how the program impacted the patient as caregiver's perception of patient health can impact caregiver wellbeing (Burridge, Barnett, & Clavarino, 2009; Weitzner, et al., 1999).

Figure 1

The Study Context and Various Data Sources from Each Family Caregiver Case

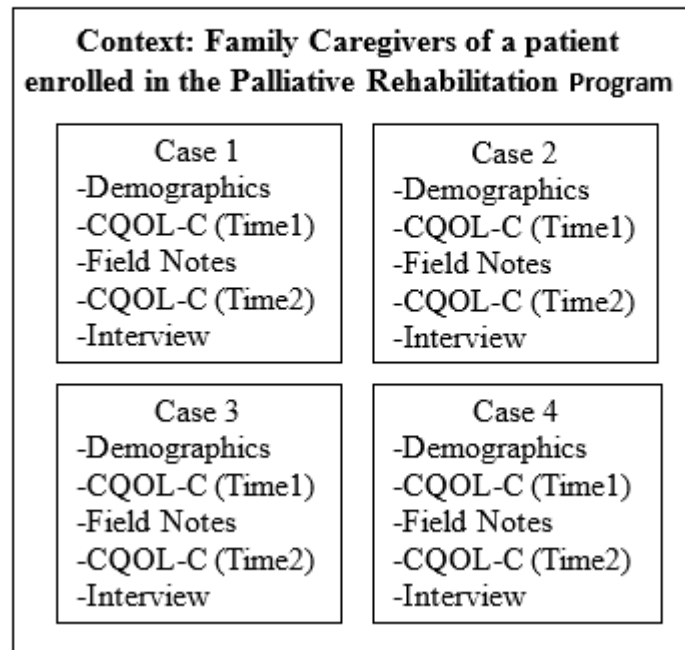
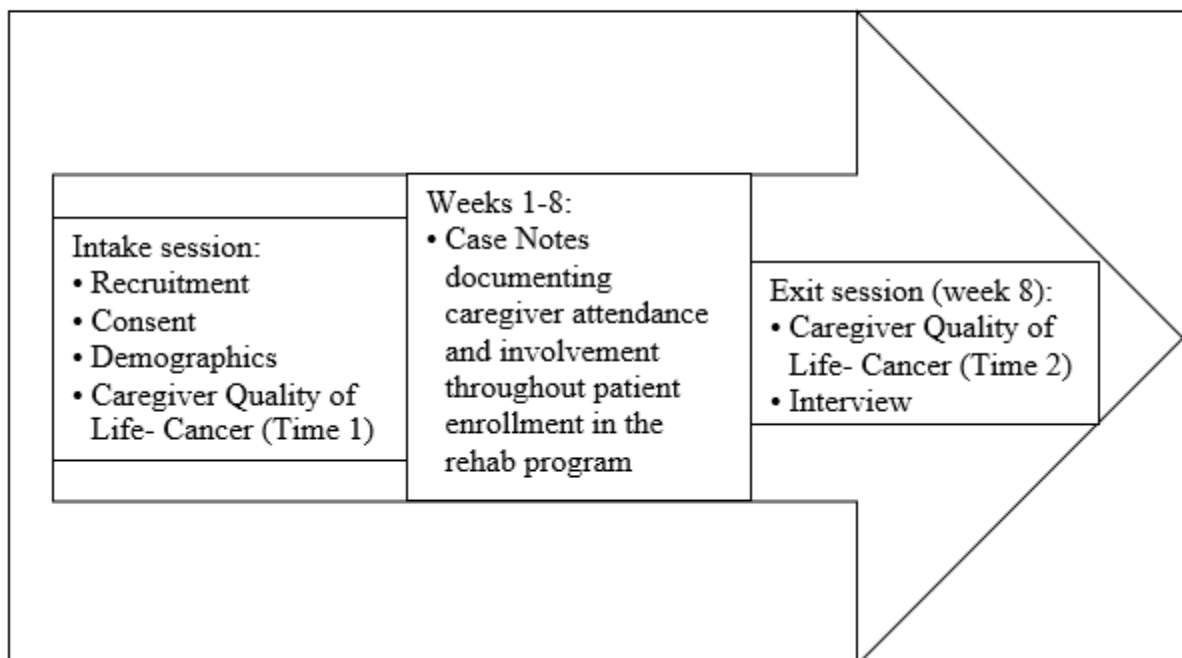


Figure 2

Organization of Data Collection over the 8-Week Palliative Rehabilitation Program

**Data Collection and Recruitment**

Case study research design is an effective research approach when working with small sample sizes based on the large amount of data that can be collected per case - four to ten cases is a suggested sample size for case study research (Stake, 2006). This current project had a sample size of four cases whom were self-identified family caregivers of a patient enrolled in the Palliative Rehabilitation Program at Bruyère Continuing Care in Ottawa Ontario. Family caregivers and patients were first informed of the study by the nurse conducting the patient intake session. Once family caregivers consented to learn more about the study, I, the researcher met with both the family caregiver and the patient to discuss the purpose of the study and the informed consent process. Both family caregiver and patient were required to consent as it was anticipated that the patient's illness may arise as a central topic of the family caregiver cases.

Caregivers were informed that their participation or non-participation would in no way impact the patient's treatment. Further, as questions regarding their experiences with the Palliative Rehabilitation Program were anticipated to potentially elicit emotions or distress, the participants were encouraged to identify such experiences with the researcher and if necessary the researcher would provide resources such as contact with the Palliative Rehabilitation Program Social Worker or a community counselling center. Participants were also able to withdraw from the study at any point with no negative consequences. Once individuals consented to participate, they were provided the pre CQOL-C questionnaire which was estimated to take 10 minutes of their time. Over the next eight weeks, participants were then observed weekly or twice weekly for attendance and participation in the patient's rehabilitation sessions. During this observation period, brief conversations between the researcher and participant took place as check-ins to see how they were or if they wanted to discuss anything with the researcher regarding their caregiving experiences. Upon patient completion of the palliative rehabilitation program, the participants scheduled a time to complete their post CQOL-C questionnaire and interview at a time convenient for them. All participants were able to complete these aspects during the patient exit process at the end of the eight-week rehabilitation program.

Data Analysis

The data analysis of this study occurs in a number of stages as suggested by Yin (2003). First, Yin suggests that data sets are to be individually examined. Next, Yin identifies that it is necessary to develop a strategy of analysis to sort the data based on the research questions and to identify how the data will be reported (ie. figures, comparisons to past literature, etc.). This section of the methodology chapter will first explain the strategies utilized to examine the individual units of analysis including the demographics, case notes, CQOL-C scores, and

interviews. Next the strategy to sort the data using individual case reports will be explained. Finally, the quality and rigor of this research study will be identified.

Within this study, the data sets (units of analysis) collected for each participant case included the demographic data, case notes, CQOL-C scores, and interviews. Each of these units were examined individually and utilized to develop a case report for each individual participant. The aim of displaying the various data sets for each participant within individual case reports was to allow the readers to develop an understanding of each participant's unique case, and how each participant's experiences may relate or differ from one another. Further, these case reports aimed to preserve the multiple realities of each individual case as is highlighted as an important feature of case study research (Stake, 1995). These results were then compared to past research. This comparison to past research allowed for the examination of how the findings may relate or differ from the literature which is identified by Yin (2003) as a key principles required in order to produce a high quality analysis. This comparison of the study results to past research will take place throughout the discussion chapter of this thesis. The individual data sets and their incorporation into the individual participant case reports will now be described beginning with the participant demographic data, followed by the QOL-C data, the case note data, and then finally the interview data.

Demographic Data. The demographic data collected at the beginning of the study provided us with background knowledge regarding the individual family caregiver, their relationship with the patient, and the patient's illness diagnosis. These demographic data sets were not statistically analyzed for significance in comparison to the various data sources in any way. They were however incorporated into the individual participant case reports utilized in combination with the other data sets to develop a holistic report of the caregiver experiences. The

demographic data was also examined in comparison to those of the other family caregiver participants to identify potential commonalities or differences.

Caregiver Quality of Life – Cancer Index Scores. The CQOL-C index results were examined using descriptive statistics in two ways. First, caregiver scores both pre and post on the quality of life scale as well as the various subscales were identified individually within each family caregiver case. These scores incorporated into the caregiver case reports provide further detail regarding the individual caregivers' experiences. Second, the CQOL-C scores were then compared to one another in the cross case summary section of the results chapter. Finally, comparisons of these findings to those of past caregiver quality of life literature were displayed throughout the discussion chapter of this thesis. Please note that due to the small sample size of this study (four participants) these scores were examined solely as descriptive data - neither statistical significance of pre-post comparisons nor statistical comparisons between participants were conducted.

Case Notes. The aim of collecting the case note data was to take account of interactions that took place with the family caregivers throughout their time enrolled in the study. Thus the case notes were not independently analyzed, but were instead incorporated into the caregiver case reports as part of their back ground details. Only at this point were the case notes, in combination with the other various data sources, examined at a descriptive level. Specifically, the case notes were informative in the cross case comparisons between participant cases for aspects such as their attendance and participation in the program, their experiences over the course of patient enrollment in the program, as well as which program resources they did, or did not access.

Interviews. The interview data collected within this present study required rigorous and detailed analysis in order to develop an understanding of the family caregiver participants' perceptions throughout caring for an advanced cancer patient enrolled in a palliative rehabilitation program. As the design of the present study is a case study, it was important to select a method of analysis for the interview data which was rigorous but would not steer away from the purpose of the overall study – to explore and develop an understanding of the perception of the family caregiver participants through the various sources of data collected. In exploring various analytic approaches, the rigorous coding methods utilized within grounded theory methodology in order to identify, organize, and understand common participant experiences within rich data sets (Creswell, Hanson, Clark Piano, & Morales, 2007) was of interest. However, the intensive approaches of grounded theory, including the requirement to reach saturation and the aim of developing a theory did not align with the purpose of the present study. Thus, through further exploration of appropriate analytic approaches and consultation with professionals in the qualitative research field, arose the thematic analysis approach developed by Braun and Clarke (2006) which was inspired by grounded theory.

More specifically, thematic analysis incorporates the rigorous data coding approaches of grounded theory to develop themes which address the research questions, but without the aim of reaching saturation and developing a theory as is the aim of grounded theory (Braun & Clarke, 2006). Further, thematic analysis is flexible in that it is only a data analysis method and not an approach to conducting research (Braun & Clarke, 2012), thus the rationale for the applicability of using thematic analysis to analyze the interview data, which was collected within the case study research design of the present study. Braun and Clarke (2012) provide a detailed six-phase

approach to conducting thematic analysis, in which I, the researcher, followed throughout the analysis of this present study's interview data as described in the following paragraphs.

To begin, Phase 1 of thematic analysis presented by Braun and Clarke (2012) is focused on Familiarizing Yourself with the Data. After collecting the various sources of data, I submerged myself in the interview data through listening to and transcribing verbatim the audio recordings, and reading, and re-reading the interviews. During these reviewing sessions, I noted aspects which stood out as unique or consistent across cases which led to Phase 2 of Generating Initial Codes. Specifically, aspects of the interview data which presented themselves as meaningful to their perception of their caregiving experiences were coded initially. Then, in looking to identifying themes across the various participants' interviews, I moved the analysis to Phase 3: Searching for Themes (Braun & Clarke, 2012). Within this phase, both overarching themes and sub-themes were identified. With the identification of these themes and sub-themes then came Phase 4: Reviewing Potential Themes. In this fourth phase, the aim was to ensure the individual themes and sub-themes were unique, meaningful in relation to the research topic, and consistent across the various participant interviews. Once the themes were narrowed down, I moved to Phase 5: Defining and Naming Themes.

In naming the themes, Braun and Clarke (2012) highlight that it is necessary to ensure the names first address the research question, second, have a narrowed focus on a particular aspect of the participants' experiences, and third, relate to one another or build upon but do not overlap. Thus, these aspects were taken into consideration when developing the theme and sub-theme names. An example of the analytic process is presented in Table 2. The left column of the table displays a verbatim quote from the interview data as an example. The following column to the right identifies the initial codes identified within the participant's quote. The third column

displays the relationship the initial coding has to the caregiver experiences. Finally, the final column on the right presents the named overarching themes which the sub-themes branch from. The themes and sub-themes identified throughout this analysis process then served as a guide to display the accounts of each participant in the individual case reports.

Table 2

Demonstrating the Coding and Theme Development Process

Verbatim Example	Phase 2: Codes	Phase 3: Initial Themes	Final Overarching Theme Name
<i>"We are very close. We don't have children and he pretty much shut down when he got his diagnosis and did not want to talk about it to, with anyone. No one was to know, we just had this cone of silence that went over the two of us and that made it easier for him and more difficult for me."</i>	• Changes in loved one's behaviour in an effort to cope	• Caregivers recognize the changes in the patient and can appreciate their coping efforts	• Being a Witness of the Patient's Struggles
	• Desire to support loved one's needs, despite challenges	• Caregivers attend to patient needs despite the implications on caregiver wellbeing	• A Duty Paired with a Desire to Support Patients - Regardless of the Challenges

The Case Reports

Following the analysis of the individual data sets, all of the data collected from each participant was incorporated into the participant case reports. Within the case reports, the demographic, CQOL-C, and case note data were taken together to provide a background context to the reader. The interview data, including direct quotes, were placed into the themes discovered through the analysis of the qualitative data using thematic analysis. The cases were designed to organize all of the data within each case in a way that would highlight the unique caregiver experiences within their own context and would allow for the data to then be compared to past literature.

This comparison to past research will allow for the examination of how the findings may relate or differ from the literature which is identified by Yin (2003) as a key principle required in order to produce a high quality analysis. This comparison of the study results to past research will take place throughout the discussion chapter of this thesis. Producing high quality analysis also requires the identification of measures of trustworthiness taken by the researcher, which will be described in the following section.

Research Quality and Rigour

Trustworthiness, the means of acquiring confidence that participant's experiences are accurately depicted within the study's findings, can be achieved through addressing credibility, dependability, and transferability (Lincoln & Guba, 1985). This section of the study methods will first identify the measures taken to increase credibility of the study results using triangulation, as well as the validity of both the qualitative and quantitative data collected. The strategies to increase the transferability and dependability of the study will follow.

Credibility. The trustworthiness element of credibility were addressed throughout this study in a number of ways. First, validation of the data occurred through data triangulation which involves the collection of multiple sources of data to support the phenomenon (Yin, 2003). The phenomenon being explored in this study are the experiences of family caregivers of patients enrolled in the Palliative Rehabilitation Program. The various units of data collected (the interviews, CQOL-C scores, observations, and demographics) were selected in order to contribute to the development of an understanding of family caregivers' experiences. In order to preserve the multiple realities of each case, the various units of analysis were combined to depict the unique individual case of each caregiver. Then, the comparison of all cases took place in

order to develop an understanding of the overarching context – how family caregivers perceive caring for a patient enrolled in a palliative rehabilitation program.

Trustworthiness specifically done throughout the qualitative data collection period involved in vivo member checking - a means to check with participants during the interview that you have understood their response correctly and are able to provide them with an opportunity to correct or rephrase comments if desired. Trustworthiness in regards to qualitative data analysis also involves an outside observer who examined the data, a practice to assure data accuracy (Lincoln & Guba, 1985). The outside observer for this study has both palliative care work experience as well as research expertise and was involved in debriefing throughout the data collection and analysis as well as auditing the analysis of transcripts.

It is also necessary for the trustworthiness of qualitative data that the researchers aim to bracket their biases. I as the researcher, am aware of my biases that may arise from having lived with a family member with a life-threatening cancer diagnosis as this experience led me to recognize the impact the patient illness can have on family members. Further, working in a palliative care research team has allowed me to see the workings of palliative care. Being aware of my personal experiences has allowed me to bracket them in order to be fully engaged in the experiences of the participants throughout the data collection and analysis process. Also, I must identify that my philosophical assumption is an ontological assumption as I believe the realities of family caregiving can be seen through many views and so it is necessary to gain perspectives from a variety of individuals to develop themes within the data.

Dependability and reliability. As this study utilized both qualitative and quantitative data collection methods both dependability and reliability must be assessed. Dependability, the expectation of consistent results across researchers and over time (Morrow, 2007), was addressed

for the qualitative research components by creating an audit trail. This audit trail was documented in a reflective journal. Included in these notes are the recruitment process, the various stages of analysis, the emergence of themes, and the developing identification of the phenomenon (Corbin & Strauss, 2008). Regarding the quantitative data, the CQOL-C is a well validated and reliable instrument (Weitzner, et al., 1999) providing the expectation that caregiver quality of life levels have been reliably represented in their CQOL-C scores.

Transferability. Transferability is the ability to apply research results from the initial sample population to a theory and to other populations (Gall, Borg, & Gall, 1996). Through the use of a collective case study approach, this study collected detailed information from four family caregivers in order to describe the phenomenon - their experiences - which is a fundamental aspect of addressing transferability (Corbin & Strauss, 2008). This in-depth account of the phenomenon invites readers to transfer the findings to other cases to assess if they are suitable.

Data security

All hard copy data are stored in a locked filing cabinet at Bruyère Hospital. All electronic data is securely stored in password protected files on the secure Bruyère Continuing Care server. Audio-recorded interviews were recorded on a digital recording device and transferred onto the Bruyère server directly after the interview and then were deleted from the recording device. All electronic and hard copy data will be destroyed after 10 years following ethical guidelines outlined in ethics approvals received from the Bruyère Research Ethics Board and the University of Ottawa's Research Ethics Board. To protect the confidentiality of the participants, all participant data has been coded with a unique personal identifier and personal identifying

information included in the audio files will be replaced with non-identifying terms in the transcripts (i.e. Using the word “husband” instead of the husband’s name).

Chapter 4: Results

A note about the use of identifiers. In order to provide as much lucidity as possible for the reader, participants are referred to as pseudonyms throughout this section.

In attempt to answer “How do family caregivers perceive their experiences of caring for a loved one diagnosed with advanced cancer and who is enrolled in a palliative rehabilitation program?” the case study design of this research project first examined all of the units of analysis. The themes identified throughout the thematic analysis of the interview data, described in the methodology chapter, were then utilized as a guide to display the accounts of each participant in individual case reports. By using the themes to organize the case reports, it is my hope as the researcher, to enable the reader to developing an understanding of the unique experiences of each caregiver case, while highlighting the transferability of the themes to varying caregiver experiences. These case reports for each participant include the various units of analysis that were collected throughout this study – including the demographics, case notes, and CQOL-C scores which were included as descriptive data to establish the participants’ personal case context, as well as the interview data which provides detailed accounts of their perceptions of their caregiving experiences throughout their unique context. The aim of displaying the data of each participant case within individual case report allows for the readers to develop an understanding of each participant’s unique case and how their experiences may relate or differ from one another.

This section of the thesis will first present the individual family caregiver case reports, incorporating all of the units of analysis collected for each participant. Case comparisons will then be displayed through reviewing the themes and sub-themes which arose through the thematic analysis of the cases, and descriptively reviewing the CQOL-C scores. A summary of the case reports will also be presented at the end of this chapter in Table 3.

Owen

Context

Owen is the primary caregiver for his brother who was diagnosed with brain cancer approximately seven months prior to participating in the Ottawa Palliative Rehabilitation Program. The brothers had originally lived across the country from one another, one in British Columbia and the other in Ontario, but since the illness treatment began, his brother has moved in to Owen's home and is living with he and his wife. Further, Owen identified that he had not personally accessed any services or resources to support his needs since taking on the caregiver role.

Case note observations identified that Owen accompanied his brother to all of his sessions at the Palliative Rehabilitation Program. Prior to attending the program, the siblings went through many challenges as a result of the illness and treatment and following the rehabilitation attendance, many of these challenges persist, leaving Owen with still a heavy family caregiver role. Owen shared that in order to ensure all of his family members understood where his brother's functioning needs were at, he took it upon himself to coordinate a family meeting with the health care team and various family members (case note data).

His overall caregiver quality of life scores decreased from his pre assessment score (84) to his post assessment score (65). Specifically, increases occurred in the factors of disruptiveness (pre = 12, post = 18) and burden (pre = 15, post = 21), while no change occurred in his positive adaptation factor score (pre and post = 13). This first section of Owen's case will focus on the impact of the illness and treatment on the patient as experienced by Owen.

Being a Witness of the Patient's Struggles

An Engrained Memory from the Time of the Initial Diagnosis. Owen began by explaining his brother's cancer diagnosis as unexpected he explained, "I got a phone call from him one night saying he was in the hospital expecting brain surgery having been diagnosed with a brain tumor". His brother went on to explain to him that "it didn't look good and he was pretty, pretty worried". Owen explained his brother's diagnosis story as "he had a splitting headache and self-diagnosed over the couple of days of the headache not going away that he must have a brain tumor, went into the emergency and they concurred that it didn't look normal". Owen went on to explain, "he got put into the neurology ward on a standby basis and was waiting for the opportunity for the surgery to happen". However, Owen shared that his brother grew impatient and left the hospital unannounced and that eventually they were able to get him back to the hospital, explaining, "it took about two weeks, he didn't want to go but the pain kept getting worse and worse". Owen's brother's illness escalated quickly and eventually re-assessed by the neurosurgeon who said "'this is very serious' and he 'would do the best he could', he 'couldn't promise anything' and gave us his elective surgery date which was not until the following Thursday". Owen explained that his brother "would have been dead by then I'm sure because he ended up being operated on the very next day". Owen went on to explain that "his tumor had

grown more than 50% ... from the first time he was in the hospital to the time he went in so he just barely made it through the process of having the surgery”.

A Time of Witnessing the Illness and Treatment Impact on Patient Functioning. After the surgery, Owen’s mother stayed with his brother for a time but eventually Owen travelled back to British Columbia to learn more about the impact of the surgery on his brother’s functioning, explaining, “I think that’s part of the brain surgery the parietal lobe has been effective and he’s got cognitive dissonance issues”. Owen began to notice that his brother who is “very independent and very willful, doesn’t believe in any limitations even though he’s clearly got some” following the surgical procedure to remove his tumor. Owen was successful in convincing his brother that he does require support for his daily living as he explained, “I convinced him that he, you know he needs support, he couldn’t do this on his own”, a conversation which eventually led to Owen moving his brother from British Columbia to Ontario to live with he and his wife.

A Transition Period for the Patient’s Wellbeing and Relational Behaviours. This “cognitive disconnect”, as Owen explains it has continued long after the surgery, resulting in his brother becoming frustrated with the recovery process. Owen identified that his brother still feels as though he can still function at the same level he used to, despite the effects of the surgery on his brain which have impacted his psychological and physical abilities. Owen took a few moments to share the amazing abilities his brother had and reflected that “he’s got all these skills of the past that were incredible” naming some of his talents in carpentry, skiing, and cycling. However, upon returning to some of these activities such as cycling through participating in a bike spin class as part of his rehabilitation, his frustrations became evident to Owen. His brother expressed interests in “spinning on a bike to get back in shape” so Owen set up an appointment

for his brother to begin training. However, upon minor feedback from the instructor, whom was experienced working with brain injury patients, Owen's brother quickly became frustrated and angry stating "you think I don't know how to ride? You think I don't know how?". In his mind he is still a professional cyclist who is just out of shape, however in reality he is not aware that his physical abilities are no longer present and he will have to re-learn the techniques. Owen shared, "he realizes somethings and understands them but... They don't really connect in reality". Owen recognizes this is a challenge for his brother explaining, "he's having a hard time coming to grips with that". Owen further explained, "I don't think he's given up at all but his idea of what he can do is not in-sync with his reality and that's the issue".

Beyond the challenges his brother is experiencing in terms of his physical and psychological abilities, Owen explained that he knows his brother also recognizes that he requires extensive attention, stating, "he understands he's an imposition and he doesn't want to be". Owen further went on to explain that he and his wife, "we tell him 'no, no, you're welcome here' and that sort of stuff but he obviously understand it".

Summary

Taken together, Owen's perception of his brother's illness was a life altering experience for both he and his brother. Following the brain surgery, Owen recognized that his brother's functioning was drastically changed. His brother whom was once a very independent and talented athlete and carpenter, now no longer holds the skills to complete even basis training in these areas. The primary challenge arising for his brother is that he still thinks that he holds these skills yet when he attempts to use such skills, he is unsuccessful and becomes quickly frustrated with those hoping to support his rehabilitation. Further, Owen recognizes that it was difficult for his brother to accept that he must leave his established and independent life on the other side of

the province and move in with Owen and his wife. Now living with the couple, Owen's brother actively expresses that he feels like a burden on Owen and his wife despite their efforts to ensure he knows that he is welcome to stay with them.

A Duty Paired with a Desire to Support Patients - Regardless of the Challenges

A Fully Accepted and Committed Role to Support Patient Needs. Since taking on the family caregiver role, Owen has faced numerous challenges in working to support his brother's needs as a result of his cancer and brain surgery. He identified that his caregiving role is a large portion of his life, explaining, "obviously it's taking most of my life at the moment". Owen recognizes that his brother is seriously impaired as a result of the illness and brain surgery, sharing, "I think he does need psycho-social adjustment". Thus, Owen has spent copious amounts of time accessing resources in order to learn methods to improve his brother's functioning, both physically and mentally. He shared some of the various resources he has accessed in an effort to support his brother's needs, explaining, "we go to a cancer coach... I managed to get us a trial at the RA center... a practicing neuropsychologist in town who specializes in brain trauma, I'm seeing him". Owen continued to explain, "I keep looking all the time... until I get a solution to taking care of him, I'm not going to be able to stop looking". Researching, accessing, and assessing supports has been a large part of Owen's adaptation to his caregiving role as a means to find a way to address his brother's needs as best as possible. When asked about his self-care efforts as a caregiver

Despite the large amount of effort and time it has taken Owen thus far to explore various resources to support his brother's needs, Owen has openly accepted the responsibilities required to be a primary family caregiver. First he explained, "I don't regret helping him or feel it's a chore but it's something that needs to be done and I realize that and he's my brother, I've got to

do it”. He further expressed his acceptance of his new role by stating, “it’s an obligation and a duty but, that I accept”.

A Period of Limited Social Interactions and Support. Owen’s feeling around the caregiving role taking up much of his life have provided him with challenges in his home life explaining, “it’s taking up so much time and its hard on the stability of my life with my wife and my dogs and, things have changed”. He recognizes that having his brother living in his home is also impacting his wife as he explained, as an example, that his brother often “gets up in the middle of the night many times” and has meals, leaving a mess which she cleans up in the morning, “it’s hard for her to get up every morning and... the kitchen is just a mess and it’s half an hour often for her to clean up”. Owen has been able to provide both he and his wife a break from caregiving through asking his sister for support when they need a night out he explained, “I called on one of my sisters...she said ‘sure yeah he can come and stay with me for the weekend’... so that’s what we did”. In taking all of these challenges into consideration, Owen explained, “at times it’s incredibly stressful, most of the time it’s not”.

In identifying that there are times his caregiving role is not stressful, Owen also identified that taking on this primary caregiver role has strengthened his relationship with his brother. Owen explained, “it’s brought me closer to him for sure which I really appreciate and we’re closer than ever and I didn’t really know his life until this happened and he opened up to us”. He further shared, “I think we’ve got a pretty good relationship, he trusts me obviously” explaining, “I’ve got all his powers of attorney. I’ve set up his will and all that sort of stuff for him”. Owen feels that his brother is happy to be supported by him and that the trust he has in Owen is positive, as he shared, “he’s happy with being looked after that way I think, he trusts me which is good”.

A Transition Period into Experiencing Emotional Struggles. With all of his efforts to try to find a solution to caring for his brother's needs, Owen reflected on a time when he experienced emotional challenges and frustrations around the trial and error approach to explore support resources. Owen shared, "I did have a little, sort of depression period" when he felt as though, "it was just getting too much". He explained that over and over he has been trying to find an approach to address his brother's challenges, yet he has not found an answer to his questions, describing this frustrating experience as, "you keep banging against the same questions" continuing on to state, "you work hard trying" while seeing little improvements for the amount of effort he is putting in.

Taken together, since moving his brother across the country to live with he and his wife, Owen's life has drastically changed. He now spends much of his life exploring supports and resources to find a way to address his brother's physical and psychological functioning which have been significantly affected by following brain surgery to remove his cancerous tumor. Owen recognizes and understands his brother has significant challenges in differentiating what he is currently able to do versus what he remembers he was able to do in the past, which in turn leave him frustrated when participating in rehabilitation supports. Upon his frustrated reactions he quits and Owen is left to find other supports. Such repetitive encounters have created frustrations for Owen and eventually led to him self-identifying a depression period where it felt like too much to cope with. Despite these frustrations, Owen openly accepts the responsibilities that come with being a caregiver and he has been able to identify the positive implications taking on this role has had on their brotherly relationship – including developing trust and getting to know one another.

A Role Which Requires Tailored Knowledge, Support, and Resources to Aid in Improving Patient Functioning and in Managing Caregiving Tasks

An Opportunity to Witness Patient Changes in Light of Rehabilitative Supports.

Owen and his brother were referred to the Ottawa Palliative Rehabilitation Program as a resources to provide them support and other networks to work towards improving the patient's functioning. In assessing any changes that may have occurred in the patients functioning after participating in the program, Owen shared "we've noticed his dexterity with his hands is a little better for something. He's using a knife and fork at times, a bit better in the last month I would say". Owen was able to recognize improvements in his brother's physical functioning, however, he did identify that his brother's functioning only improved to a certain extent and identified significant limitations that still exist, explaining "still doesn't do his shoes, shoe laces or anything like that, I help him with that". Owen went on to share that he was hoping for more of a physical improvement but that he recognizes that his brother is not practicing his rehabilitation lessons and feels as though the lack of improvement he has observed may be due to his brothers lack of exercise practice. Owen explained, "I was hoping he would have a little more physical abilities as a result and I guess he's gained a little bit but he's not practicing so therefore he's not getting the returns I think, and that's frustrating". In this statement Owen identified that he felt frustrated seeing his brother not work to improve his functioning, particularly when he thinks about the incredible athletic abilities his brother once had which he is now not attempting to regain. He expressed, "it's hard to accept that [lack of practice] especially to know how, what amazing physical dexterity he used to have and that he's not working to retain that or get that back". Owen actively works to remind himself that the lack of improvement and lack of practice is his brothers choice and not his, stating "that's him, not me".

However, Owen feels as though his brother's cognitive functioning was effected by his brain surgery and that this may be having an impact of his understanding that he must practice to improve his functioning. Owen explained, "that's the disconnect with his brain somehow that has happened". He went on to identify, "it's not the programs problem" but he does hope that another program will be able to address these complex needs to help his brother function more independently sharing, "hopefully some of these other social psycho programs will direct him to more reality of what he can do and how he can get more out of his life". As Owen recognizes that his brother's challenges may be largely related to his problem solving abilities and understanding the realities of his new physical limitations, Owen was pleased to learn from the Palliative Rehabilitation Program's physiotherapist that his brother may be beginning to recognize that he may not have the ability to live on his own. Owen shared this encounter with the physiotherapist explained, "[she] actually came to me at the end and said 'you know [your brother] is talking about he wants to go back to [British Columbia] and get himself an apartment to be on his own but he can't do that because he needs support'". Owen was excited to learn this, explaining "he actually said that out loud to somebody else for the first time and I didn't hear it but I believe she didn't make it up!" Just knowing that his brother has said this to someone provided Owen with a sense of hope that they may eventually get to the point where he and his brother have a shared understanding of how to support his physical limitations.

A Transition to Feeling Social Support from Care Professionals to Develop Methods to Manage Day-to-day Life as a Caregiver. Throughout his brother's enrollment in the Palliative Rehabilitation Program, Owen attended every session, twice a week and connected with team members weekly for discussions around next steps and brain storming ideas to best support his brother, expressing that, "I know there's a team approach here and I'm part of the

team, that's the way I look at it". Owen also took the initiative to schedule a family meeting with the Palliative Rehabilitation Program's team and some of his family members to ensure everyone in his family had the same understanding of his brother's functioning status. Owen explained, "we had a family meeting... with the team, or most of the team, [the physician] described a lot of stuff and he explained more about [my brother] than we had heard from any other health care professional". Further describing the physician as, "he was very well put and helpful". Further, they discussed the challenges of his brother not completing his exercises as, "if he's not helping himself, there's not a lot of hope for progress". As the program went on, Owen explained that his discussions with the program's Social Worker helped him find new resources and was able to provide them with referrals as he explained, "I'm really happy with the efforts they made and especially I like [the Social Worker]". He went on to explain what he appreciated about the Social Worker sharing, "she's been dynamite trying to walk me through situations and helping me and directing me, plus getting me some services for [my brother] if possible". Further, Owen explained his comfort in asking for support from the program Social Worker as, "I know she's an open door to talk to about that stuff". Owen closed his experiences of the program by share, "this is a great organization, I wish we could stay longer".

Taken together, Owen was able to see some improvements in his brother's physical functioning, however he recognized that the physical improvements may have been limited due to his brother's lack of practice for his rehabilitation exercises. This lack of effort presented by his brother caused Owen to feel frustrated, however Owen made efforts to not take responsibility for his brother's lack of practice and also felt sure that it was not the programs fault for the lack of improvements. Owen felt as though his brother's cognitive challenges which were a result of his brain surgery may have impacted his lack of understand that he needs to practice in order to

improve his functioning. In regards to his brother's psychological functioning, he feels as though his brother is slowly coming to terms with the idea that he may not be able to function on his own and that he may need support throughout his daily life as he shared these thoughts with the program's Social Worker who then updated Owen. Owen was pleased to learn that his brother had expressed these thoughts as he hopes they will soon be able come to a shared understanding of his brother's new reality. Owen also shared that he greatly appreciated the support of the program's Social Worker who assisted him in finding resources to further support his brother and whom was a sounding board to discuss next steps and caregiving approaches. Over all, Owen felt as though he was part of a team in the Palliative Rehabilitation Program setting and felt it was a great program.

Fara

Context

Fara is the primary caregiver for her husband who was diagnosed with throat cancer approximately one year prior to participating in the Ottawa Palliative Rehabilitation Program. The couple live together and have no children. Prior to attending the program, the couple went through many changes as a result of the illness and treatment. Fara identified that she did not access any supports for her personal needs, other than gaining a flexible work arrangement.

Case note observations found that Fara accompanied her husband to all of his sessions at the Palliative Rehabilitation Program. She did not seem to engage with any of the other caregivers – however her appointments did not overlap with the other caregivers of this study, and she and her husband chose for him to attend only bi-weekly over the eight weeks of enrollment based on their personal perception of her husband's rehabilitation needs. One

interaction I, the researcher, had with Fara was brief but emotional for her as she explained she was saddened and frustrated with the idea of her husband being ill. When asked if she would like to discuss her experiences with the rehabilitation team's Social Worker, she did not want to. The social worker was informed about this interaction as something to keep in mind.

Fara's overall caregiver quality of life scores increased from her pre assessment score (74) to her post assessment score (94.7). Specifically, decreases occurred in the factors of disruptiveness (pre = 14, post = 8) and burden (pre = 24, post = 18), while a small decrease occurred in her positive adaptation factor score (pre = 16, post = 15). This first section of Fara's case summary will focus on the impact of the illness and treatment on the patient as perceived by Fara.

Being a Witness of the Patient's Struggles

An Engrained Memory from the Time of the Initial Diagnosis. Fara began by explaining her husband's cancer diagnosis as something that was unexpected, "he had a bad cold about a year ago but he felt that he had swelling in both sides, at least one side of his neck which... wasn't going down so he went to see his family doctor who suggested a scan". At this point the couple attended meetings and appointments to learn more about the swelling. Fara went on to explain, "I think we progressed from a sonogram to something else to something else and that whole process took about two months". At this period of time she and her husband were not expecting a cancer diagnosis as she noted, "at all points the doctors were saying well there is a swelling there you know but it's nothing, were just doing this as, you know, to rule out the problems". However, she explained further, "we got a call from his an ear, nose and throat doctor who had order the last scan. We thought we were going in to have her say that everything's fine and that's when she said, you've got cancer". At this point, Fara took a deep breath out sighing at

the memory of the diagnosis conversation that occurred approximately seven months ago. From this point on the couple was faced with the challenges of the cancer treatment which Fara felt as though there were so many unknown aspects of the treatment and illness that they had to learn about as she explained, “everyday we were learning something or there was something new to deal with”. She went on to explain how she perceived the effects of the treatment on her husband, identifying that, “the debilitating, the cumulative effects of the radiation and the first chemo treatment and things fairly quickly went downhill after starting the treatment”.

A Time of Witnessing the Illness and Treatment Impact on Patient Functioning. The physical impact of the treatment had a large impact on her husband’s ability and interest in eating. She explained, “when you’re cooking when they’re in their treatment, everything is exaggerated, the smells are exaggerated and of course he feels sick because he can’t stand the smell”. However, Fara’s husband’s decreased nutritional intake has persisted long after having completed his treatment, an unexpected challenge the couple is currently facing. Fara explained there are “still effects of the treatment which are lasting a lot longer than advertised. We pretty much were told, the big issue for him is because he had throat cancer he has lost his sense of taste”. She shared that her husband is frustrated with his lost taste senses and has a desire of “being able to take real food in, as he calls it”. She went on to explain that his sense of taste “has come back 5% and we were told it was going to come back a lot faster than that initially”. At this point now Fara and her husband are being told that the return of his sense of taste may take much longer than anticipated, explaining “everyone we see here after says... ‘it could take between’ it was two months then it was four months then it was six months and last week we were told it could be a year and 18 months so that is discouraging”.

A Transition Period for the Patient's Wellbeing and Relational Behaviours. Upon diagnosis and throughout the treatment, Fara's husband did not want to discuss his illness with anyone nor did he want her to share as she explained, "he pretty much shut down when he got his diagnosis and did not want to talk about it with anyone". It was not until after his treatment Fara explained, that her husband felt comfortable in sharing his illness experiences with one of his close friends, "now that the treatments are over he's actually opened up a little bit to a friend. I'm thinking 'ha you wait 'til is all over, now you talk about it'" as she laughed for a moment then noted, "but that's the only way he could get through it".

Summary

Taken together, Fara's perception of her husband's illness was one of unexpected encounters. She described that they felt as though they were learning something new every day and had more challenges continue to arise throughout treatment. Still now her husband's sense of taste has yet to return and this is causing an ongoing challenge as he has little interest in eating. There has been a lack of clarity regarding the return of his sense of taste as his medical professionals continue to extend the estimated time his sense of taste may return. Throughout the whole treatment process, Fara explained that her husband completely shut down and would not discuss his illness and treatment experiences with anyone. She further identified that this was his personal way of coping and that it was the only way he could get through the challenges he experienced throughout his illness treatment. It was only after treatment that he shared some of his experiences with a close friend.

A Duty Paired with a Desire to Support Patients - Regardless of the Challenges

A Fully Accepted and Committed Role to Support Patient Needs. Throughout the course of her husband's illness, Fara experienced a variety of personal challenges, including both emotional and physical difficulties. First, regarding her emotional difficulties, Fara identified that she was angry about his illness, as she shared, "I was angry, I was angry about the situation". She further explained that she felt in shock by learning about the illness and watching the treatment affect her husband, she explained, "you're sort of stunned by what's going on". This stunned experience impacted her physical wellbeing as she identified that she lost her appetite and experienced a significant weight loss after her husband's diagnosis. She shared, "I lost 10 pounds in that first month...I just lost my appetite". Fara went on to explain that it was not only the shock of her husband's diagnosis and treatment that affected her appetite but it was also the change in his interest and ability to eat as a result of the cancer treatment. Fara reflected on her thoughts at the time as, "he's not having supper so I'm not going to bother having supper". The couple's routine meals together suddenly changed for them and Fara was expected to now have meals alone. It was when Fara recognized that she was experiencing a decreased level of energy to care for her husband that she began to address her eating habits as she explained, "after that first month, that's when I gave myself a kick in the ass and thought wait a minute, I'm getting tired... I can't mimic what he's doing, not eating. I mean I have to eat".

When describing her caregiving experiences Fara explained that there are really no other options when your spouse is sick, you just do what you need to do as a caregiver to support the patient. She explained this perception as, "I had no choice. You just do it". She went on to share, "you don't even think about it, you just do", further identifying, "there is really no time to feel sorry for yourself or I mean you're mad at the process. I mean the fact that this is going on but

you don't stop". She reiterated that "you just do and do and do". Fara upheld this "you just do" attitude as a part of her adaptation to taking on her family caregiver role.

A Period of Limited Social Interactions and Support. From the time of diagnosis and throughout the treatment, the couple barely spoke about their situation and did not share the illness diagnosis with anyone. This change in their regular communication with one another and others was one of the most significant challenges Fara felt as she explained, "from my perspective it's been difficult. We are very close. We don't have children". This transition led to Fara feeling a lack of support as she felt unable to share her experiences with anyone as she shared, "no one was to know, we just had this cone of silence that went over the two of us and that made it easier for him and more difficult for me". She further explained, "it made it very difficult for me to do that alone but because I respect what he wanted to do, we did it".

By not speaking to others about her husband's illness, Fara became limited in asking others for support throughout the treatment. She explained, "I think because he didn't want to share his story with anybody, and in our neighbourhood we've got fabulous neighbours... they've all been wondering 'well where's [your husband], he's not out walking the dog' or 'I haven't seen your husband in a while' or 'why are you out' you know, 'why are you doing the raking? why are you cutting the grass?'". Despite feeling that her neighbours already knew her husband was sick, Fara felt unable to let them know just how sick he was and unable to ask for assistance in completing some of the physical house work, as she explained, "they all knew that he was ill but I was not able to say 'he's seriously ill, can you give me a hand?'. They would have done it in a heartbeat". Abiding by her husband's desire to not tell people about his illness, also made it a challenge for Fara to gain emotional support throughout her caregiving. However, Fara noted that she did eventually share her husband's illness diagnosis with her brother explaining that "I

was able to make my own outlet with reaching out to my brother” however, she did feel pressure to “confess to my husband that I had actually talk to somebody”. Even when she began to share her experiences with another individual, she found that “when you’re talking to friends and family you can rant and rave and they remember the ranting and raving. They don’t realize that it’s... just verbalizing all sorts of stress”. Fara felt a lack of understanding from her support system at this point as well which increased her difficult experiences with gaining social support for her emotional needs.

Even in reflecting on the question, have there been any positive aspects of being a caregiver, Fara explained her ‘you just do’ approach, “it didn’t make me closer to my husband because we already are like two peas in a pod. So I didn’t have that experience. Looking after him is just, as I said, is just something you do. It doesn’t give you more satisfaction because you’re doing more. I mean you literally just do it”. At this point in her reflection, she returned back to the question asking herself, “Is there a positive part about being the caregiver?” Her response being, “I can’t tell you. It’s just a shared experience...I guess I just, I was lucky that I was able to do it. I think that’s about it”. Despite these ongoing challenges, Fara shared that she was grateful to share the difficult experience with her husband.

A Transition Period into Experiencing Emotional Struggles. In reflecting on the approach to coping with the illness she and her husband took (not sharing their experiences with other), Fara explained, “because of the way we approached it, it was sometimes difficult”. She went on to identify, “I think just twice... maybe three times when I just had to cry. For nothing, you’re just reeling against the universe, it’s not going to change anything. It was my little outlet”. Fara went on to further explain her emotions, only thinking of a few times where she wished all of the emotional challenges of the illness would just go away. “Twice I thought...I don’t want

this to be, I don't want to do this again tomorrow, I don't want to feel like this again tomorrow but you know for the most part you just do, just do and do". This "you just do it" attitude was Fara's way to push through her emotional experiences and return her focus back to her caregiving role to support her husband's needs.

Fara continues to feel emotionally uneasy regarding her husband's health, especially because of his ongoing loss of taste bud functioning. She described that this ongoing challenge is "as difficult on the caregiver, as it was on him, because you're looking forward to having survived, and you do it together, this horrible thing, and then you think well now we're going to start feeling better and it's not happening and it's very worrying". She had anticipated that after completing treatment that her husband would regain his previous functioning. However after having completed treatment several months ago and not seeing improvements in his sense of taste, she still experiences the worry that her husband is not well.

Further contributing to this unease Fara continues to experience was the lack of information she and her husband received regarding his health status upon completion of his cancer treatment. The couple left the treatment center unsure of what to do next and who to access for support if needed as their next follow-up appointment was booked for months away. Fara explained, "when you finish treatment and you ring your little bell and you leave the cancer center, what? You, you don't know anything". Fara continued to explain, "you don't know whether it has been successful. You don't know what the prognosis is". She went on to clarify, "I mean they [the health care professionals] don't know, they can't tell you but", she continued, "when you go through such an intensive program there then you walk out ... well okay, now what?"

Summary

In summary, within this section Fara spoke to the impact her husband's illness had on her personal wellbeing and how taking on the caregiver role was a challenge for her to engage in alone. As she wanted to meet her husband's wishes of not sharing the illness diagnosis or experiences with others, Fara felt socially isolated, unable to discuss her experiences with other family members and unable to ask for help from neighbours with daily household duties, despite knowing they would be willing to help. She explained that she could recall only a handful of times where she was emotionally upset frustrated with their situation. To address these challenges, Fara developed personal coping techniques with a "you just do it" attitude. Despite the challenges of taking on this caregiver role, Fara did not regret taking it on to be with her husband and support him throughout his illness.

A Role Which Requires Tailored Knowledge, Support, and Resources to Aid in Improving Patient Functioning and in Managing Caregiving Tasks

An Opportunity to Witness Patient Changes in Light of Rehabilitative Supports. At the end of his cancer treatment Fara's husband was referred to the Ottawa Palliative Rehabilitation Program to assist him in improving functioning which he had lost as a result of the illness and treatment. After her husband was assessed by the rehabilitation program's interprofessional team his physical mobility and nutritional intake were identified as priority areas of focus. This section will first review the implications the program had first on her husband's physical mobility, and second on his nutritional intake.

Regarding his physical mobility, Fara explained that she and her husband, "we have fairly physical good health", however, after treatment her husband, "he'd lost so much weight, he was

so frail” and unable to engage in many physical activities. Fara explained their worry about reengaging in their previous physical activities as, “you are always a little nervous about going back to the gym”. However, during the program, her husband engaged in gym activities and Fara shared that it was good to have the supervision of the physiotherapist. Further, she felt comforted by the idea that “[The physiotherapist] is right there saying well okay let’s just try this and see, then looking at him”. She felt that “it was really important to have somebody trained... look at him and say ‘well okay I think you can do this’”.

Regarding her husband’s nutritional intake, Fara highlighted her appreciation for the nutritionists approach to supporting the couple with the nutritional challenges they were facing as she explained, “the nutritionist, she’s fabulous...partly because of who she is and how dedicated she was”. She went on to explain, “I mean every time we came she had more information or something else to try”. This support provided both Fara and her husband with education to assist them in developing a shared understanding of means to improve the patient’s functioning together.

A Transition to Feeling Social Support from Care Professionals to Develop Methods to Manage Day-to-day Life as a Caregiver. In discussing how the program may have impacted Fara’s sense of isolation in attempting to improve her husband’s eating alone was also addressed through engaging in conversations with the nutritionist and her husband together as she explained, “it was extremely helpful for him as well to have somebody besides me pushing”. Fara went on to identify that having professional education regarding his nutritional intake is what her husband needed, rather than just her begging him to eat as she shared, “he needed somebody to give him facts and science and drive him, not just, an emotional plead to have dinner”.

Similarly, Fara explained how simply having access to health care providers comforted her following the completion of her husband's treatment: "having this program in place is excellent because you've got some place to go and if you need to, I could have talked to a social worker, he's been able to access the doctor, the nurse because it's all very very scary even though the worst of it is over". She went on to explain, "just having professionals available once or twice a week is, because you can always get through the weekend if you're feeling bad, it's fabulous". She added while laughing, "you [the rehabilitation program] got an A+". Fara further highlighted that although she and her husband did not use the resources to their full capacity, having only attending once a week instead of twice, just being enrolled in the program provided her with a comfort that they have resources they could access if needed. She shared, "it is not just using the services, it is being able to access the services if you needed them". Fara continued to explain regarding both she and her husband, "we have fairly physical good health and pretty good mental health so we were probably not using it [the program] to what you would like to see but boy it is tremendous to be here, it really is".

Summary

Taken together, Fara felt as though she and her husband experienced anxieties when he finished his cancer treatment and they learned that they would not have a follow-up for a number of months. They were then referred to the Palliative Rehabilitation Program where they were comforted by gain access to an interprofessional health care team whom could work with them to improve her husband's functioning. Working with the team's physiotherapist provided the couple comfort that they could work towards returning to their regular gym activities together. Meeting with the team's nutritionist provided Fara's husband with knowledge around the importance of his nutritional intake, while these meetings provided Fara with support to

encourage her husband to eat, addressing her experiences of feeling alone in her pleading efforts to get him to eat. As Fara felt she and her husband were quite well both physically and mentally, they chose to only attend the program once a week but still felt an incredible amount of support in their transition from finishing cancer treatment, to functioning in their new day to day lives.

Theresa

Context

Theresa is the primary caregiver for her husband who was diagnosed with lung cancer approximately a year and a half prior to participating in the Ottawa Palliative Rehabilitation Program. Prior to this cancer diagnosis her husband was fighting a prior muscle disease. The couple live together and have three children whom now live independently away from home. Case note observations and discussions identified that Theresa accompanied her husband to nearly all of his sessions at the Palliative Rehabilitation Program – she shared that the one session she missed was due to a personal appointment. Other encounters over the eight weeks included discussions around previous family challenges she wanted to share. Prior to attending the program, the couple experienced very challenging relational experiences as a result of the life style change throughout her husband's illness battles. Theresa identified that she had accessed the support of a mental health professional to support her personal wellbeing. Further case note data included observations of Theresa chatting with Stephanie (another family caregiver participant) over the eight weeks while their husbands were completing their physiotherapy sessions at the same time. Theresa shared that she really enjoyed the opportunity to chat and share experiences with another caregiver.

Theresa's overall caregiver quality of life scores increased from her pre assessment score (101.9) to her post assessment score (111.4). As Theresa did not answer some of the questions on the CQOL-C some of the factors cannot be reported on both pre and post. However, her score on disruptiveness at the end of the eight-weeks was 2 which is low in comparison to the maximum possible score of 28 and her positive adaptation score at pre assessment was 6 which was low in comparison to the maximum possible score of 28. To build on this demographic and quantitative data, the first section will focus on the impact of the illness and treatment on the patient as experienced by the Theresa.

Being a Witness of the Patient's Struggles

An Engrained Memory from the Time of the Initial Diagnosis. Theresa explained that her husband was diagnosed with "cancer in a lymph node behind the esophagus" approximately a year and a half prior to participating in the Ottawa Palliative Rehabilitation Program. The cancer diagnosis was discovered while he was being treated for a "muscle disease called dermatomyositis" which "attacked his muscles" as Theresa explained. From this point Theresa's husband lost much of his independent functioning, spending much time in the hospital, she shared, "I had to feed him, he couldn't hold his head up, he had to have a neck brace and it was really bad". The cancer diagnosis on top of this muscle disease required the clinicians to provide large doses of steroids along with the chemo and other required medications to address both illnesses which Theresa recognized had an impact on her husband's personality, explaining, "he was on a lot of, not mind altering things, but like his fuse was pretty short, pretty short".

A Time of Witnessing the Illness and Treatment Impact on Patient Functioning. With the side effects of the treatment, Theresa husband's frustrations grew and grew as his ability to function in daily activities decreased. She shared, "the chemo and the radiation took so much out

of him and it was just really really hard”. His functioning abilities continued to decrease as she explained, “things that he used to do, he could not do anymore, he did not do anymore”. The debilitating effects of the illness and treatment left Theresa’s husband with very little he could physically do as Theresa went on to explain, “even the little things like loading and unloading the dishwasher and stuff like that, he hasn’t done that in over a year and a half now, but he used to do that”. Theresa also explained that his taste buds were effected by treatment as depicted in her recollection of a conversation in which she explained, “I would say ‘can I get you something to eat?’” and her husband responded, “No! It all tastes like sawdust!”. His lost enjoyment of eating led to a decrease in nutritional intake and frustrations with any efforts towards improving his eating and functioning.

A Transition Period for the Patient’s Wellbeing and Relational Behaviours. Theresa explained that the combination of his significant decrease in physical functioning abilities along with the various other side effects of the illness and treatment left her husband with little to be motivated by. She shared, “as far as he was concerned he was a dead man walking”. The decrease in physical abilities left Theresa to care for the daily chores of the home on her own which led to a strain on their relationship as she explained, “what he did was he sat in his chair, his recliner, in front of the TV, and he noticed everything that was not done”. Instead of attempting to support and contribute in a positive way to his wife’s efforts to care for him and maintain the home, Theresa’s husband began pointing out what she had yet to do as she explained, “it wasn’t what I had done that was ever noticed, it was what I had not done”. There was very little that he expressed appreciation towards while adapting to his illness.

Summary

Taken together, as perceived by Theresa, her husband experienced extensive implications of battling two illness, with the loss of his taste senses and other physical abilities as well as his lost sense of life purpose, aware that death was upon him. In living in this state, his personality and behaviours had drastically changed. She saw this first through his disengagement in their daily activities, which seemed to be not only due to his decreased physical abilities but also by choice. She also saw these changes in her husband's personality and behaviour as he began to criticize his wife's methods to support him, which left her feeling a strain in their relationship.

A Duty Paired with a Desire to Support Patients - Regardless of the Challenges

A Fully Accepted and Committed Role to Support Patient Needs. From the beginning of her husband's cancer diagnosis, Theresa felt as though she should not show her sadness or frustrations as it is her husband whom is sick. This experience was first displayed as she explained her memory of him first sharing his diagnosis with her, "I just held him and I could hear myself sobbing, I could hear myself sobbing and real quick I said 'oh my god!, he's laying there, his eyes are all watery, he's just told me he has cancer and I'm crying?' like it wasn't fair for him". Once this came to her attention, that she should not be the one crying, he quickly returned back to her husband's needs asking how she can support him. Her suppression of her feelings continued for many months to follow despite recognizing the relational challenges developing between the couple.

During his treatment, as displayed in the previous section, Theresa perceived many changes in her husband's behaviours and wellbeing which impacted her experiences of caregiving. She expressed that she felt as though her efforts to care for him were unappreciated,

“it didn’t matter what I did, it wasn’t good enough”. She became more and more secluded and began to hold in her thoughts and feelings sharing her perception of her families thoughts, “they all felt as though I was very capable of looking after [my husband], I think. I think they know that I am very capable, but it was really hard”. She rarely asked for help in her caregiving role despite her difficulties maintain the home and caring for her husband whom was experiencing his own challenges adapting to his illness. She pushed and pushed herself to meet her husband’s every need and expectation alone, “I’d never really been a “yes” person but he’s never ever been this sick so there’s that so he should be self-absorbed”. She began to recognize that she was suppressing her feelings and experiences in order to meet her husband’s needs, explaining “I ended up getting this thing where I had an inner voice and I had an outer voice. My outer voice was more compliant and more what he wanted to hear. But deep down I was so upset”. After each frustrating instance Theresa experienced, she attempted to justify her husband’s behaviours through reminding herself that “he’s very sick, he’s a sick sick man”. However, this could only last so long and the couple’s relationship continued to struggle for a number of months until Theresa eventually experienced a “dark time” as she explained it where she felt exhausted and alone.

A Period of Limited Social Interactions and Support. The specific instance was brought on by a fight between the couple which broke her into tears and she explained, “I thought, ‘Oh shit I can’t do this, I can’t do this, I just gotta sleep’”. She went onto explain when she checked into a hotel alone and was asked to provide personal information, “I started crying and I said ‘I don’t want to be found, I don’t want my husband to find me’ and I thought oh my god and I was sobbing”. Once she was in her hotel room she shared, “I went to my room and I just went to bed. I was so tired but I cried and I cried, I didn’t phone anybody. There was no body I could confide

in. nobody that could help me... There was nobody I could share this with”. Theresa further explained the feelings she was experiencing at the time as, “I was barely holding my head above water at that point when I left”. After taking a few days to herself she returned home only to be met with negativity for her behaviours as she went on to explain, “my boys were angry at me for doing that. Because what happened too was...my Son had to bring him to the hospital...So ‘how could I leave such a sick man? How thoughtless. How awful I was. What a terrible wife. Terrible person’. And that’s how my sons felt”. Theresa felt very alone with no social support and at the end of her rope with little energy left to give. During this “dark time” especially Theresa expressed “I did not want to involve the family”.

A Transition Period into Experiencing Emotional Struggles. Soon after this traumatic experience, Theresa explained a fluke incident which led to her coming into contact with a psychotherapist. It was only upon this encounter that she began to feel understood as a caregiver as she explained, “going to [the psychotherapist] helped a lot... he said ‘you don’t need your inter-voice you need a voice...He is self-absorbed, he is sick but rudeness is no excuse for sickness and he cannot talk to you that way, you know? And he needs to thank you, he needs to appreciate that you’re there’”. This psychotherapist was able to assist Theresa in developing new coping techniques and during their first session her strong feelings of isolation were displayed as she shared, “I cried through the whole session. He wanted me to, now he says ‘this is just a formality, do you have anyone I can contact just in case you fall down the stairs or something, do you have that kind of contact?’ And I said ‘no, no one’. There was no one that I felt comfortable putting down”. When asked how she now feels after having learned new coping techniques from her sessions with this psychotherapist, she stated that she feels, “really good, really really good. That made a huge difference”. She went on to share that she felt “it is a shame that it came to that

point. I wish I had have known highlighting that, you don't know when you're breaking point is going to be but I endured a lot, I did. I endured a lot".

Summary

To recap, Theresa's recognition and respect of the challenges her husband was facing became her initial coping technique to help her get through his daily criticisms of her methods to support him. However, this approach could only last her so long and she eventually experienced a break down where she felt completely alone and unsupported by anyone. She did not feel comfortable in asking for support or sharing her experiences with her family as she felt they thought she was capable of caring for her husband on her own. It was only when she gained support external from the family through a psychotherapist whom she felt heard and supported by. This psychotherapist was able to assist Theresa in developing new personal coping approaches such as returning to being respectfully honest with her husband when she is feeling unappreciated instead of suppressing her feelings. Since gaining this support for her personal needs, Theresa has felt better about her caregiving role and was keen to gain more support for her husband to assist him in improving his functioning.

A Role Which Requires Tailored Knowledge, Support, and Resources to Aid in Improving Patient Functioning and in Managing Caregiving Tasks

An Opportunity to Witness Patient Changes in Light of Rehabilitative Supports. As previously described, Theresa's husband experienced decreased interest in eating and physical functioning abilities which all impacted his behaviours day to day. He was referred to the Ottawa Palliative Rehabilitation Program to assist him in improving functioning in which he had lost as a result of the illness and treatment. After her husband was assessed by the rehabilitation

program's interprofessional team his physical mobility and nutritional intake were identified as priority areas of focus. Regarding his physical mobility, Theresa noticed, her husband's participation in the program, that "he's more mobile, instead of saying 'your dog wants out'... now he gets up and lets the dog out". She went on to express, "this program here for him has been wonderful, just wonderful. He is getting more strength, he's been doing some exercises at home". Further, she could visibly tell that, "he looks better, he's got a better colouring". Regarding his nutritional intake, Theresa noted that "he's actually eating better...he is eating a lot better".

A Transition to Feeling Social Support from Care Professionals to Develop Methods to Manage Day-to-day Life as a Caregiver. In discussing the changes she noticed in her husband's behaviours and functioning, Theresa was able to identify how tips and resources she gained from the Palliative Rehabilitation's nutritionist assisted her in assisting her with addressing her husband's nutritional intake. She explained that "the nutritionist lent me a couple of books and she's given us a lot of really good pointers on his eating". She went on to share that "when he eats stuff now he'll say 'oh that was good'". Now that he is expressing his appreciation for her efforts, particularly in applying her new meal preparation techniques, Theresa is now feeling more appreciated and able to support her husband's eating. She is also please that his taste buds seem to be returning as she shared, "he is getting his taste buds back so it's good", knowing that he will begin to return to enjoying meals she prepares for him. When asked how his improved functioning and eating has impacted their relationship she expressed, "it's really, really good" and further expressed that she feels that "the program is fantastic, everybody has been so good to him".

Summary

Over all, Theresa recognized improvements in her husband's physical functioning abilities in the light of participating in the physical rehabilitation aspect of the program, noticing his reengagement in daily household tasks. She also noticed that her husband may be regaining his sense of taste as he has begun to show his appreciation for her efforts in preparing meals for him, particularly after learning new meal preparation strategies from the program nutritionist. She expressed that she really enjoyed the program and felt it met her husband's needs.

Stephanie**Context**

Stephanie is the primary caregiver for her husband who was diagnosed with pancreatic cancer approximately just over one and a half years prior to patient enrollment in the Ottawa Palliative Rehabilitation Program. Case noted identified that she accompanied her husband to nearly all of his sessions at the Palliative Rehabilitation Program – she brought him to all appointments but one and explained that a friend brought her husband that week. Over the eight-weeks, observations were made of Stephanie chatting with Theresa (another family caregiver participant) over the eight weeks while their husbands were completing their physiotherapy sessions at the same time. Stephanie shared in her interview that she thoroughly enjoyed the opportunity to share experiences and make friends with another caregiver. At one point Stephanie shared she was experiencing depression which she discussed with the program's Social Worker and explained further in her interviews.

In the demographic information, Stephanie identified that she has personally accessed mental health support, she also identified that she accessed the support of friends throughout her

caregiving. She also identified in the demographics that she was retired, and she built of this in the interview explaining that both she and her husband are retired. Further she shared that they have one child whom was living at home but was soon to be moving away which she feels is playing a role in her depressive experiences. Stephanie and her husband both have experienced challenges with their mental health, especially since his cancer diagnosis.

Stephanie's overall Caregiver Quality of Life scores increased from her pre assessment score (54) to her post assessment score (73). Specifically, decreases occurred in the factors of disruptiveness (pre = 21, post = 14) and burden (pre = 26, post = 23), while a small decrease occurred in her positive adaptation factor score (pre = 19, post = 14). This first section of Stephanie's case summary will display her perception of the impact the illness has had on her husband.

Being a Witness of the Patient's Struggles

An Engrained Memory from the Time of the Initial Diagnosis. She explained his diagnosis as, "he was jaundiced and then he had an endoscopy which showed that he had, likely, pancreatic cancer... it took a few weeks for him to have a follow up because that was over Christmas". A month after his diagnosis he had his surgery to address the illness which she explained, "went very well". Following the surgery, "when he got home from the hospital he couldn't do an awful lot and then he started chemo once a week, preventative". On top of his cancer diagnosis, Stephanie's husband more recently has been diagnosed with Parkinson's disease she shared, "now he has Parkinson's".

A Time of Witnessing the Illness and Treatment Impact on Patient Functioning.

Throughout his illness treatment Stephanie shared that her husband's functioning abilities

decreased, explaining, “he wasn’t able to do as much as he used to”. Primarily it was his physical functioning which he was experiencing challenges with, which led the couple to the Palliative Rehabilitation Program to gain support through the physiotherapy aspects.

A Transition Period for the Patient’s Wellbeing and Relational Behaviours. Stephanie shared that she recognized that her husband has been unable to motivate himself when it comes to efforts of improving his functioning and wellbeing, sharing that “he’s not very self-motivating”. She went onto explain that she feels the diagnosis of Parkinson’s Disease on top of his cancer diagnosis has led him to feel depressed discouraged and that she is unsure how they as a team could be handling these experiences as she explained, “he is very discouraged and very depressed and we don’t seem to have a way of handling that”.

Summary

Over all, after diagnosis and throughout the treatment of his cancer, Stephanie perceived that her husband’s functioning abilities were quite limited. Further, she recognized that his motivation to attempt to improve his functioning was low. Following a further diagnosis of Parkinson’s disease, on top of his cancer diagnosis, Stephanie felt her husband became discouraged and very depressed while she as a caregiver is unsure how they can address these experiences.

A Duty Paired with a Desire to Support Patients - Regardless of the Challenges

Acceptance of the caregiver role and doing anything to support the patient. As the primary caregiver for her husband, Stephanie identified, “I was taking him to all of those [appointments]” during his chemotherapy treatment. She further shared, “I’m very tired; we still have lots of appointments”. While discussing her self-care methods, Stephanie explained that she

has been trying self-care techniques but has not felt successful. She shared, “I was trying to do a few things. I have an exercise class that’s only once a week and lately it’s been really hard to motivate myself to go”. With little energy to care for herself, Stephanie shared that she is having a challenge in caring for and motivating her husband. She explained, “I feel like I’m supposed to be motivating [my husband] too”. She went on to describe her perception of her ability to motivate herself and her husband as, “nobody seems to be succeeding”.

A Period of Limited Social Interactions and Support. In recounting her experiences as a family caregiver, Stephanie explained, “there is a lot of loneliness involved and isolation”. She went on to explain, “I sort of, well we tend to get withdrawn”. She noted that, “I think we can probably reach out and I think friends would want to help but they don’t know how to approach you and I haven’t figured out how to approach them”. The main source of social support Stephanie and her husband have is her daughter whom is soon moving away from the area they live which Stephanie believes, “I think that’s going to be hard on both of us”. Their daughter, “was always home for lunch and she was quite helpful”.

A Transition Period into Experiencing Emotional Struggles. Stephanie explained that the idea she and her husband will soon lose the little social support they have is having an impact on her psychological wellbeing. She shared, “I seem to have fallen into some kind of a depression lately. Maybe it’s got to do with her leaving. I don’t know”. She went on to share, “I lost all that adrenalin and energy I had before”.

Summary

Taken together, Stephanie has felt isolated and lonely throughout her caregiving role. Despite feeling as though she could ask for support from friends, she feels unsure how to ask for

help and expects the friends are unsure how to approach offering support to her as well. Thus she is providing the majority of support to her husband on her own resulting in her feeling exhausted. She did however, have support from her daughter throughout her husband's illness, however her daughter is now moving away and Stephanie recognized that this next life transition is going to be a challenge for she and her husband. A consequence of this new situation is that Stephanie is experiencing psychological challenges, feeling she is in a depression and is experiencing a lack of motivation to care for herself while also feeling as though it is her responsibility to motivate her husband as well.

A Role Which Requires Tailored Knowledge, Support, and Resources to Aid in Improving Patient Functioning and in Managing Caregiving Tasks

An Opportunity to Witness Patient Changes in Light of Rehabilitative Supports.

Regarding her husband's care she explained her appreciation for the nutritionists reconfirming support explaining, "the nutritionist was encouraging that we seemed to be on that right track". Stephanie expressed that she was happy with her husband's engagement in the program as she was keen for him to gain more social interaction opportunities, explaining, "I thought that he did well. He's committed and he actually came out of his shell and talked to the different ones [program care providers]". However, she noted that, "I thought the physio was going to be more group oriented and he'd have more interaction with the other guys which that didn't really happen, it was pretty one-on-one, but I think it was a good thing to get him to". In asking if she would recommend the Palliative Rehabilitation Program to other family caregivers and families, Stephanie expressed, "Oh yeah, I think so. Yeah I think it's good".

A Transition to Feeling Social Support from Care Professionals to Develop Methods to Manage Day-to-day Life as a Caregiver. As previously described, Stephanie has felt very

isolated and unmotivated throughout her caregiving experiences. Through participation in the Ottawa Palliative Rehabilitation Program Stephanie was able to identify indirect and direct aspects of the program which she felt were helpful for her and her husband. First, she explained how attending the program with her husband allowed her to meet spouses of other patients, she expressed, “I found it really helpful here talking to the other spouses, made a couple of friends while we were here”. She reconfirmed to herself stating, “that I found really good”. These social encounters, which occurred spontaneously and where an indirect aspect of the program, assisted Stephanie in addressing her primary challenge of feeling socially isolated. She now developed friendships with other spouses whom she could share and discuss caregiving experiences with. A recommendation she had for the program was that she found, “it was a little awkward that the spouses were all lined up in a straight line on the wall” while they waited for the patients to complete their rehabilitation sessions. She went on to suggest, “it might have been better if we had somewhere else where we could interact better, like a circular area [laughing]”.

Not only indirectly did the program help Stephanie to enrich her poor social network but it also assisted her directly in meetings with the program’s social worker to developing new personal supports, including connecting her to mental health support resources. Stephanie shared that she met with the social worker on occasion to learn about other resources to support her throughout her caregiving role as she explained, “I spoke to the social worker a few times and I’m also seeing another social worker myself elsewhere that she, I think she [program social worker] got me in touch with that group which sort of helps”.

Summary

Over all, Stephanie’s lack of social support and resources was addressed throughout accompanying her husband to the program. She greatly appreciated the opportunity to spend time

with other spouses who had a partner participating in the palliative rehabilitation program, although they were not seated in a manner to easily chat with one-another. Although this was not a goal of the program, it did assist her in gaining social encounters, feeling as though she had made friends over the 8-weeks. The program was also able to further support her in connecting her to mental health resources through Stephanie participating in one-on-one meetings with the program's social worker. Regarding her husband's participation in the program, Stephanie expressed that she appreciated the support her husband received from the health care team and that she was pleased to see him become actively engaged in the rehabilitation process and socially interact with the various health care team members to meet his needs, despite hoping that he may have had more opportunities to have social connection with the other patients enrolled.

Summary across Cases

All of the family caregiver participants included in this study were the primary caregiver for a patient who was enrolled in the Ottawa Palliative Rehabilitation Program. All of the patients were diagnosed with varying advanced cancer illnesses and had been diagnosed between 7 months to a year and a half prior to participating in the palliative rehabilitation program. Three of the family caregiver participants were wives and one family caregiver was brothers with the patient. All family caregivers shared a residence with the patient, caring for them on a daily basis from diagnosis to present. The caregivers all identified being responsible for bringing the patient to their varying appointments, including attending the palliative rehabilitation program with the patient and attending sessions with the patient to learn methods to support the patient's needs. A summary of the individual case reports is displayed in Table 3.

This section of the results chapter will review the results of the thematic analysis of the interview data which yielded three overarching themes which were then divided into eight sub-themes. These themes were utilized as an outline to display each of the four individual cases in the case reports. Cross case comparisons of the CQOL-C scores will then be reviewed descriptively. These quantitative measures were not assessed for any statistical significance but purely to explore these scores in relation to the caregiver experiences reported throughout the patient enrollment in the palliative rehabilitation program to gain a further understanding of their reported quality of life experiences. The overarching themes and their sub-themes are described below in Figure 3.

Being a Witness of the Patient's Struggles

The first major theme that arose regarding how participants perceived their caregiver role was as *Being a Witness of the Patient's Struggles* which contained the following three sub-theme depicting their experiences as An Engrained Memory from the Time of the Initial Diagnosis, A Time of Witnessing the Illness and Treatment Impact on Patient Functioning, and A Transition Period for the Patient's Wellbeing and Relational Behaviours. This theme arose as all participants were able to recount patient's encounter with their illness in great detail from the first diagnosis, to the changes and struggles they perceived the patient experience throughout treatment and acceptance of their advanced illness.

A Duty Paired with a Desire to Support Patients - Regardless of the Challenges

The second overarching theme caregiver perceptions highlighted was that their role as a caregiver was *A Duty Paired with a Desire to Support Patients - Regardless of the Challenges*. This theme spoke to the acceptance these family caregivers had in taking on their caregiving

role, recognizing it was something they felt they had to do but also having a great desire to support their loved one as best as they possibly could. In the midst of their efforts to support the patient in every way possible, all of the family caregivers shared challenges that arose for them, particularly within the areas of social and emotional experiences. Thus, this theme included three sub-themes regarding how caregiver perceived caregiving as A Fully Accepted and Committed Role to Support Patient Needs, A Period of Limited Social Interactions and Support, and A Transition Period into Experiencing Emotional Struggles.

A Role Which Requires Tailored Knowledge, Support, and Resources to Aid in Improving Patient Functioning and in Managing Caregiving Tasks

All of the family caregiver participants identify ways in which gaining access to a rehabilitation health care team, which aimed at improving patient functioning, positively impacted their unique experiences as a caregiver. Thus, the third overarching theme looking at how family caregivers perceive caregiving is as *A Role Which Requires Tailored Knowledge, Support, and Resources to Aid in Improving Patient Functioning and in Managing Caregiving Tasks*. All of the family caregivers were able to identify how the one-on-one and individualized services of the Ottawa Palliative Rehabilitation Program were able to both support the improvement of patient functioning and support the caregiver in developing methods to improve managing day-to-day life caregiving for an advanced cancer patient, all based on their unique needs. Thus, this theme broke into two sub-themes to understand caregiver perceptions, which described caregiving as An Opportunity to Witness Patient Changes in Light of Rehabilitative Supports, and as A Transition to Feeling Social Support from Care Professionals to Develop Methods to Manage Day-to-day Life as a Caregiver.

Figure 3

Overarching Themes and Sub-themes Drawn from the Caregiver Interviews

Being a Witness of the Patient's Struggles
• An Engrained Memory from the Time of the Initial Diagnosis • A Time of Witnessing the Illness and Treatment Impact on Patient Functioning • A Transition Period for the Patient's Wellbeing and Relational Behaviours
A Duty Paired with a Desire to Support Patients - Regardless of the Challenges
• A Fully Accepted and Committed Role to Support Patient Needs • A Period of Limited Social Interactions and Support • A Transition Period into Experiencing Emotional Struggles
A Role Which Requires Tailored Knowledge, Support, and Resources to Aid in Improving Patient Functioning and in Managing Caregiving Tasks
• An Opportunity to Witness Patient Changes in Light of Rehabilitative Supports • A Transition to Feeling Social Support from Care Professionals to Develop Methods to Manage Day-to-day Life as a Caregiver

Caregiver Quality of Life – Cancer Scores

The CQOL-C scores can also be examined through basic descriptive comparisons of the scores pre-post and between participants (none of the scores were examined based on statistical significance or analysis due to the small sample size). The overall quality of life scores on the CQOL-C index could result in a maximum score of 140 – higher scores reflect a better quality of life. While the maximum possible scores for the factors within the CQOL-C index are as follows: burden is 40, disruptiveness is 28, positive adaptation is 28, and financial concerns is 12 (none of the caregiver scores reported financial concerns).

The overall quality of life scores of the three female participants, who are wives of the patients enrolled in the rehabilitation program, increased in the pre - post comparison (Fara: pre = 74, post = 94.7; Theresa: pre = 101.9, post = 111.36; Stephanie: pre = 54, post = 73). Both Fara

and Stephanie's scores showed decreases on the factors of burden (Fara pre= 24, post= 18; Stephanie pre=26, post=23) and disruptiveness (Fara pre = 14, post = 8; Stephanie pre = 21, post = 14). Theresa had missing data within these categories so her factor comparison was not completed – the calculation of her overall quality of life scores were adjusted to account for the missing data as suggested in the scoring tool.

As for Owen, his results identify a decrease in his overall quality of life scores between the pre and post assessments (pre = 84, post = 65). Further, increases occurred in his scores on the factors of disruptiveness (pre = 12, post = 18) and burden (pre = 15, post = 21). Owen's opposite scores, in comparison to the other participants of this study, may be accounted for by the ongoing and complex cognitive functioning changes his brother acquired as a result of the brain surgery to remove his cancerous tumor. In returning to Owen's case summary, much of the challenges he experienced as a caregiver were a result of these cognitive changes which is an aspect the Ottawa Palliative Rehabilitation Program does not specialize in. However, in the interview data, Owen was able to identify small improvements he noticed in his brother's functioning and identify many ways the rehabilitation services supported his caregiving needs. This aspect of Owen's results highlights the crucial need to collect various forms of data in order to develop and understanding of how caregivers experience caregiving for an advanced cancer patient enrolled in a palliative rehabilitation program.

Regarding the Positive Adaptation scores of the participants, very little change occurred in their scores (Owen pre and post = 13; Fara pre= 16, post 15; Stephanie pre=19, post 14; Theresa pre=6, post= missing data so this factor was not calculated). As all of the family caregiver's focused their time at the rehabilitation program on gaining knowledge in order to assist them in learning methods to best support and manage day-to-day life caring for the patient, only

Stephanie actually shared that she spent one-on-one time with the program's social worker discussing her personal challenges and experiences. The others identified in their interviews that although they knew they could speak to the providers for their own needs, they did not or felt they did not need to.

Table 3

Summary of the Findings from each Caregiver Case Report

Being a Witness of the Patient's Struggles				
Theme	Owen	Theresa	Fara	Stephanie
An Engrained Memory from the Time of the Initial Diagnosis	• Unexpected onset of brain cancer • Diagnosed approx. 7 months prior to participation in the Ottawa Palliative Rehabilitation Program	• Unexpected onset of lung cancer • Diagnosed approx. 1.5 years prior to participation in the Ottawa Palliative Rehabilitation Program	• Unexpected onset of throat cancer • Diagnosed approx. 1 year prior to participation in the Ottawa Palliative Rehabilitation Program	• Unexpected onset of colon cancer • Diagnosed approx. 1.5 year prior to participation in the Ottawa Palliative Rehabilitation Program
	• Patient in great pain • Frustrated with being in the hospital			
	• Lost high level athletic and dexterity abilities • Unable to understand functioning abilities have changed	• Very limited physical functioning • Low interest in eating	• Limited physical functioning • Low interest in eating	• Limited physical functioning

A Transition Period for the Patient's Wellbeing and Relational Behaviours	• Frustrated with efforts to improve functioning • Choosing not to practice – does not understand he needs to	• Disengaged from physical day-to-day activities • Frustrated with loss of functioning abilities and holds high expectations for wife to do things his way	• Closed off - shut out social supports and any conversations around illness	• Disengaged from physical and social activities • Lacking of motivation

A Duty Paired with a Desire to Support Patients - Regardless of the Challenges

<u>Theme</u>	<u>Owen</u>	<u>Theresa</u>	<u>Fara</u>	<u>Stephanie</u>
A Fully Accepted and Committed Role to Support Patient Needs	• Took on primary caregiver role no questions asked • Supporting brother's needs as best as possible • Researching any and all supports and resources • Personal needs are not priority	• Took on primary caregiver role no questions asked • Supporting husband's needs as best as possible • Personal needs are not priority	• Took on primary caregiver role no questions asked • Supporting husband's needs as best as possible • "you just do it" attitude • Personal needs are not priority	• Took on primary caregiver role no questions asked • Supporting husband's needs as best as possible • Personal needs are not priority
A Period of Limited Social Interactions and Support	• Caregiving is taking up most of his time • Impacting his personal family life with his wife • Improved relationship between he and his brother	• Felt as though family expected she could support husband independently • Patient's adaptation to the illness strained spousal relationship • Felt isolated	• Felt unable to speak to personal support system • Felt unable to ask for support in caring for daily house hold tasks • Felt isolated	• Felt unsure of how to ask for help from others • Felt others did not know how to speak to her due to husband's illness • Felt isolated

A Transition Period into Experiencing Emotional Struggles	• Frustrated with brother's lack of effort to improve • Encountered a depression period when it felt like too much	• Developed a compliant "outside voice" and a frustrated, angry "inside voice" • Encountered a "dark time" where she experienced an emotional break down • Sought support from a psychotherapist which assisted her in regaining her voice	• Frustrated that patient is sick and that there are ongoing side effects • Emotional break downs – recalls only crying a few times as an outlet	• Experiencing a lack of energy and motivation making it hard for her to motivate her husband • In a depression, feeling it is due to her daughter (main support) moving away
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A Role Which Requires Tailored Knowledge, Support, and Resources to Aid in Improving Patient Functioning and in Managing Caregiving Tasks

<u>Theme</u>	<u>Owen</u>	<u>Theresa</u>	<u>Fara</u>	<u>Stephanie</u>
An Opportunity to Witness Patient Changes in Light of Rehabilitative Supports	• Some improvements in physical dexterity • Felt there was a lack of patient practice and effort • Patient began to share his acceptance that he may not be able to function independently	• Large improvements in physical functioning • Now helps in some daily tasks • Shows appreciation for wife's caregiving efforts • Expresses pleasure in eating – feels taste buds are beginning to return	• Improved comfort in reengaging in gym activities with wife after physiotherapist support • Increased eating after receiving education from nutritionist	• Engaged in rehabilitation program • Socialized with team
A Transition to Feeling Social Support from Care	• Felt he was part of the care team • Social worker was always	• Gained knowledge to support husband's eating	• Felt comforted that she and her husband had access to	• Decreased sense of isolation: appreciated connecting

Professionals to Develop Methods to Manage Day-to-day Life as a Caregiver	• available to discuss challenges and new options • Became better informed about patient's health status and functioning experiences	• Appreciated connecting with other family caregivers (mentioned in case notes)	• a team of health care providers in case any issues arose • No longer felt as though she was alone in trying to convince her husband to eat –shared discussions with the nutritionist	• with other family caregivers (made friends) • Gained personal supports and resources • Appreciated the efforts the team made to engage her husband
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Chapter 5: Discussion

The purpose of this study was to develop an understanding of how family caregivers perceive caring for an advanced cancer patient enrolled in a palliative rehabilitation program. Specifically, the study aimed to look at caregiver experiences through various sources of data including: interviews, case notes, scores on a caregiver quality of life assessment, and demographic details. These data sets were examined individually through caregiver case reports to gain an understanding of the unique caregiver experiences, and through descriptive comparisons across cases.

The research findings of this current study implied that the caregivers of advanced cancer patients experienced their caregiver role as *Being a Witness of the Patient's Struggles* throughout the course of the illness. They watch their loved one decline physically and change behaviourally throughout their transitions – all with unique experiences. In observing the implications of the illness effect on their loved one, caregivers experience a desire to support patients to the best of their abilities.

Caregivers vividly recount *A Duty Paired with a Desire to Support Patients - Regardless of the Challenges*. They accepted the duty of caring for their loved one and worked tirelessly to support the patient needs. However, throughout their caregiving efforts, the caregivers encountered their own personal challenges and struggles. Specifically, the family caregivers identified challenges in both their social and emotional experiences as a result of putting their personal needs on hold in order to fully support the patients' needs. It was not until encountering these very difficult personal times that the family caregivers began considering their personal needs. However, personal needs were still secondary for the caregivers as their primary objective was to care for the patients.

Finally, the findings of this present study highlight that caregivers perceived their roles as *A Role Which Requires Tailored Knowledge, Support, and Resources to Aid in Improving Patient Functioning and in Managing Caregiving Tasks*. More specifically, they were able to identify how the Ottawa Palliative Rehabilitation Program supported them in their unique ways by offering services to both the patient and themselves. The various health care providers available in this interprofessional team provided an opportunity for patients and caregiver to gain knowledge and support to address the varying needs of the patient – from meetings with the nutritionist and physiotherapists, to meetings with the physician, nurse, occupational therapist, and social worker. These meetings provided an opportunity to ensure caregivers and patients were under the same understanding of the varying aspects of the illness implications and approaches to care. Caregivers also had the opportunity to meet with the rehabilitation staff to discuss their personal needs. However, the caregivers of this study felt as though they were involved in the program to support the patient, and most chose not to utilize the services for their own needs. The conversations with the care providers primarily focused on gaining further

information in order to assist them in supporting the patient and gaining referrals for future care needs.

Taken together, there are three main findings of this study. First caregivers are highly involved in patient care since time of diagnosis and view themselves as witnesses to the patients' experiences and struggles. Second, caregivers transition through difficult times in taking on the caregiving role – they first accept it as a duty to care for their loved one but then begin to experience challenges. Specifically, caregivers experience social challenges through feeling unsupported in their caregiving roles and in cutting back on personal and social time for themselves. They then begin to experience emotional challenges in feeling depressed while trying to manage their caregiving efforts on their own and feeling frustrated with seeing little improvement or acknowledgement from the patient, despite their copious caregiving efforts. The third main finding of this current study highlights that a palliative rehabilitation program designed to support and improve patient functioning can indirectly support family caregivers. Through involvement of caregivers, they gain an opportunity to feel supported by a team who they can discuss and consult with. Further, caregivers are able to learn effective care methods to support and manage the unique needs of their loved one day-to-day. Thus, the involvement of caregivers in such a program may improve their abilities to care for the patient and in turn improve the support the patient may receive from the caregiver within the home setting. However, this present study also found that caregivers may perceive such patient based programs as designed only to support the patient and to gain knowledge in order to care for the patient – despite the providers being open to discuss caregiver personal experiences as well.

This chapter will relate and contrast the published literature and the findings of this study in three separate categories. First, the role of caregiver perceptions of the illness and treatment

impact on the patient will be explored. Second, the context upon accepting the caregiver role will be reviewed. Third, the caregiver needs for knowledge and support will be highlighted.

Following these reviews, the study implications for health care providers, limitations, and suggestions for future research will be described. Finally, a conclusion of this study will be presented.

Caregiver Perceptions of the Illness and Treatment Impact on the Patient

There is a large body of literature regarding the implications of cancer and treatments on patient functioning and wellbeing (Chasen & Bhargava, 2009; Metri, Bhargav, Chowdhury, & Koka, 2014). Much of this literature is based on patient self-report measures. Recent research has begun to examine the implications of cancer on patients from the perspective of caregivers.

Past literature has examined the congruence between patient and caregiver perceptions of patient symptoms through the use of reporting scales (Kristjanson, Nikoletti, Porock, Smith, et al, 1998; Lobchuk, Kristijanson, Degner, Blood, & Sloan, 1997; Lobchuk & Vorauer, 2003). More specifically, family caregiver perspective-taking in assessing patient symptom experiences have been found to have the least discrepancy with patient reports when the caregiver is asked about the patient's symptoms in a neutral way – in comparison to perspective taking from their personal view or from the view of the patient (Lobchuk, McClement, Daenick, Shay, & Elands, 2007). Further research has highlighted differences in caregiver and patient symptom ratings, specifically finding a small to moderate tendency for caregivers to overestimate patient symptoms, particularly more for psychological symptoms than for physical symptoms. (McPherson, Wilson, Lobchuk, & Brajtman, 2008). More recent research has shown that family caregivers are often highly involved in care from the time of patient diagnosis and are able to recall and report on details of the patients' illness and transitions they encountered throughout

care (Engebretson, Matrisian, & Thompson, 2015). Thus, reiterating that caregiver perceptions of the patients' illness and transitions can be an important perception to take into account.

Taken together, literature regarding caregiver reports and perceptions of patient illness and symptoms have highlighted some discrepancy with patient perceptions of symptoms (McPherson, et al., 2008). However, in terms of reflecting back on the illness from early symptoms and throughout treatment and care, family caregivers are able to provide accounts of the patient's illness progression and interactions with the care system as they are highly involved in care (Engebretson, Matrisian, & Thompson, 2015).

The findings of this current study adds to these past research findings through developing a further understanding of the detailed accounts caregivers are able to provide regarding the patient encounter with the illness. The caregivers of the present study were able to vividly recall and share details regarding the patients' early encounter with the diagnosis – which took place between 7 months to 1.5 years prior. A large aspect of the interview data collected throughout this study related to the theme of caregivers *Being a Witness of the Patient's Struggles*. The caregivers also actively recounted their perception of the impact the illness and treatment had on the patient.

The first main finding of this present study highlighted that caregivers perceive declines in both patient functioning and emotional experiences throughout daily life. Further these perceptions are unique for caregivers and change based factors such as the patients' illness diagnosis and treatment approach, as well as the patients' personal coping approaches. The findings in past research have primarily been based on quantitative caregiver reports on questionnaires (Engebretson, et al., 2015; Kristjanson, et al, 1998; Lobchuk, et al., 1997; Lobchuk & Vorauer, 2003). By exploring these caregiver recollections through interview data

collection and qualitative analysis, this present study has shown that these memories and perspectives of the patient experiences throughout the illness transitions are easily accessible and vivid for caregivers. Further, these recollections are an important source of information to assist in developing an understanding of the unique experiences of caregivers through taking into account the various factors that can influence their perceptions such as the patients' diagnosis, implications of treatment, and the patients' behaviours within the home.

Thus, the findings of this present study confirm that research should continue to take into account family caregiver perceptions of patient experiences throughout an illness as a resource to learn about patient experiences. Although past research has highlighted that it is possible that caregiver reports of patient experiences may differ from reports of patients (McPherson, et al., 2008), these varying perspectives may be an important aspect to consider. In particular, the findings of this study highlighted that caregivers recalled their perception of the patients' transitions throughout the illness from a perspective of witnessing the changes in their loved one day-to-day within the privacy of their personal lives. Within the present study, caregivers were not asked to rate the patients' experiences, but were merely asked to share their perspective. Through this qualitative approach to learning from the caregiver, they were able to provide detailed recounts throughout the illness transitions providing insight into both patient experiences and their personal experiences as a witness to the challenges and struggles of the patient.

Exploring Caregiver Transitions and Experiences in the Caregiver Role

Context upon Accepting the Caregiver Role. Previous research has found that family caregivers may perceive taking on the caregiving role in two ways – first some felt they were not given an option and second some felt they took on the caregiving role to meet patients' desire to

be cared for at home (LeSeure, & Chongkham-ang, 2015; Wennman-Larsen & Tishelman, 2002). This pressure of either not feeling they had an option or feeling they must take on the role to support patients' desires has also been described as a duty. Specifically, research has highlighted that family caregivers often take on their caregiving role voluntarily while describing these responsibilities as a moral duty to their loved one (Linderholm & Friedrichsen, 2010).

From the point of patient diagnosis, family caregivers enter into a transition of accepting and taking on the role and its responsibilities. Specifically, researchers have created a transitional model to develop an understanding of caregiver transitions (Nijboer, et al., 1998). First, caregivers encounter the stressor of their loved one being diagnosed with a life threatening illness. Second, they experience the outcomes of the stressor – taking on the caregiver role with the responsibilities and challenges that come with it. Third, and finally is the moderators which can impact the caregivers' ability to adapt to their caregiving role.

A more recent model further expanded on past caregiver transitional models by identifying that not only do caregiver transition through stress processes, which include both caregiving demands and personal welling, as well as the moderators identified as their personal context, but they also transition based on the illness trajectory of the patient (Fletcher, Miaskowski, Given, & Schumacher, 2012). Specifically, these transitions based on illness trajectories occur from patient diagnosis, throughout treatments, remissions or recurrence, survivorship or end-of-life and bereavement (Fletcher et al., 2012). Thus, all of these aspects are important to take into account when supporting caregivers.

The current study is able to relate and add to the past literature examining family caregiver experiences throughout the transition into the role of caregiver. Specifically, through analysis of the qualitative data using thematic analysis, it was found that caregivers were able to clearly

describe in detail their early days following the patient diagnosis and their transition into their long-term role as caregiver.

Analysis showed that after the patients' diagnosis, the participants' role in the family quickly changed to that of a family caregiver. Specifically it was found that an immediate urge and desire arose in caregivers to support their loved one throughout this difficult time. Descriptions of the role were highlighted throughout the caregiver interviews as a "duty" that had been "accepted" and that the responsibilities throughout the role are something "you just do" with no questions. Further, caregivers provide this support but often may feel inadequate in their abilities (LeSeure, & Chongkham-ang, 2015). Specifically, the analysis of the current study highlighted and aligned with past research in that the caregivers felt their efforts were often not helpful to the patient, despite the copious time and energy they were putting in, and that their efforts were going unnoticed. However, the caregivers continued to strive to meet their goal of supporting the patient to whatever lengths necessary, despite the implications their efforts had on themselves. The next section will describe the past research findings and the findings of the present study regarding social and emotional challenges caregivers may experience.

Social Wellbeing. The literature regarding the social implications family caregivers encounter through taking on a caregiving role is wide spread. Past research has identified that due to the abundance of time required to care for a patient, caregivers can feeling the need to take time off of work and self-care activities (Stajduhar, 2013). Mosher and colleagues (2013) research has found that a large percentage of family caregivers experienced a change for the worse in: time for family activities, relationships with friends, and time for social activities with friends – thus experiences of social isolation.

Even though caregivers perceive a shrinking social network, other past research has found that caregivers felt their social network was still important to them (Jansma, et al., 2005). More specifically, Jansma and colleagues' research (2005) found caregivers identified it was important to maintain contact with social supports in particular to gain assistance in coping with emotional and practical concerns, learning to discuss how they are feeling, and asking for support. Further, recent research has identified accepting support from family and friends as an important aspect of the caregiver phenomenon (LeSeure, & Chongkham-ang, 2015).

The findings of the present study align with the past research findings of caregivers experiencing social isolation. Further, the analysis of the current study highlighted a need for social support but limitations around accessing the social support. Specifically, in taking on the primary caregiver role independently caregivers not only felt they had a lack of time for themselves and their social life, they also felt a pressure to not show a need for help. An important finding of this study was that the caregivers expressed not feeling comfortable asking for support to care for the patient. These discomforts arose from, personal expectations that they should be able to handle caring for the patient, feeling as though others had expectations that they should be able to handle caring for the patient, or feeling unsure how to approach asking others for support. Thus, the findings of this study highlight that not only does being a caregiver impact individuals' social lives but there is also a discomfort in asking for support from social networks. These discomforts carry over to the social support that caregivers could access within health care settings.

Previous research has highlighted that caregivers can feel powerless in their role if they do not establish a relationship with the healthcare professionals, and that in order to feel seen, caregivers expressed a desire to share their experiences with the professionals (Linderholm &

Friedrichsen, 2010). Further, past research has found that caregivers have a desire to be heard, discuss their difficulties, discuss cancer freely, stand up for themselves, and participate in the decision making process within the health care setting (Jansma, et al., 2005). Further this past research also showed that caregivers wanted support to discuss practical information around: gaining skills and knowledge to manage both patient and personal needs (Jansma, et al., 2005).

Thus, the findings of the present study align with past research in that cancer caregivers can experience a sense of social isolation in both their personal life and in the health care system, despite desires to gain support. Specifically, the findings of this study highlight that the experiences of social isolation can arise from feeling as though socializing is not a priority in comparison to supporting the patients' needs, and/or feeling uncomfortable or unable to ask for support from others. Similarly, if caregivers are not involved in discussions with the health care providers, they can feel isolated and unsupported in their caregiving efforts. Past research has linked caregivers experiences of lack of time for social relations and support, as well as lack of control over daily schedules to mental health difficulties (Kurtz, et al., 2004) – findings which were also highlighted in the current study.

Emotional Wellbeing. From time of patient diagnosis, caregivers of cancer patients experience emotional struggles such as reports of feeling devastated shocked, or anxious (Engebretson, et al., 2015; LeSeure & Chongkham-ang, 2015). Ongoing into the caregiver role, past research has found that a high percentage of family caregivers experience psychological distress (Dumont, et al., 2006). Further, previous research has found that family caregivers of terminal cancer patients experience mental health difficulties and lowered health-related quality of life, significantly more than a general population sample (Song, et al., 2011). The anxiety and

depression scores of family caregivers caring for advanced cancer patients have also been found to be worse in comparison to that of a normative sample (Grov, et al., 2005; Song, et al., 2011).

Past research has also identified that the quality of life levels of family caregivers of palliative cancer patients have been found to be lower than those of family caregivers caring for a curative cancer patient (Weitzner, et al., 1999). Further, previous research has found patient functioning status can correlate to caregiver psychological wellbeing – specifically, psychological distress experiences of caregivers is strongly associated with decreased patient performance (Dumont, 2006). Further past research has found that caregivers’ anxiety and depression levels increase based on their perception of patients’ stage of cancer (Burridge, et al., 2009).

The current study’s analysis found that all of the caregiver participants experienced a time where their role and efforts as a caregiver felt like too much to handle. Each described their unique experiences of encountering an emotionally challenging point throughout their caregiving role which was described as a “depression”, “breaking point”, or “dark time”. Within these times they expressed feelings of isolation and exhaustion, along with feeling “frustrated” and as though they “can’t do it”. These findings of the current study overlapped with the current study’s findings around caregivers’ social wellbeing. Specifically, the findings confirmed those of past research in that as caregivers reduced personal time and increased their focus on caring for the patient, they also increasingly experienced emotional and mental health challenges (Kurtz, et al., 2004).

The demographic data collected within the present study asked caregivers to identify any supports they had accessed for their personal needs. All participants identified very few resources for personal support. Further, if mental health supports were accessed by a caregiver, it

was only after encountering a personal struggle throughout their caregiving experiences. None of the caregiver participants in this present study identified accessing personal supports early in their caregiving efforts as a preventative approach to maintain their own personal wellbeing. Thus, the caregivers of this current study experienced the challenges and hardships that are represented in the literature within this advanced cancer caregiver population. They also identified that focusing their life on their caregiving responsibilities worked for a period of time, however it was not something they could sustain. Eventually they all experienced the emotional and social struggles highlighted in the literature.

Taken together, the findings of the present study are comparable to those highlighted in past research. Specifically, family caregivers may feel as though caregiving is a duty that they must take on to support their loved one (Linderholm & Friedrichsen, 2010). In taking on the caregiving role, family caregivers encounter difficulties in their social life as they spend much of their time and energy caring for their ill loved one – spending little time caring for their personal needs (Mosher, et al., 2013). Finally, the difficulties they experience throughout their caregiving role can eventually result in emotional struggles where they experience feelings of depression and exhaustion (Kurtz, et al., 2004). Based on the consistency between the findings of past research and this current research, regarding the experiences of caregivers, it is plausible that the sample population of this current study is no different than those demonstrated in past research.

Exploring Approaches to Supporting Caregiver Needs

Gaining Knowledge and Support. Previous research has identified that caregivers highlighted that it is important for them to feel prepared with a health care plan and to have supports available to care for the patient after hospital discharge (Heyland, Dodek, Rocker, Groll, Gafni et al., 2006). Further, facilitators to caregiving have been identified as gaining

support around emotional and practical needs of caring for a palliative patient, from both formal health care teams and informal networks (Woodman, Baillie, & Sivell, 2015). As well, past research has found that caregivers of palliative cancer patients indicated that they need support and that communication, gaining knowledge regarding skills in order to care for the patient, and their own personal health were rated the top most important factors for them in their caregiving role (Jansma, et al., 2005).

Thus, previous research has begun to examine methods of supporting these needs of family caregivers. Specifically, psychoeducational interventions, which combine both educating and discussing care and emotional experiences with caregivers, have consistently shown improvements in the various aspects of family caregivers' quality of life (Northouse, Williams, Given, & McCorkle, 2012). Further, a systematic review examined research on psychosocial interventions which aimed to improve cancer family caregivers' quality of life: all were classified as skills-training with cognitive-behavioral and psychoeducation components and had small to significant changes in CQOL-C scores (Waldron, et al., 2013). These studies suggest that such educational interventions have an impact on improving family caregiver quality of life. Further, providing caregivers education to assist them in caring for the patient, as well as providing them psychosocial support, is included in the description of the collaborative family-centered care.

Family centered care is known in the literature to support these caregiver needs through involving the family in a collaborative care delivery approach (Kuo, Houtrow, Arango, Kuhlthau, Simmons, & Neff, 2012). This approach aims to support patients in emotional and physical comfort care, and to educate family members in caring for the patient and support emotional needs, while providing both patient and family opportunities to engage in daily

decision making (Teno, et al., 2001). Research has noted the significant importance that has been placed on this family centered philosophy in palliative care (Kissaine, 1999), cancer care (Lederberg, 1998), and rehabilitation care (Bamm & Rosenbaum, 2008) to ensure the needs of both patient and family caregivers are met.

Within the next two sections of this discussion chapter, I will highlight ways in which the context of caregiving for a patient enrolled in the Ottawa Palliative Rehabilitation Program (Chasen, et al., 2013) has address some of the caregiver needs highlighted in past literature. Further I will identify ways in which caregiver needs could be more proactively addressed as according to past literature and the findings of the present study. Thus, the two sections will be broken down into the social wellbeing and emotional wellbeing of caregivers.

Social Wellbeing. Through exploring the context of the Ottawa Palliative Rehabilitation Program (Chasen, et al., 2013) from the perspective of family caregivers, this current study was able to highlight the great importance this program placed on including the caregivers in the care of the patient by incorporating a family centered approach. The program invited caregivers to attend and participate in rehabilitation sessions and meetings with the patient. The findings of this present study highlight that these opportunities to engage in the sessions were view as a positive experience by the caregivers. Specifically the analysis of the qualitative interview data showed that caregivers appreciated gaining knowledge about patient functioning and skills to support patient needs. This finding aligns with the findings of past research which highlight the important role gaining knowledge and skills to care for the patient plays in improving caregiver quality of life (Waldron, et al., 2013).

In addition, this study further highlighted and adds to the literature, the importance of ensuring rehabilitation care for such a palliative cancer population is tailored to provide

individualized support and knowledge to ensure the unique needs of patients and caregivers are heard and addressed. Specifically, the one-on-one care approaches taken by the Ottawa Palliative Rehabilitation Program's interdisciplinary team were found in this study's analysis, to be an important aspect of having caregivers feel as though their loved one was being supported and they were gaining knowledge and skills to support the patients' needs. Thus, this study found that by involving caregivers in the rehabilitation program, they felt as though they gained social support from the providers who were accessible for consultation regarding practical caregiving needs to care for the patient.

This study's analysis also showed that participants positively experienced informal discussions with other caregivers. Although it was not the aim of the program, to provide caregivers an opportunity to discuss experiences with one another, the caregivers who gained the instantaneous opportunity appreciated it. This current study found that these informal conversations provided as a gateway for caregivers to begin building a new social network with someone who shares similar caregiving experiences. As identified in the literature, family caregivers often take away personal time for themselves in order to care for the patient (Mosher, et al., 2013). Thus, this study found that such opportunities for caregivers to spend time sharing experiences with other caregivers and building a new social network may be a valuable addition to such an out-patient palliative cancer rehabilitation program.

Taken together, the findings of this study highlight that the Ottawa Palliative Rehabilitation program was able to provide social support to caregivers in both formal and informal ways. In a formal way, the analysis found that caregivers experienced having access to a team of health care providers who specialized in varying care needs as an efficient social support resource. The opportunity to have professionals available to consult and discuss care

strategies allowed the caregiver to feel both heard and supported in their caregiving efforts which has been highlighted in the literature as an important caregiver need (Linderholm & Friedrichsen, 2010). Further, gaining knowledge regarding methods of caring for the patient aligns with aspects included in both family centered care (Kuo, et al, 2012) and aspects included in interventions which have been found to improve caregiver quality of life (Waldron, et al., 2013). In an informal way, the program supported caregiver social wellbeing through opportunities for caregivers to informally share their experiences and relate to one another – in turn building a new social network. Thus, these findings add to the literature by highlighting that involvement of caregivers in such palliative rehabilitation programs can provide them with formal opportunities to gain support from professionals regarding knowledge and skills to care for the patient; as well as informal opportunities to gain support from other caregivers through building a new personal social network. However, as past research has identified, many of the interventions which improve caregiver quality of life, include not only education towards providing care for the patient, but they also provide education for caregiver to care for themselves (Waldron, et al., 2013). Thus, the next aspect I will review in this gaining knowledge and support section of the discussion chapter is the emotional wellbeing of caregivers.

Emotional Wellbeing. Caregivers both in both past research and in the present research take time away from their personal needs, including both social and personal time (Mosher and colleagues, 2013). Further, past research has highlighted that caregivers can experience mental health difficulties throughout their time as a caregiver (Dumont, et al., 2006; Grov, et al., 2005; Song, et al., 2011). Thus, research examining methods of supporting caregiver needs not only included skills training to care for the patient, but also education for caregivers to care for their personal wellbeing (Northouse, et al., 2012). As the primary focus of this program was to

support the patient, the second aspect highlighted in the literature as important in supporting caregivers was not greatly addressed – the education and support around caregiver personal wellbeing.

The findings of the study found that only one of the family caregivers spent time with the social worker discussing their personal needs and gained a referral for ongoing support. Through the analysis of the various sources of data, it was found that the others identified that they knew they could access the health care professionals for their own needs however, chose not to. One caregiver in particular provided suggestions for the Ottawa Palliative Rehabilitation Program to schedule caregivers private meetings with the social worker to discuss their personal needs as the caregivers are often with the patient and may not feel comfortable asking for personal support as they feel they, as a caregiver, are there to support the patient.

Thus, based on the success of past research examining the improvements in caregiver quality of life in light of participating in psychoeducational interventions (Northouse, et al., 2012), this current study's findings suggest that rehabilitation programs take a more proactive approach to supporting caregiver emotional wellbeing. With increasing responsibility being placed on caregivers to care for patients at home, both by the care system needs (Ministry of Health and Long Term Care, 2014; Guerriere, et al., 2010) and by patient desires (Gomes, et al., 2013) it is necessary for such out-patient rehabilitation programs to ensure that caregivers feel able to care for both the patient and themselves. Thus, such a rehabilitation program could take a more proactive approach to discussing and educating caregivers on self-care techniques to assist them in effectively managing their own needs in order to continue to effectively support the needs of the patient day-to-day.

Implications for Health Care Practitioners

The current research has many implications for health care providers who work with advanced, terminal cancer patients and their families. Firstly, from a social support perspective, this current study's findings reiterate the literature in highlighting the importance of the family centered care model. Family caregivers perceived themselves as being alongside the patient throughout the illness transitions, from observing their struggles to caring for their ongoing needs. Thus, caregiver involvement in care is crucial in order for both themselves and the patient to have a shared understanding of the illness and methods of care at home.

Further, the tailored support from the interprofessional care team was appreciated by caregivers as the program was able to tailor the services to the unique needs of the patient. The interdisciplinary approach of a rehabilitation program, such as the Ottawa Palliative Rehabilitation Program, was perceived by caregivers as an incredible resource to have gained access and again supported their desires for social support in their caregiving efforts. The caregivers of this study felt the individualized approach of the rehabilitation program played an integral role in aiding both them and the patient in managing their day-to-day lives.

Regarding the emotional and self-care needs of caregivers, the current study poses to health care professionals the importance of ensuring supports are being offered and encouraged for caregivers personal needs. Although rehabilitation programs may be designed to address patient needs, the caregivers are often left to continue on caring for the patient after they leave a rehabilitation setting, thus they need to feel able and supported to take on the caregiving duties in a way which also allows them to care for their personal needs as well. Thus, it could be suggested that health care professionals, particularly within rehabilitation programs, spend time with the caregivers one-on-one discussing their caregiving experiences and sharing knowledge

regarding self-care techniques. This may be especially important for this particular population as their caregiving role will be on going while the patient lives with the advanced cancer.

Limitations and Recommendations for Future Research

Beyond the contributions of this study, there is always room for growth and improvement. This section of the discussion chapter will speak to both limitations of this current study and recommendations for future research.

First, a limitation of this current study was that all of the caregiver participants were caring for a male patient who was enrolled in the Ottawa Palliative Rehabilitation Program. It is possible that the patient's sex or gender could also pose a different experience for the caregivers, which this study was not able to explore. Thus, I would encourage future research to take into account not only the sex and gender of the caregiver participants but also these demographic details of the patients enrolled in the program of study, aiming to gain a wider variation of participants.

A second limitation of this study was that it only explored caregiver experiences over the course of the patient's 8-week enrollment in the Ottawa Palliative Rehabilitation Program. An area for future research to explore would be a follow-up with the family caregivers regarding their experiences after leaving a palliative rehabilitation program. It would be of interest to develop an understanding of how perceptions of participating in such a program may carry out over an extended period of time.

Other areas I would encourage future research to explore include the following. First, the aim of this research was to develop an understanding of caregiver experiences within the context of caring for a patient enrolled in a palliative rehabilitation program. The hope was to identify the transferability of the experiences and needs of caregivers from varying caregiver

circumstances. Although, this study was limited to caregiver experiences within the specific context of the Ottawa Palliative Rehabilitation Program, it is the hope of this research that the findings will be transferable to those caregiving for patients in varying palliative cancer rehabilitation programs.

Second, as the current study was exploratory in nature and utilized CQOL-C scores as a descriptive measure to support the development of the case reports, it may be of interest for future research to gain a larger sample size for the quantitative components in order to examine the correlations between caregiver CQOL-C scores and patient improvements while also examining the correlations between CQOL-C scores and ratings of feeling supported via education for caring for the patient as well as caring for themselves. This further examination could provide further insight into identifying which aspects of such a rehabilitation program correlated with the changes in CQOL-C scores. In suggesting this future quantitative addition to the research, may the current study provide as a reminder that the collection of only quantitative data may miss caregivers' true and unique experiences. Thus was the rationale for collecting various data sources within the current exploratory study. Perhaps with a larger sample size, the use of mixed methodology may be appropriate in further examining and exploring this caregiver population.

Third, and finally, future research could further explore the varying experiences of caregivers based on the unique patient diagnosis and needs. Specifically, this study highlighted that the patients' illness diagnosis and their care needs differed from one another and such aspects may have different implications on caregiver experiences. Thus, future research is encouraged to expand on this current study through the exploration of how patient diagnosis and

care needs may relate to caregiver perceptions of their experiences caregiving for a patient enrolled in a palliative rehabilitation program.

Conclusion

Taking on a primary family caregiver role of an advanced, terminal cancer patient provides to be a complex and challenging journey for family caregivers. The current study examined the experiences of family caregivers who were the primary caregivers for an advanced cancer patient who was enrolled in the Ottawa Palliative Rehabilitation Program. The findings described may allow researchers, medical staff, patients, and loved ones, to better comprehend the experiences of these family caregivers and their experiences of actively engaging in a palliative rehabilitation program. It is hoped that this research will lead to an increased priority of engaging and including family caregivers in such patient rehabilitation programs, so they can benefit from gaining knowledge to both support the patients' needs and their personal needs.

References

- Bamm, E. L., & Rosenbaum, P. (2008). Family-centered theory: Origins, development, barriers, and supports to implementation in rehabilitation medicine. *Archives of Physical Medicine and Rehabilitation*, 89, 1618–1624.
- Barawid, E., Covarrubias, N., Tribuzio, B., & Liao, S. (2015). The Benefits of Rehabilitation for Palliative Care Patients. *American Journal of Hospice & Palliative Medicine*, 32: 34-43. doi: 10.1177/1049909113514474.
- Bektas, H., & Ozer, Z. (2009). Reliability and validity of the caregiver quality of life index-cancer (CQOLC) scale in Turkish cancer caregivers. *Journal of Clinical Nursing*; 18: 3003-3012. doi: 10.1111/j.1365-2702.2009.02915.x.
- Blum, K., & Sherman, D. (2010). Understanding the experiences of caregivers: A focus on transitions. *Seminars in Nursing Oncology Nursing*, 26: 243-258. doi:10.1016/j.soncn.2010.08.005.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3: 77-101. doi: 10.1191/1478088706qp063oa.
- Braun, V., & Clarke, V. (2012). Chapter 4: Thematic Analysis. In H. Cooper, P. Camic, D., Long, A. Panter, D. Rindskopf, & K. Sher (Eds.), *APA Handbook of Research Methods in Psychology: Vol. 2. Research Designs: Quantitative, qualitative, neuropsychological, and biological*. (57-71). Washington, DC: American Psychological Association.
- Buck, J. (2011) Policy and the Re-Formation of Hospice: Lessons from the Past for the Future of Palliative Care. *Journal of Hospice Palliative Nursing*, 13: 35–43. doi:10.1097/NJH.0b013e3182331160.

- Burridge, L., Barnett, A., & Clavarino, A. (2009). The impact of perceived stage of cancer on carers' anxiety and depression during the patients' final year of life. *Psycho-Oncology*, 18: 615–623. doi: 10.1002/pon.1435.
- Canadian Cancer Society's Advisory Committee on Cancer Statistics. 2015. Chapter 3: Mortality: How many people in Canada die of cancer? In *Canadian Cancer Statistics* Toronto, ON: Canadian Cancer Society.
- Chasen, M., & Bhargava, R. (2009). A descriptive review of the factors contributing to nutritional compromise in patients with head and neck cancer. *Support Care Cancer*, 17: 1345–1351. doi:10.1007/s00520-009-0684-5.
- Chasen, M., Feldstain, A., Gravelle, D., MacDonald, N., & Pereira, J. (2013). An interprofessional palliative care oncology rehabilitation program: effects on function and predictors of program completion. *Current Oncology*, 20: 301-309. doi:http://dx.doi.org/10.3747/co.20.1607.
- Clark, D. (1998). Originating a movement: Cicely Saunders and the development of St. Christopher's Hospice, 1957-1967. *Mortality*, 3:43-63, doi: 10.1080/713685885.
- Cora, A., Partinico, M., Munafo, M., & Palomba, D. (2012). Health risk factors in caregivers of terminal cancer patients: A pilot study. *Cancer Nursing*, 35: 38-47. doi:10.1097/NCC.0b013e31820d0c23.
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Sage Publication, Inc.
- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. London: Sage Publications.

- Creswell, J. W., Hanson, W. E., Clark Plano, V. L., & Morales, A. (2007). Qualitative research designs: Selection and implementation. *Counseling Psychologist*, 35(2), 236-264.
- Creswell, J., 2012. Educational research: Planning, conducting, and evaluating quantitative and qualitative research (4th ed.). Boston, MA, Pearson Education.
- De Backer, I., Vreugdenhil, G., Nijziel, M., Kester, A., van Breda, E., & Schep, G. (2008). Long-term follow-up after cancer rehabilitation using high-intensity resistance training: persistent improvement of physical performance and quality of life. *British Journal of Cancer*, 99: 30-36. doi:10.1038/sj.bjc.6604433.
- Deeken, J., Taylor, K., Mangan, P., Yabroff, R., & Ingham, J. (2003). Care for caregivers: A review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *Journal of Pain and Symptom Management*, 26: 922-953. doi:10.1016/S0885-3924(03)00327-0.
- Dumont, S., Turgeon, J., Allard, P., Gagnon, P., Charbonneau, C., & Vezina, L. (2006) Caring for a loved one with advanced cancer: Determinants of psychological distress in family caregivers. *Journal of Palliative Medicine*, 9: 912-921. doi:10.1089/jpm.2006.9.912.
- Eisenhardt, K. (1989). Building Theories from Case Study Research. *The Academy of Management Review*, 14: 532-550.
- Engebretson, A., Matrisian, L., and Thompson, C. (2015). Pancreatic cancer: Patient and caregiver perceptions on diagnosis, psychological impact, and importance of support. *Pancreatology*; 15: 701-707. doi: 10.1016/j.pan.2015.05.471.
- Fletcher, B., Miaskowski, C., Given, B., & Schumacher, K. (2012). The family caregiver experience: An updated and expanded conceptual model. *European Journal of Oncology Nursing*, 16: 387-398.

- Fridriksdottir, N., Sigurdardottir, V., & Gunnarsdottir, S. (2006). Important needs of families in acute and palliative care settings assessed with the family inventory of needs. *Palliative Medicine*, 20: 425-432. doi:10.1191/0269216306pm1148oa.
- Fujinami, R., Otis-Green, S., Klein, L., Sidhu, R., & Ferrell, B. (2012). Quality of life of family caregivers and challenges faced in caring for patients with lung cancer. *Clinical Journal of Oncology Nursing*, 12: 210-220. doi: 10.1188/12.CJON.E210-E220.
- Gall, M., Borg, W., & Gall, J. (1996). *Educational research: An introduction*. White Plains, NY: Longman.
- Gomes, B., Calanzani, N., Gysels, M., Hall, S., & Higginson, I. (2013). Heterogeneity and changes in preference for dying at home: A systematic review. *BMC Palliative Care*, 12: 1-13. doi: 10.1186/1472-684X-12-7.
- Gomes, B., Higginson, I., Calanzani, N., Cohen, J., Deliens, L., Daveson, B., Bechinger-English, D., Bausewein, C., Ferreira, P., Toscani, F., Meñaca, A., Gysels, M., Ceulemans, L., Simon, S., Pasman, H., Albers, G., Hall, S., Murtagh F., Haugen, D., Downing, J., Koffman J., Pettenati, F., Finetti, S., Antunes, B., & Harding, R. (2012). Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Annals of Oncology*, 23: 2006-2015. doi:10.1093/annonc/mdr602.
- Grant, M., Padilla, G.V., Ferrell, B.R., & Rhiner, M. (1990). Assessment of quality of life with a single instrument. *Seminars in Oncology Nursing*, 6, 260–270. doi:10.1016/07492081(90)90028-4.

- Grov, E., Dahl, A., Moum, T., & Fossa, S. (2005). Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Annals of Oncology*, 16: 1185–1191, doi:10.1093/annonc/mdi210.
- Guerriere, D., Zagorski, B., Fassbender, K., Masucci, L., Librach, L., Coyte, P. (2010). Cost variations in ambulatory and home-based palliative care. *Palliative Medicine*, 24: 523–532. doi: 10.1177/0269216310364877.
- Haley, W., LaMonde, L., Han, B., Burton, A., & Schonwetter, R. (2003). Predictors of depression and life satisfaction among spousal caregivers in hospice: Application of a stress process model. *Journal of Palliative Medicine*, 6: 215–224.
- Harding, R., List, S., Epiphaniou, E., & Jones, H. (2012). How can informal caregivers in cancer and palliative care be supported? An updated systematic literature review of interventions and their effectiveness. *Palliative Medicine*, 26: 7–22. doi: 10.1177/0269216311409613.
- Heyland, D., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D., Shortt, S., Tranmer, J., Lazar, N., Kutsogiannis, J., & Lam, M. for the Canadian Researchers, End-of-Life Network (CARENET). (2006). What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *Canadian Medical Association Journal* 174: 1–9. doi:10.1503/cmaj.050626.
- Higginson, I., & Evans, C. (2010). What is the evidence that palliative care teams improve outcomes for cancer patients and their families?. *The Cancer Journal*, 16: 423–435. doi: 10.1097/PPO.0b013e3181f684e5.
- Hudson, P., Aranda, S., & Kristjanson, L. (2004). Meeting the supportive needs of family caregivers in palliative care: Challenges for health professionals. *Journal of Palliative Medicine*, 7: 19–25.

- Hudson, P., & Hayman-White, K. (2006). Measuring the psychosocial characteristics of family caregivers of palliative care patients: Psychometric properties of nine self-report instruments. *Journal of Pain and Symptom Management*, 31: 215-228.
doi:10.1016/j.jpainsymman.2005.07.010.
- Jansma, F., Schure, L., & Meyboom de Jong, B. (2005). Support requirements of caregivers of patients with palliative cancer. *Patient Education and Counselling*, 58: 182-186.
doi:10.1016/j.pec.2004.08.008.
- Jensen, W., Baumann, F., Stein, A., Bloch, W., Bokemeyer, C., de Wit, M., & Oechsle K. (2014). Exercise training in patients with advanced gastrointestinal cancer undergoing palliative chemotherapy: a pilot study. *Supportive Care in Cancer*, 22: 1797–1806.
doi:10.1007/s00520-014-2139-x.
- Jones, L., Fitzgerald, G., Leurent, B., Round, J., Eades, J., Davis, S., Gishen, F., Holman, A., Hopkins, K., & Tookman, A. (2013). Rehabilitation in advanced, progressive, recurrent cancer: a randomized controlled trial. *Journal of Pain and Symptom Management*, 46: 315–325. doi:10.1016/j.jpainsymman.2012.08.017.
- Kanach, F., Brown, L., & Campbell, R. (2014). The role of rehabilitation in palliative care services. *American Journal of Physical Medicine Rehabilitation*; 93: 342-345.
doi:10.1097/PHM.0000000000000005.
- Kasven-Gonzalez, N., Souverain, R., & Miale, S. (2010). Improving quality of life through rehabilitation in palliative care: case report. *Palliative Support Care*, 8:359-369.
doi:10.1017/S1478951510000167.
- Kissane (1999). Importance of Family-Centred Care to Palliative Medicine. *Japanese Journal of Clinical Oncology*; 29: 371-373. doi: 10.1093/jjco/29.8.371.

- Kjaer, T., Johansen, C., Ibfelt, E., Christensen, J., Rottmann, N., Terp Hoybye, M., Ross, L., Svendsen, M., Oksbjerg Dalton, S. (2011). Impact of symptom burden on health related quality of life of cancer survivors in a Danish cancer rehabilitation program: A longitudinal study. *Acta Oncologica*, 50: 223–232. doi:10.3109/0284186X.2010.530689.
- Korstjens, I., Mesters, I., van der Peet, E., Gijzen, B., & van den Borne, B. (2006). Quality of life of cancer survivors after physical and psychosocial rehabilitation. *European Journal of Cancer Prevention*, 15: 541–547.
- Kristijanson, L., Nikoletti, S., Porock, D., Smith, M., Lobchuk M, & Pedler, P. (1998). Congruence between patients' and family caregivers' perceptions of symptom distress in patients with terminal cancer. *Journal of Palliative Care*, 14: 24-32.
- Krouse, R. (2008). Palliative Care for Cancer Patients: An Interdisciplinary Approach. *Cancer Chemotherapy Review*; 3:152-160.
- Kuo, D., Houtrow, A., Arango, P., Kuhlthau, K., Simmons, J., & Neff, J. (2012). Family-Centered Care: Current Applications and Future Directions in Pediatric Health Care. *Maternal and Child Health Journal*, 16: 297-305. doi: 10.1007/s10995-011-0751-7.
- Kurtz, M., Kurtz, C., Given, C., & Given, B. (2004). Depression and physical health among family caregivers of geriatric patients with cancer – a longitudinal view. *Medical Science Monitor*, 10: 447-456.
- Lafaye, A., De Chalvron, S., Houédé, N., Eghbali, H., & Cousson-Gélie, F. (2013). The Caregivers Quality of Life Cancer index scale (CQoLC): an exploratory factor analysis for validation in French cancer patients' spouses, *Quality of Life Research*; 22: 119-122. doi: 10.1007/s11136-012-0113-y.

- Lederberg MS. The family of the cancer patient. In: Holland J, editor, *Psychooncology*, New York: Oxford University Press 1998.
- LeSeure, P., & Chongkham-ang, S. (2015). The Experience of Caregivers Living with Cancer Patients: A Systematic Review and Meta-Synthesis. *Journal of Personalized Medicine*; 5, 406-439. doi:10.3390/jpm5040406.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic Inquiry*. Thousand Oaks: Sage Publications.
- Linderholm, M., & Friedrichsen, M. (2010). A desire to be seen: Family caregivers' experiences of their caring role in palliative home care. *Cancer Nursing*, 33: 28-36. doi:10.1097/NCC.0b013e3181af4f61.
- Lobchuk, M., McClement, S., Daeninck, P., Shay, C., & Elands, H. (2007). Asking the Right Question of Informal Caregivers About Patient Symptom Experiences: Multiple Proxy Perspectives and Reducing Interrater Gap. *Journal of Pain and Symptom Management*; 33: 130–145. doi:10.1016/j.jpainsymman.2006.07.015.
- Lobchuk, M., Kristijanson, L., Degner, L., Blood, P., & Sloan, J. (1997). Perceptions of symptom distress in lung cancer patients: I. Congruence between patients and primary family caregivers. *Journal of Pain and Symptom Management*; 14: 136-146. doi:10.1016/S0885-3924(97)00022-5
- Lobchuk, M., Vorauer, J. (2003). Family caregiver perspective-taking and accuracy in estimating cancer patient symptom experiences. *Social Science & Medicine*; 57: 2379 –2384. doi:10.1016/S0277-9536(03)00132-1.
- Llobera, J., Esteva, M., Rifà, J., Benito, E., Terrasa, J., Rojas, C., Pons, O., Catalán, G., & Avellà, A. (2000). Terminal cancer: duration and prediction of survival time. *European Journal of Cancer*, 36: 2036-2043

- McPherson, C., Wilson, K., Lobchuk, M., & Brajtman, S. (2008) Family Caregivers' Assessment of Symptoms in Patients with Advanced Cancer: Concordance with Patients and Factors Affecting Accuracy. *Journal of Pain and Symptom Management*; 35: 70-82.
doi:10.1016/j.jpainsymman.2007.02.038.
- McPherson, C., Wilson, K., & Murray, A. (2007). Feeling like a burden to others: a systematic review focusing on the end of life. *Palliative Medicine*, 21: 115-128.
doi:10.1177/0269216307076345.
- Meleis, A., Sawyer, L., Im, E., Hilfinger Messias, D., & Schumacher, K. (2000). Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science*, 23: 12-28.
- Metri, K., Bhargav, H., Chowdhury, P., & Koka, P. (2014). Ayurveda for chemo-radiotherapy induced side effects in cancer patients. *Journal of Stem Cells*, 8: 115-29.
doi:jsc.2014.8.2.115.
- Ministry of Health and Long-Term Care. (2014). Chapter 3: Palliative Care. In *2014 Annual Report of the Office of the Auditor General of Ontario*: 258-288.
- Morrow, S. (2007). Qualitative research in counseling psychology: Conceptual foundations. *The Counseling Psychologist*, 35: 209-235. doi:10.1177/0011000006286990.
- Mosher, C., Bakas, T., & Champion, V. (2013). Physical health, mental health, and life changes among family caregivers of patients with lung cancer. *Oncology Nursing Forum*, 40: 53-61. doi: 10.1188/13.ONF.53-61.
- Nijboer, C., Tempelaar, R., Sanderman, R., Triemstra, M., Spruijt, R.J., & Bos, G. (1998). Advanced cancer and caregiving: The impact on the caregiver's health. *Psychooncology*, 7: 3-13.

- Northouse, L., Williams, A., Given, B., & McCorkle, R. (2012). Psychosocial care for family caregivers of patients with cancer. *Journal of Clinical Oncology*, 30: 1227-1234. doi: 10.1200/JCO.2011.39.5798.
- Okamura, H. (2011). Importance of Rehabilitation in Cancer Treatment and Palliative Medicine. *Japanese Journal of Clinical Oncology*, 41: 733–738. doi:10.1093/jjco/hyr061.
- Pallium Canada. (2013). *The Pallium Palliative Pocketbook: A peer-reviewed reference resource*.
- Patton, M. (1990). Qualitative evaluation and research methods. Beverly Hills, CA: Sage.
- Public Health Agency of Canada (2012). *Canadian Cancer Statistics 2012*. Retrieved from: <http://www.phac-aspc.gc.ca/cd-mc/cancer/ccs-scc-2012-eng.php>.
- Santiago-Palma, J., & Payne, R. (2001). Palliative Care and Rehabilitation. *Cancer*, 92: 1049–52.
- Saunders, C. (2000). The evolution of palliative care. *Patient Education and Counseling*, 41: 7-13.
- Schulz, R., & Sherwood, P. (2008). Physical and Mental Health Effects of Family Caregiving. *The American Journal of Nursing*, 109: 23–27. doi: 10.1097/01.NAJ.0000336406.45248.4c.
- Song, J., Shin, D., Choi, J., Kang, J., Baik, Y., Mo, H., Park, S., Choi, S., Kwak, J., Kim, E. (2011). Quality of life and mental health in family caregivers of patients with terminal cancer. *Supportive Care Cancer*, 19:1519–1526. doi: 10.1007/s00520-010-0977-8.
- Spill, G., Hlubocky, F., & Daugherty, C. (2012). Oncologists' and physiatrists' attitudes regarding rehabilitation for patients with advanced cancer. *Physical Medicine Rehabilitation*, 4:96-108. doi: 10.1016/j.pmrj.2011.08.539.

- Stajduhar, K. (2013). Burdens of family caregiving at the end of life. *Clinical and Investigative Medicine*, 36: E121-E126.
- Stajduhar, K., & Davis, B. (2005). Variations in and factors influencing family members' decisions for palliative home care. *Palliative Medicine*, 19: 21-32.
doi: 10.1191/0269216305pm963oa.
- Stake, R. (2006). *Multiple case study analysis*. New York, NY: Gilford Press.
- Stake, R. (1995). *The art of case research*. Thousand Oaks, CA: Sage Publications.
- Stenberg, U., Ruland, C., Olsson, M., & Ekstedt, M. (2012). To live close to a person with cancer-Experiences of family caregivers. *Social Work in Health Care*, 51: 909-926.
doi:10.1080/00981389.2012.714847.
- Teno, J., Casey, V., Welch, L., & Edgman-Levitan, S. (2001). Patient-focused, family-centered end-of-life medical care: views of the guidelines and bereaved family members. *Journal of Pain and Symptom Management*, 22: 738–751.
- Wadhwa, D., Burman, D., Swami, N., Rodin G., Lo, C., & Zimmermann, C. (2013). Quality of life and mental health in caregivers of outpatients with advanced cancer. *Psycho-Oncology*, 22: 403–410. doi: 10.1002/pon.2104.
- Waldron, E., Janke, E., Bechtel, C., Ramirez, M., & Cohen, A. (2013). A systematic review of psychosocial interventions to improve caregiver quality of life. *Psycho-Oncology*, 22: 1200-1207. doi: 10.1002/pon.3118.
- Walshe, C., Caress, A., Chew-Graham, C., & Todd, C. (2004). Case studies: A research strategy appropriate for palliative care? *Palliative Medicine*, 18: 677-684.
doi:10.1191/0269216304pm962ra

- Weitzner, M. A., Jacobsen, P. B., Wagner, H. J., Friedland, J., & Cox, C. (1999). The caregiver quality of life index-cancer (CQOLC) scale: Development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. *Quality of Life Research*, 8, 55–63.
- Weitzner, M. A., McMillan, S. C., & Jacobsen, P. B. (1999). Family caregiver quality of life: Differences between curative and palliative cancer treatment settings. *Journal of Pain and Symptom Management*, 17: 418–428.
- Wennman-Larsen, A., & Tishelman, C. (2002). Advanced home care for cancer patients at the end of life: a qualitative study of hopes and expectations of family caregivers. *Scandinavian Journal of Caring Sciences*, 16: 240–247.
- Wilson, C., Stiller, C., Doherty, D., & Thompson, K. (2015). The Role of Physical Therapists Within Hospice and Palliative Care in the United States and Canada. *American Journal of Hospice & Palliative Medicine*. 1-8 doi:10.1177/1049909115604668.
- Witt Sherman, D. (1998). Reciprocal suffering: the need to improve family caregivers' quality of life through palliative care. *Journal of Palliative Medicine*, 1: 357-366.
- Woodman, C., Baillie, J., & Sivell, S. (2015). The preferences and perspectives of family caregivers towards place of care for their relatives at the end-of-life. A systematic review and thematic synthesis of the qualitative evidence. *BMJ Supportive & Palliative Care*, 0:1–12. doi:10.1136/bmjspcare-2014000794.
- World Health Organization. (2013). *WHO definition of palliative care*. Retrieve from: www.who.int/cancer/palliative/definition/en.
- Yin, R. (2003). *Case study research: Design and methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Appendices

Appendix A: Recruitment Text

Screening of Initial Interest Script for Clinical Staff Member Conducting the Intake Session

For Patient: “Hi Mr/Ms _____. We have a research study going on right now for family caregivers of individuals enrolled in the Palliative Rehabilitation Program and I wonder if you might be interested in hearing more about this study? The study involves interviewing a family caregiver to learn about their experiences. A family caregiver could be a family member/ partner/ friend/ or anyone else that may be helping you with daily activities throughout your illness. This study (interview and questionnaire) would occur here at the hospital and would involve a family caregiver whom you identify or whom self identifies themselves in such a role. Would you be interested in learning more about this study and suggesting a family caregiver we could contact?”

If Yes – Clinical Team Member informs the family caregiver of the study, if No, no further discussion.

For Family Caregiver: “Hi Ms/Mr _____. We have a research study going on right now for family caregivers of individuals enrolled in the Palliative Rehabilitation Program and I wonder if you might be interested in hearing more about this study? The study involves interviewing a family caregiver to learn about their experiences. A family caregiver could be a family member/ partner/ friend/ or anyone else that may be helping a patient with daily activities throughout their illness. This study (interview and questionnaire) would occur here at the hospital and involve you, a family caregiver whom was identified by the patient or whom self-identified, to be in a caregiving role. Would you be interested in learning more about the study?”

If Yes – Clinical Team Member informs the researcher, if No, no further discussion.

Recruitment Script for Researcher

“Hi Ms/Mr and Ms/Mr (patient and family caregiver) _____. My name is Shauna Daly and I’m involved in a research study with family caregivers here at the hospital. Is this a good time to talk for a few minutes? Would you be interested in hearing a bit more about our study?”

If no – “Okay – thanks for your time”

If yes – “This study is trying to further our understanding of family caregivers experiences in caring for a loved one as well as their experiences with of the Palliative Rehabilitation Program. Participating would involve ____ (family caregiver) to complete a questionnaire at the beginning of the patient’s enrollment in the program and at the end of the patient’s enrollment in the program. ____ (family caregiver) will also be invited to partake in a one-on-one, confidential, 30-45 minute interview at the end of the patient’s enrollment in the program. The study would also involve _____’s (the patient) consent to their family caregiver potentially discussing relevant health information with the researcher in sharing their caregiving experiences. Is this something you might be interested?”

If yes – explore the informed consent together in depth with both patient and family caregiver.

If no – “Okay – thanks for your time”

Appendix B: Informed Consent Form



INSTITUT DE RECHERCHE
BRUYÈRE
RESEARCH INSTITUTE
Affilié à l'Université d'Ottawa
Affiliated with the University of Ottawa



PARTICIPANT INFORMED CONSENT FORM

*Adresse postale
Mailing Address*
43, rue Bruyère St.
Ottawa ON K1N 5C8

Title of Study: Family caregiver experiences: A case study of caregiving for an advanced cancer patient enrolled in a palliative rehabilitation program.

*Bureau central
Corporate Office*
Tél./Tel.: 613-562-6045
Téléc./Fax: 613-562-4266

Local Site Principal Investigators (PI):

Shauna Daly (MA Candidate) 613-562-6262 Ext. 1425 and
Dr. Andre Samson, 613-562-2800, ext. 4029

*Éducation et recherche en soins palliatifs
Palliative Care Education and Research*
Tél./Tel.: 613-562-6262 poste/ext. 1352
Téléc./Fax: 613-562-6371

Participation in this study is voluntary. Please read this Participant Informed Consent Form carefully before you decide if you would like to participate. Ask the study team as many questions as you like.

Why am I being given this form?

*Centre de recherche C.T. Lamont
en soins de santé primaires
C.T. Lamont Primary Health Care
Research Centre*
Tél./Tel.: 613-562-6262 poste/ext. 1589
Téléc./Fax: 613-562-6099

You are being asked to participate in this research study because of your enrollment in the Palliative Rehabilitation and your relationship to a family caregiver whom is interested in participating in this study.

Why is this study being done?

*Recherche sur les soins aux aînés
Care of the Elderly Research*
Tél./Tel.: 613-562-6262 poste/ext. 1434
Téléc./Fax: 613-562-4266

This study aims to gain a deeper understanding of family caregiver experiences, particularly while you, the patient, are enrolled in the Rehabilitation Program.

We estimate that 4-6 family caregiver cases will be enrolled in the study from the outpatient Palliative Rehabilitation Program at Bruyère Continuing Care, in Ottawa, Ontario.

How is the study designed?

The study mainly involves a family caregiver who you have selected. Your family caregiver will be invited to complete questionnaires and a confidential interview regarding their caregiving experiences.

What is expected of me?

As your family caregiver will be sharing their caregiving experiences, it is necessary for the researcher to have a general understanding of your health information. Therefore, during this study, the researcher will collect information from the Palliative Rehabilitation Program's medical files, such as your gender, age, current diagnosis, presenting difficulties upon entering the program and changes in presenting difficulties throughout the 8-week program. Also, the interview with your family caregiver may result in discussions regarding your health information that are relevant to their caregiving experiences.

How long will I be involved in the study?

The entire study will last roughly 7 months. Your family caregiver's participation in the study will last roughly 8 weeks while you are enrolled in the rehabilitation program. The study will recruit family caregivers between November 24th, 2014 and June 30th, 2015.

What are the potential risks I may experience?

As your family caregiver will be asked to discuss their caregiving experiences, they may discuss topics related to your illness. All interview audio recorded files will be transferred from the recording device to a password protected computer and located on the secure Bruyère server. Audio files will be deleted from the recording device at this point. Audio files will be transcribed and any personally identifying information will be removed to ensure participant confidentiality. You will not, at any time, gain access to your family caregiver's confidential data despite the possible mention of your health information as relevant to their caregiving experiences. If you do not feel comfortable with your family caregiver potentially discussing aspects your health with the researcher, you can choose not to participate in the study. If you choose not to participate, your family caregiver will not be asked to participate in the study.

Can I expect to benefit from participating in this research study?

You will not receive any direct benefit from your participation in this study. Your participation may allow the researchers to develop an understanding of family caregivers' experiences of caring for a patient enrolled in the Palliative Rehabilitation Program which may benefit future family caregivers.

Do I have to participate? What alternatives do I have? If I agree now, can I change my mind and withdraw later?

Your participation in this study is voluntary. The alternative to this study is not to participate.

You may decide not to be in this study, or to be in the study now, and then change your mind later without affecting the care of yourself or other services to which you are entitled or are presently receiving at this institution. If you would like to withdraw from the study, you can notify the researcher and the researcher will no longer collect information from you for research purposes. If you choose to withdraw from the study, data will no longer be collected from your family caregiver.

How is my personal information being protected?

- All information collected during your family caregiver's participation in this study will be coded with a unique study number, and will not contain information that identifies you or your family caregiver, such as your name, address, etc.
- The link between your unique study number and your name and contact information will be stored securely and separate from your study records, and will not leave the Bruyère Continuing Care secure server.
- Any documents utilized by the University of Ottawa or Bruyère Research Institute will contain only your unique study number. This includes publications or presentations resulting from this study.
- Information that identifies you will be released only if it is required by law.
- For audit purposes only, your original study records may be reviewed under the supervision of Shauna Daly by representatives from:
 - the University of Ottawa Research Ethics Board,
 - the Bruyère Research Ethics Board.
- Research records will be kept for 10 years, after this time they will be destroyed.

Who do I contact if I have any further questions?

If you have any questions about this study, please contact Shauna Daly, 613-562-6262 extension 1425.

The Bruyère Research Ethics Board and the University of Ottawa Research Ethics Board have reviewed the plans for this research study. The boards consider the ethical aspects of all research studies involving human participants at Bruyère Continuing Care. If you have any questions about your rights as a study participant, you may contact the Bruyère Research Ethics Board Chairperson, 613-562-6262 extension 1420 or the University of Ottawa Research Ethics Board Chairperson, 613-562-5387.



INSTITUT DE RECHERCHE
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Affiliated with the University of Ottawa



Family caregiver experiences: A case study of caregiving for an advanced cancer patient enrolled in a palliative rehabilitation program.

Adresse postale
Mailing Address
43, rue Bruyère St.
Ottawa ON K1N 5C8

Bureau central
Corporate Office
Tél./Tel.: 613-562-6045
Télé./Fax: 613-562-4266

Éducation et recherche en soins palliatifs
Palliative Care Education and Research
Tél./Tel.: 613-562-6262 poste/ext. 1352
Télé./Fax: 613-562-6371

Centre de recherche C.T. Lamont
en soins de santé primaires
C.T. Lamont Primary Health Care
Research Centre
Tél./Tel.: 613-562-6262 poste/ext. 1589
Télé./Fax: 613-562-6099

Recherche sur les soins aux aînés
Care of the Elderly Research
Tél./Tel.: 613-562-6262 poste/ext. 1434
Télé./Fax: 613-562-4266

Consent to Participate in Research

- I understand that I am being asked to participate in a research study about family caregiver experiences caring for a relative or friend who is enrolled in a palliative rehabilitation program.
- This study has been explained to me by Shauna Daly.
- I have read this 4 page Participant Informed Consent Form or have had it read to me.
- All of my questions have been answered to my satisfaction.
- If I decide later that I would like to withdraw my participation and/or consent from the study, I can do so at any time.
- I voluntarily agree to participate in this study.
- I will be given a copy of this signed Participant Informed Consent Form.

I agree to be audio taped. Yes ☐ No ☐ Initials: _____

☐ By checking this box, I agree to be contacted by phone if necessary to schedule the interview session.

My phone number: _____

_____ Participant's Printed Name	_____ Participant's Signature	_____ Date
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Investigator or Delegate Statement

I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

_____ Investigator Printed Name	_____ Investigator Signature	_____ Date
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Affilié à / Affiliated with

Appendix C: Demographic Questionnaire

Demographics

1. Date of Birth: (DD/MM/YY) ____/____/____
2. The patient is my:
 - a) Partner (ie. Husband/ Wife/ Common Law)
 - b) Parent
 - c) Sibling
 - d) Friend
 - e) Other (please specify) _____
3. Distance you live from the patient's residence:
 - a) Live in the same residence
 - b) Under 25km
 - c) 50km-100km
 - d) 101km-150km
 - e) 151km-200km
 - f) Over 200km
 - g) Other (please specify) _____
4. Ethnicity/Race:
 - a) Caucasian
 - b) Black
 - c) Hispanic
 - d) Asian or Pacific Islander
 - e) Indigenous/Torres Strait Islander/First Nations
 - f) Other or Unknown (please specify) _____
5. Religion:
 - a) Catholic
 - b) Protestant
 - c) Jewish
 - d) Muslim
 - g) Other (please specify) _____
 - e) None
6. Please indicate highest level of education completed:
 - a) No Formal Education
 - b) Primary/Elementary School
 - c) Secondary/High School
 - d) University/College/Technical/Tertiary
 - e) Postgraduate
7. Present Occupation:
 - a) Unemployed
 - b) Home maker
 - c) Employed – full time as _____
 - d) Employed – part time as _____
 - e) Employed – casual as _____
 - f) Retired from _____
 - g) Other (please specify) _____
8. Income
 - a) < 10 k
 - b) 10 - 20k per year
 - c) 21-40 k per year
 - d) 41- 60 k per year
 - e) 61 – 80 k per year
 - f) 81 -100 k per year
 - g) >100 k per year
9. What type of support have you had to help you cope with your relative's illness? Check as many as apply:
 - a) Support group
 - b) Counselling (Social Work, Psychologists, Psychiatrists)
 - c) Employment Insurance Compassionate Care Benefits
 - d) Flexible work arrangements
 - e) Other (please specify) _____
 - f) None

Appendix D: Caregiver Quality of Life – Cancer Index

Caregiver Quality of Life - Cancer Index
(Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999)

Below is a list of statements that other people caring for loved ones with cancer have said are important. By circling one number per line, please indicate how true each statement has been for you during the past 7 days.

0 = Not at all **1** = A little bit **2** = Somewhat **3** = Quite a bit **4** = Very much

During the past 7 days:

1.	It bothers me that my daily routine is altered.	0	1	2	3	4
2.	My sleep is less restful.	0	1	2	3	4
3.	My daily life is imposed upon.	0	1	2	3	4
4.	I am satisfied with my sex life.	0	1	2	3	4
5.	It is a challenge to maintain my outside interests.	0	1	2	3	4
6.	I am under a financial strain.	0	1	2	3	4
7.	I am concerned about our insurance coverage.	0	1	2	3	4
8.	My economic future is uncertain.	0	1	2	3	4
9.	I fear my loved one will die.	0	1	2	3	4
10.	I have more of a positive outlook on life since my loved one's illness.	0	1	2	3	4
11.	My level of stress and worries has increased.	0	1	2	3	4
12.	My sense of spirituality has increased.	0	1	2	3	4
13.	It bothers me, limiting my focus to day-to-day.	0	1	2	3	4
14.	I feel sad.	0	1	2	3	4
15.	I feel under increased mental strain.	0	1	2	3	4
16.	I get support from my friends and neighbors.	0	1	2	3	4
17.	I feel guilty.	0	1	2	3	4
18.	I feel frustrated.	0	1	2	3	4

Caregiver Quality of Life - Cancer Index (Continued)

0 = Not at all 1 = A little bit 2 = Somewhat 3 = Quite a bit 4 = Very much

19.	I feel nervous.	0	1	2	3	4
20.	I worry about the impact my loved one's illness has had on my children or other family members.	0	1	2	3	4
21.	I have difficulty dealing with my loved one's changing eating habits.	0	1	2	3	4
22.	I have developed a closer relationship with my loved one.	0	1	2	3	4
23.	I feel adequately informed about my loved one's illness.	0	1	2	3	4
24.	It bothers me that I need to be available to chauffeur my loved one to appointments.	0	1	2	3	4
25.	I fear the adverse effects of treatment on my loved one.	0	1	2	3	4
26.	The responsibility I have for my loved one's care at home is overwhelming.	0	1	2	3	4
27.	I am glad that my focus is on getting my loved one well.	0	1	2	3	4
28.	Family communication has increased.	0	1	2	3	4
29.	It bothers me that my priorities have changed.	0	1	2	3	4
30.	The need to protect my loved one bothers me.	0	1	2	3	4
31.	It upsets me to see my loved one deteriorate.	0	1	2	3	4
32.	The need to manage my loved one's pain is overwhelming.	0	1	2	3	4
33.	I am discouraged about the future.	0	1	2	3	4
34.	I am satisfied with the support I get from my family.	0	1	2	3	4
35.	It bothers me that other family members have not shown interest in taking care of my loved one.	0	1	2	3	4

Appendix E: Case Notes

Case Notes

Week	Accompany Patient to Program	Attend Rehabilitation Session with Patient	Attend sessions for Personal learning/support	Any discussions with participant re: their experiences
1	Yes/No Comments:	Yes/No Comments:	Yes/No Comments:	Yes/No Comments:
2	Yes/No Comments:	Yes/No Comments:	Yes/No Comments:	Yes/No Comments:
3	Yes/No Comments:	Yes/No Comments:	Yes/No Comments:	Yes/No Comments:
4	Yes/No Comments:	Yes/No Comments:	Yes/No Comments:	Yes/No Comments:
5	Yes/No Comments:	Yes/No Comments:	Yes/No Comments:	Yes/No Comments:
6	Yes/No Comments:	Yes/No Comments:	Yes/No Comments:	Yes/No Comments:
7	Yes/No Comments:	Yes/No Comments:	Yes/No Comments:	Yes/No Comments:
8	Yes/No Comments:	Yes/No Comments:	Yes/No Comments:	Yes/No Comments:

Appendix F: Interview Guide

Interview Guide

Recording starts **Introduction script:** Hello, thank you for agreeing to participate in this interview. As you have read and signed the consent form I just want to remind you that the session will be recorded and if you mention any personal identifying information it will be removed from the interview when it is transcribed, is this still alright with you?

Also, if at any time you wish to not answer any questions, stop the interview, or leave the study, please do not hesitate to let me know. Okay? I am going to ask you some questions regarding your experiences as a family caregiver and regarding the Palliative Rehabilitation Program.

Are you ready to start?

- 1) Could you tell me how it began when your family member became ill?
Probe: Level of involvement in care
- 2) Generally, how are things for you at the moment?
- 3) Can you tell me about some of the positive experiences you have encountered since taking on your caregiver role?
- 4) Can you tell me about some of the challenges you may have faced since taking on your caregiver role?
Probe: Social, physical, psychological, spiritual, changes that have occurred in life
- 5) How have you dealt with these challenges?
Probe: Seeking support/home care, friends and family, self-care, etc.
- 6) Are you able to think of ways this program has impacted your experiences as a caregiver?
Probe: Met needs; provided more info/resources; educated you on pt. care?
- 7) Were there other supports you would have hoped the program could offer you as a caregiver?
- 8) How did you feel about your family member enrolling in the Palliative Rehabilitation Program?
- 9) Have you see any changes occur in the patient throughout the course of the program, if so, how did you feel about those changes?
Probe: improved pt. functioning/ pt. decline; mood change
- 10) Any other comments?

That concludes our interview. Thank you for your time and participation. If at any time you wish to remove yourself from the study, please do not hesitate to contact me.