Who cares for the caregiver?

How are the needs of caregivers of primary malignant brain tumour patients met through structured neuro-oncology programs in Canadian Centres?

by

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Abstract

This qualitative multi case research asks how the needs of caregivers of primary malignant brain tumour (PMBT) patients are met through structured neuro-oncology programs in Canadian centres. Utilizing telephone interviews with eleven social workers and one psychologist the study analyses their perspectives on the scope and nature of services to brain tumour patients and their caregivers. PMBT is a rare and palliative disease often with neurocognitive and neurobehavioral effects posing special challenges for caregivers. Health care system reliance on family caregivers has resulted in significant implications for their emotional and physical risk. Findings show exclusive patient focused health care in ambulatory programs with fragmented care resulting in marginalization and invisibility of caregivers. This approach is inconsistent with current literature promoting collaborative family centered care, recommended for continuity of care throughout the illness trajectory. Recommendations focus on systemic caregiver service improvements.

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Thank you all.

Dedication

This thesis is dedicated to family caregivers without whom our health care system would collapse.

I also dedicate this work to my sisters Talia Hassan and Shelley Reuter, and all the women in my life, who share in the hardship and rewards of caregiving.

Table

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1. J. S. Rolland, 2005. Cancer and the family: An integrative model. (Appendix I). John Wiley and Sons License, obtained January 29, 2011.

2. P. Hudson, 2003. A conceptual model and key variables for guiding supportive interventions for family caregivers of people receiving palliative care. (Appendix J). Cambridge University Press License, obtained January 29, 2011.

3. P. Sherwood et al., 2004. Caregivers of persons with a brain tumor: A conceptual model. (Appendix K). John Wiley and Sons License, obtained January 29, 2011.

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Chapter 1: Problem Statement

This thesis addresses the following central research question: How are the needs of caregivers of primary malignant brain tumour patients met through structured neuro-oncology programs in Canadian centres? This question and the idea for this qualitative multi case study arose from years of curiosity regarding services to brain tumour patients and their caregivers in other Canadian facilities. The interest I developed in this area stems from my professional experience as a front line social worker responsible for the delivery of psychosocial intervention to brain tumour patients and their families from diagnosis and throughout their illness trajectory. I am an allied health care team member in the neurosurgery program at Health Sciences Centre (HSC), which is administered by the Winnipeg Regional Health Authority. The HSC is a tertiary care facility where the provincial neurosurgery program is centralized and service is provided by a multidisciplinary and interdisciplinary health care team that includes, but is not limited to core representation from neurosurgery, nursing, occupational therapy, physiotherapy, nutrition services, speech and language pathology, social work and home care. Other specialized health care providers are consulted as needed. My practice extends to the ambulatory brain tumour clinic at CancerCare Manitoba where patients and families are referred following the neurosurgical admission to hospital. The core members of this health care team include radiation oncology, medical oncology, nursing, nurse clinician, pharmacy and social work. I am in the unusual position of being employed by the HSC but have the privilege of also providing service in the ambulatory setting of CancerCare Manitoba. I have the flexibility of initiating social work service that involves extensive collaboration and liaising between service providers in the hospital setting, extending to the ambulatory care facility and with community services. I believe that the unique arrangement that I enjoy has allowed me to practice in a way that is consistent with the Canadian Association of Social Workers *Code of Ethics* (2005). My practice has therefore focused on the empowerment of vulnerable individuals by respecting and upholding their inherent dignity and right to self-determination consistent with their beliefs and capacity.

I am intimately involved in the provision of care to the brain tumour group in the Province of Manitoba. I have had the privilege of participating as a core team member for over 20 years. This association has afforded me the chance to participate in program development and implementation of comprehensive services, which has involved the incorporation of caregivers in the front line care offered to brain tumour patients. However I was not sure how many other clinicians were provided with the same opportunity. My past professional experience, and the questions I had about social work practice and programs across the country, led to the formulation of the following research question: how are the needs of caregivers of primary malignant brain tumour (PMBT) patients met through structured ambulatory neuro-oncology programs in Canadian centres? My personal history and professional experience as a front line social worker has affected the research question, design and analysis, as well as the assumptions I have made. I wish to state that I am a Caucasian woman and an immigrant as well as a professional working in the setting I have described. Qualitative research acknowledges that the researcher brings their own worldviews, which impact and inform the research analysis and reporting (Creswell, 2007). My subjectivity cannot be ignored, but has challenged me to be reflexive in my understanding of what was generously shared with me and in reporting those experiences.

Definitions

A number of specific terms are used throughout this report and warrant explanation. All but one of the respondents are social workers. However, in acknowledgement of the one psychologist, I refer to the cohort as 'psychosocial clinicians' instead of social workers.

I refer to the recipient of medical care as the 'patient'; this is to distinguish the caregiver from the recipient of care. The 'caregiver' or 'carer' is the informal provider who assists the ill individual "with personal activities of daily living" (Berg & Woods, 2009, p. 376). This help is without pay and the caregiver is often a spouse.

I refer to tumour site, as the place in the body where the tumour is growing. As well, I refer to some aspects of the brain tumour illness as sequelae. This term is defined in Stedman's Medical Dictionary (2012) as "a condition following as a consequence of disease" (p. 1525).

I use the terms 'specialized' psychosocial clinicians and 'generic' psychosocial clinicians throughout the document. The reference to specialized psychosocial clinicians refers to those colleagues who are specifically assigned to specialized brain tumour clinics in cancer treatment facilities, thereby "specializing" in interventions with brain tumour patients and their caregivers. Generic or general psychosocial clinicians, all of whom were social workers in this study, are distinguished by their general clinical practice; they are not assigned to specific tumour site clinics but are expected to answer consults/ referrals regarding any cancer patient in the ambulatory care facility.

Purpose of the Study

The purpose of this study is twofold. It is important to advance knowledge about the nature of the problems associated with the needs of caregivers of patients with PMBTs (Sherwood, Given, Given, Schiffman, Murman, & Lovely, 2004). Their importance is distinguished by virtue of the abrupt and dramatic diagnosis and sequelae associated with primary brain tumour illness resulting in the immediate need for extensive and intensive caregiver support from diagnosis and throughout the illness trajectory (Sherwood et al., 2004; Speice et al., 2000; Catt, Chalmers, & Fallowfield, 2008; Janda, Eakin, Bailey, Walker, & Troy, 2006; Schubart, Kinzie, & Farace, 2008; Ergh, Hanks, Rapport, & Coleman, 2003; Khalili, 2007); caregivers "of persons following neurotrauma function as *de facto* extensions of our health care system" (Ramkumar & Elliott, 2010, p. 105). Family caregivers are expected to provide care for those they care about, despite their lack of preparation for the role; in many cases this serves to undermine their own health and well being (Kristjanson, 2004; Hooyman & Gonyea, 1999). There is also evidence that meeting caregiver needs sustains them and consequently can have a direct impact on their ability to provide and maintain patient care to the extent needed (Kim & Given, 2008; Ramkumar & Elliott, 2010).

The literature is limited in the brain tumour area and mostly focuses on medical intervention for patients (Cahill & Armstrong, 2011). However in the caregiver literature there is evidence that caregiver needs are as relevant and pressing as those of the patient (Thomas, Morris, & Harman, 2002; Soothill et al., 2003), but their perspectives and needs may be dramatically different (Hauser et al., 2006; Walsh et al., 2007). This study aimed to learn more about the needs of caregivers from the perspective of psychosocial professionals working in Canadian centres.

The second purpose of this study is to learn more about the scope and nature of the various psychosocial programs that are currently offered for brain tumour patients and their caregivers. It was hoped that this research would generate information that could be shared with colleagues, which, in turn, might impact the provision of services to the caregiver group. It was also hoped that information about the scope and nature of the various programs designed for patients and caregivers would generate discussion about best practices and generate preliminary recommendations for the future.

The Importance of the Study

Primary malignant brain tumour is a rare and aggressive cancer that arises in the brain and typically does not spread out of the brain (Catt, Chalmers & Fallowfield, 2008). It is a life limiting, incurable illness. This diagnosis is typically made in an abrupt and dramatic way following unusual symptoms. The neurocognitive and neurobehavioral changes, which manifest in short term memory loss and/or physical impairments, highlight the uniqueness of this group and the extraordinary burden associated with the role of caregiving. Despite aggressive medical treatment, this disease remains palliative (Cahill & Armstrong, 2011).

The importance of studying caregivers of brain tumour patients is embedded in the uniqueness of this patient population. Although in Canada more than 136,900 cases of cancer are reported annually, PMBT is relatively rare and accounts for less than 2% of all cancers (Cahill & Armstrong, 2011; Lipsman, Skanda, Kimmelman, & Bernstein, 2007; Dumont, Dumont, & Turgeon, 2005; Janda et al., 2006). The mean age at diagnosis is 54 and higher incidence rates are reported among males than females (Wen & Kesari, 2008) with no identified underlying cause. The diagnosis is determined by pathology from a surgical specimen; the diagnosis and grade determines the treatment and prognosis, with low-grade survival being approximately 4.5 years and high grade, 12 months (with treatment). Slow growing tumours may significantly shorten a patient's life or cause debilitating symptoms and low-grade tumours may evolve over time into a malignant phenotype. The illness trajectory is determined by cell type and stage, tumour location and treatment. Clinical presentation involves functional, cognitive and neuro-psychiatric status, which are significant determinants of care demands. The changes can be temporary or permanent affecting insight, judgment, short term memory (the ability to process new information), and the ability to communicate (receptively and expressively) all of which have immediate implications for safety; limitations in physical function contribute to additional coping challenges for family caregivers (Schubart et al., 2008; Sherwood et al., 2004).

PMBT disease is uniquely marked by its acute onset and intensity as well as the way in which it concurrently straddles both the acute trajectory as well as the palliative continuum. Standard treatment is acute and aggressive in the hope of stalling tumour progression, however, this acute treatment serves to disqualify families from benefiting from the formal palliative care programs that are available in different jurisdictions across Canada. Although palliative care is on a continuum that overlaps with acute care, our current medical system determines level and type of community home care service based exclusively on medical decisions related to treatment. In this setting then, PMBT patients do not qualify for the enriched palliative services.

The cancer experience is defined by a series of phases, all of them stressful: diagnosis, surgical intervention, adjuvant medical treatment, follow-up, recurrence, and terminal phase followed by the bereavement phase. The diagnosis of a malignant brain tumour is catastrophic and impacts the whole family. The effect depends on when illness strikes relative to the family's development and that of each member within it (Rolland, 2005). Brain tumour illness affects relationships, roles and responsibilities (Schubart et al., 2008) and frames all that caregivers do whether the trajectory is short or long. In this setting, family caregivers face special challenges posed by the neurocognitive and neurobehavioral effects, all of which are detrimental to the patients' and caregivers' quality of life, regardless of social support further suggesting that these impairments in persons with injury are particularly difficult to manage (Ergh et al., 2003). Caregivers do not have much time to adapt to intervention initiated to mitigate against negative consequences for their emotional and physical health (Sherwood et al., 2008). In the area of PMBT, caregivers have little option about getting involved and the level of burden associated with the care is high (Tepper, 2003; Speice et al., 2000).

The importance of sustaining caregivers is paramount due to current policies and practice in health care that shifts care from hospitals to community care, meaning to care by family members (Berg & Woods, 2009; Armstrong & Armstrong, 2004; Stajduhar, Allan, Cohen & Heyland, 2008). There has been a dramatic rise in the number of family members providing care. Hospital stays have been shortened; earlier discharges of patients with acute needs rely on family caregivers to immediately adapt to the caregiver role by providing the bulk of care which includes complex interventions. The literature refers to caregivers as the "hidden patients" (Kristjanson, 2004) and the "other cancer survivors" (Golant & Hoskins, 2008), and almost without exception, highlights that caregivers tend to have more unmet needs than patients (Soothill et al., 2003). Family caregivers are frontline providers of extraordinary and uncompensated care in the form of most of the day-to-day care of patients; they are usually untrained and inadequately prepared for the daunting tasks of caregiving (Schubart et al., 2008; Sherwood et al., 2004). They struggle to adjust to unanticipated and unchosen new roles and responsibilities (Kim, Baker, Spillers, & Wellisch, 2006). This role expectation is also in the setting of a "broader social and political climate that emphasizes 'personal responsibility' or 'self-reliance'" (Hooyman & Gonyea, 1999, p. 150). These caregivers have little choice and their role as providers of physical and emotional support for the care recipient is promoted as a status in society that is similar in many ways to that acquired during other stages of adulthood, such as becoming a spouse, a parent, or a retiree (Gilbar & Ben- Zur, 2005). The emotional and physical aspects of caregiving often go unnoticed and unsupported (Schubart et al., 2008; Soothill et al., 2003). The focus of research and resources has typically been on the ill individual and thus, family caregivers go unrecognized as legitimate participants in the care of the patient.

While health services are under provincial jurisdictions, they must comply with the Canada Health Act, enacted in 1984, requiring universality, accessibility, portability, comprehensiveness, and public administration (Madore, 2005). The primary federal contribution to health care in Canada is provided through block funding known as the Canada Health Transfers (Gauthier, 2011). In the mid 1990's while the provinces were grappling with their own deficits, the federal governments' reduction in transfer payments forced the provinces to revise their priorities in order to compensate for the decrease in income brought about by the reductions in transfer payments (Madore, 2003). Most provinces had therefore reduced the level of health care services, which resulted in a shift to family as care providers. The shift is supported by compelling quantitative evidence that points to cost saving (Berg & Woods, 2009; Aoun, Kristjanson, Currow & Hudson, 2005; Arno, Levine, & Memmott, 1999). In the Canadian experience estimates suggest that family caregivers contribute substantially in unpaid caregiving labor exceeding what is spent by formal health care (Ramkumar & Elliott, 2010; Stajduhar, Allan et al., 2008). This is mirrored in the Australian literature where the unpaid workforce is estimated to be about five times the paid workforce, and in the UK where the current value of the support given by caregivers has been estimated to be around the same level as the total UK spending on health (Aoun et al., 2005). Because "informal" caregiving lies outside the market economy and is socially and politically invisible, its economic value is substantial yet not generally acknowledged (Stajduhar, Allan et al., 2008). Arno et al., (1999) iterate that "imputing an economic value to the extraordinary level of caregiving…enhances caregiver importance by providing a tangible measure of the vast but vulnerable base upon which our chronic care system rests" (p. 186).

While technological advances in medicine generally are contributing to people living longer in a state of chronic or terminal illness for a prolonged period of time, some limited advancements have also been achieved in the brain tumour setting. The advances include more focused surgery and targeted radiation techniques as well as chemotherapy, which is in some case more effective for a longer period of time. However, despite any advances, the prognosis for PMBT remains lethal. As well, while incidence rates of cancer are increasing, treatment is shifting toward ambulatory care (Mystakidou, Tsilika, Parpa, Galanos, & Vlahos, 2007; Arno et al., 1999). Many individuals require help to perform diverse daily life activities and this assistance is provided by family members (Lopez, Crespo, & Zarit, 2007). Bee, Barnes and Luker (2008) highlight that the growing number of informal caregivers assuming the role of primary caregiver is influenced by the modern hospice movement which is the under girding of home-based palliative care services. This is based in "the idea that home is the 'ideal location for care and death'; this ideal has taken firm hold in the minds of many health service providers and policymakers" (Stajduhar, Allan et al., 2008, p. 87) and has placed expectations on family caregivers to provide acute and chronic care on the assumption that "the quality of care by the family is superior" (Berg & Woods, 2009, p. 378). A key element to realizing this goal is the availability of a family member who is willing to provide care at home. This in many cases requires that the spouse give up work outside the home in order to be available to provide the required care. When both spouses do not to work the implications and hardships can be significant. Caregivers, however, are not always involved in this decision, nor are their preferences for location of death equally considered to that of the patient. As well, families vary significantly in their capacity to accommodate requirements and demands of care (Armstrong & Armstrong, 2004). In fact not only are informal caregivers expected to take on more and more of the care that was once provided by professionals in institutions, but they are often ambivalent about the role and are pressured to take it on. The implicit message is that if they do not want to, they should, hence "compulsory altruism" results (Armstrong & Armstrong, 2004, p. 24). Stajduhar, Allan et al., (2008) show that only half of all patients and family caregivers report a preference for a home death. This non-concordance duplicates previous evidence that patients' and caregivers' wishes, preferences and perceptions often do not coincide (Hauser et al., 2006).

Arno et al. (1999) note that informal caregivers are referred to as the "bedrock of our nation's chronic care system; [therefore] we must find more effective ways to support and sustain them" (p. 187). However, as noted by these authors, there is little evidence available that demonstrates inclusion of family caregivers in policy development and program implementation. As well, policy developments have resulted in the "marginalisation of caregivers in the social welfare system" (Aoun et al., 2005, p. 553). The resulting effect is that the needs of caregivers have been ignored by a "wide array of policies" due to the public perception that caregivers are free resources available to care for people with disabilities, the ill and the frail elderly. Aoun et al. (2005) also posit that caregivers are in an ambiguous position both conceptually and practically in relation to social policy and service provision. They have the unique position of both providing and needing support; consequently it is sometimes unclear who the 'patient' is. For example, when intervention is needed to protect their health and wellbeing they are regarded as service users and are often dependent on means-tested, rationed services. The number of caregivers is growing as people are generally living "in a state of chronic or terminal illness for a prolonged period of time" (Gilbar & Ben-Zur, 2005, p. vii); this is concurrent with the growth of Canada's elderly population (Stats Canada, 2009).

Primary malignant brain tumours are commonly classified according to the World Health Organization (WHO) criteria. As a palliative diagnosis it is appropriate to use the WHO's definition for palliative care, which stipulates the inclusion of the entire family as the “unit of care”. The aim of palliative care is to relieve suffering and improve the quality of life for patients with advanced illnesses and their families. It is based on an interdisciplinary approach that is offered simultaneously with other appropriate medical treatment and involves close attention to the emotional, spiritual, and practical needs and goals of patients and of the people who are close to them (World Health Organization, 2007; Morrison & Meir, 2008). Despite the definition and the reality that caregivers are an integral part of cancer patients’ care throughout the illness trajectory, the focus in practice remains primarily on the patients (Osse, Vernooij-Dassen, Schade, & Grol, 2006). The importance of caregivers in this setting cannot be overstated. It has been shown that lack of familial or social support correlates with poor survival (Taillibert, Laigle-Donadey, & Sanson, 2004), and without family caregivers, patients would be at high risk for injury resulting in certain dependence on institutional care.

As the above discussion indicates, caregiving has significant impact on many health policy issues having both economic and broader societal impacts (Aoun et al., 2005; Stajduhar, Allan et al., 2008; Zabalegui et al., 2008; Gilbar & Ben-Zur, 2005).

Overview of this Thesis

This thesis report presents the findings of my research study that sought to determine how the needs of caregivers were met in oncology programs in Canadian centres. After these introductory comments, chapter two provides an overview of the literature, addressing the topics of caregiver needs, interventions, and systemic issues pertinent to the caregiver population. Chapter three describes the qualitative methodology that was used to gather information from specialized and generic psychosocial clinicians in nine provinces. Chapter four presents the findings from my research and chapter five integrates the literature with these findings, presenting conclusions that are drawn from this integration and analysis. Challenges and recommendations for the future are also presented in this final chapter.

Chapter 2: Literature Review

A critical examination of the professional literature spanning the last 10 years was conducted to gain an understanding of how the needs of caregivers of primary malignant brain tumour patients are met through structured ambulatory neuro-oncology programs in the Canadian setting. The literature review was conducted using various data bases[1].

The review focuses on the following three concepts: caregiver needs, program structure, and interventions aimed at caregivers; it also highlights relevant theories that support psychosocial interventions to cancer patients, their caregivers and their families.

Caregiver Needs

There is extensive literature dealing with caregiver needs and the impact of caregiving in the cancer setting. This focus is proportionally overrepresented when compared with empirically sound interventions recommended to moderate the negative effects of caregiving. However, the focused attention to caregivers of brain tumour patients is limited, and mirrors the representation of this relatively small group in the general population. Before discussing the needs of caregivers generally, and caregivers of PMBT patients specifically, it is important to explain the term caregivers, and describe who they are.

Primary caregivers are defined as people who regularly provide the most assistance with one or more of the core activities of communication, mobility, transport, housework and self-care, companionship, supervision, handling finances and taking responsibility for medication (Aoun et al., 2005). These are often family members who are an integral part of cancer patients' care from diagnosis to conclusion of treatment. Cancer is a family experience and family is broadly defined as those persons with a significant interest and role in the patient's life, including spouses/partners, parents, siblings and children. Family members often provide meaningful support to the patient and act as the 'natural' caregivers, complementing the skills of the professional healthcare team. They bring with them a range of emotional reactions, interpersonal dynamics, and expectations for the care that their loved one should receive (Speice et al., 2000). The 'informal carer' is a also a term used to identify the person who undertakes unpaid care work for kin or friends and is likely to be the person who shares most in the illness experience (Thomas & Morris, 2002). This primary caregiver can be a self-identified main person regularly assisting in the care and support of the person with advanced disease (DuBenske et al., 2008). Caregiving takes place "in the context of relationships in which norms of obligation, responsibility, and feelings of affection and resentment intertwine" (Baines, Evans, & Neysmith, 1998, p. 5). Not all caregivers share in the ability to manage this role (Armstrong & Armstrong, 2004) nor do all caregivers identify themselves as 'caregivers' despite their concrete contribution. Speice et al. (2000) poignantly iterate that:

> How a patient defines family and support can be very different than how this is defined by health providers. Such clarifications are essential when deciding on who should be present to hear the delivery of the diagnosis, assist in planning the course of treatment, and remain in contact with the providers. (p. 102)

The experience of caregiving is influenced by the relationship to the care recipient (Rainer & McMurry, 2002), the nature and quality of the social support network, how quickly the illness moves through the trajectory and how the caregiver role is absorbed into already established social roles in addition to already existing care demands. The impact of illness can disrupt established divisions of labour associated with gender and generation within and beyond households. As well, the quantity and quality of care work is likely to change over time as levels of impairment worsen (Thomas et al., 2002). The responsibility associated with meeting the patient's multidimensional needs is referred to as *care work* and *emotion work* (Kim, Loscalzo, Wellisch, & Spillers, 2006). *Care work* involves assistance with activities of daily living, such as bathing and feeding, as well as shopping, managing the household finances and taking care of children (Kim & Given, 2008). *Care work* also includes the performance of unfamiliar complex care tasks that include treatment-related symptom management and monitoring, administration of medications and wound care (Ergh et al., 2003; Aoun et al., 2005).

The *emotion work* (Kim, Loscalzo et al., 2006) involved, focuses on the management of emotions of the patients as well as the caregivers' own feelings, both of which are seen as intimately connected (Thomas & Morris, 2002; Thomas et al., 2002). This role ensures that the patient does not feel alone or abandoned, reassuring that the illness would be faced together, being positive and keeping things normal or as normal as possible while comforting, preventing isolation, and managing the limitations of activity. This requires that the caregiver often has to deal with the patient's depression and other negative emotions; a task reported as more challenging than the physical care (Schubart et al., 2008). In the PMBT setting, the increase of cognitive and neuropsychiatric symptoms intensifies and complicates the emotion work, reducing social support resulting in increased social isolation and loneliness (Rokach, Matalon, Safarov, & Bercovitch, 2007). Some of the specific needs of caregivers that are discussed in the literature are highlighted below.

Information and concrete training needs. There is abundant literature regarding caregivers' lack of information and skills associated with the role of caregiving. This can be seen as the overarching umbrella under which all unmet needs can be identified. In fact it is difficult to separate information needs from interventions and health care delivery through formal program structure. Information needs essentially impact all dimensions associated with what is required to sustain caregivers in the role (Schubart et al., 2008). Lack of information is identified as requiring greater attention as it impacts on levels of distress in caregivers and contributes to their "hidden morbidity" (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Dumont, Turgeon et al., 2006); caregivers should not be considered only as partners in caring but also as potential patients.

The literature reflects that caregivers' sense of security is associated with having access to relevant and timely information that is presented in a logical and coherent manner. It is shown that when caregivers were able to access information early in the patients' illness, they felt prepared for what they might encounter as the caregiving proceeded. Although caregivers wanted more information sooner, some criticized the ways in which it was provided (Stajduhar, Martin, Barwich, & Fyles, 2008). Sze et al. (2006) focus on the brain tumour setting, but it applies to caregivers in general. Their study demonstrates how important it is for caregivers to have information pertinent to prognosis and anticipatory guidance for future care needs. Anticipatory guidance is defined as instructions or descriptions provided to help patients and caregivers prepare for progression of the disease. Changes along the trajectory of illness require new skills and enhanced coping strategies to meet new demands (DuBenske et al., 2008).

Associated with information needs are skills training as it pertains to the caregiver role. The literature points to the absence of deliberate and planned training; the provision of training is typically in response to arising crisis and is provided by professionals who themselves took years to learn the skills required (Ramkumar & Elliott, 2010; Armstrong & Armstrong, 2004). These fundamental skills include concrete and practical strategies associated with symptom management as well as with physical care. However, there is little systematic attention given to practically orientated support needs (Bee et al., 2008). This can undermine caregiver sense of control, capability and self-competence (referred to elsewhere as mastery), which is necessary for caregivers to provide the needed care (Scott, Whyler, & Grant, 2001). Higher levels of mastery are associated with likelihood of using problem-focused coping strategies to meet care demands and are linked to good preventative health behaviors by caregivers, which can decrease their stress response (Sherwood, Given, Given et al., 2004; Sherwood, Given, Doorenbos, & Given, 2004).

The on-going provision of anticipatory information addressing the range of activities the carer will engage in and the emotions likely to be experienced is seen to contribute to empowerment and effective intervention (Scott et al., 2001). Caregivers are often challenged by the care recipient's neurocognitive changes, which include short-term memory loss, impaired reasoning and processing, attention deficits, language difficulties, psychomotor deficits and problems with aggressive and impulsive behaviors. The literature shows that caregivers who understood that the person could not control or change behaviors were more resilient and found ways to cope. Schubart et al., (2008) shows that having a health care member explain these changes offered benefit, however, the typical situation remains that health professionals qualified to treat the patient's tumour commonly leave caregivers to confront confusion, hallucinations, and violence alone (Catt et al., 2008). Given the importance of caregivers who care for patients with brain disease, meeting their information needs begs for more attention and specialized supports (Sze et al., 2006; Lipsman et al., 2007).

The importance of having access to information cannot be overstated. It allows patients and families to exercise their autonomy and affects their ability to make informed decisions (Dumont et al., 2005). The discussion related to treatment goals can only enhance the informed consent process and as a dynamic process requires the use of communication skills that may not come easily to health care providers (Burns, Broom, Smith, Dear, & Craft, 2007). Lack of open communication serves to blur treatment goals, and obstruct informed participation in treatment planning and consequently in overall care. Much of the content pertaining to informing caregivers is emotionally laden as these discussions concern issues related to care for a loved one with a life limiting disease. Health professionals may also not know when to initiate these vital conversations as they may not want to give too much information too soon, fearful that they may cause more harm than good (Hudson, Aranda, & Kristjanson, 2004). These communication barriers not only inhibit health care professionals from providing information and practical advice but also much needed support to families. While health providers disagree over the kinds of information that they perceive needs to be shared (Dumont et al., 2005), this dilemma can be further complicated by caregivers' ability to absorb, filter and retain information, which may be compromised by memory loss, depression, fear, anxiety, and sleep deprivation. What is evident in the literature is that anxiety may be minimized if caregivers are well informed, postulating a relationship between level of information and level of anxiety as they are able to make educated decisions about managing the physical, emotional and social aspects of their experience. Overall, a proactive approach to informing and supporting brain tumour patients and carers seems necessary to increase knowledge and foster feelings of control, hope and self efficiency (Janda et al., 2006; Docherty et al., 2008).

Short hospitalization and the transition from hospital to home based care, is a particularly important but limited window of time with respect to the expectations placed on caregivers (Hudson et al., 2004; Khalili, 2007). Information is needed to make treatment decisions quickly for a complex condition that patient and family know very little about, (Schubart et al., 2008) yet they are required to understand medical treatment options and risks. Verbal and written information needs at this time frequently remain unmet due to the immediacy of treatment initiation (Janda et al., 2006). The high emotion generated by this initial crisis can prevent maximal learning by patients and caregivers, the same information, therefore, should be presented numerously at distinct times in the illness course (DuBenske et al., 2008) and in numerous formats (spoken, written and on the web). It has also been suggested that the need for information may be greatest at the conclusion of treatment, when pressure of treatment decisions has been alleviated (Sze et al., 2006). Regardless of the precise moment when information seeking or provision is identified as most necessary it is always difficult to assuage uncertainty due to wide symptom variability surrounding the sequelae of brain tumour subtypes.

Berg and Woods (2009) and Sze et al. (2006) recommend ongoing assessment of need and provision of information as anticipatory guidance, preparing the way as an ongoing process. This follows the premise that discussions regarding treatment goals is a dynamic one and requires review at different times in order to ensure patients and family do not have discrepant information (Burns et al., 2007). This is further supported by Hudson et al.'s (2004) retrospective review in the general cancer population, which showed high levels of dissatisfaction among patients and their relatives with the information they receive after a diagnosis of cancer. Because information needs emerge along the illness trajectory, care recipients and caregivers are not likely to know all of their information needs during an office visit. Information is often viewed as being incomplete and hard to grasp, owing to the technical or medical terminology typically used. The improvement in the approach to the delivery of information and education recommended in the literature dovetails with the importance given to the consideration to the family's location and emotional state in the illness trajectory (Schubart et al., 2008; Janda et al., 2006; Rolland, 2005).

Patient need for information or support is often not congruent with caregiver need (Soothill et al., 2003). Patients consistently under-report their own needs and the level of support that they receive as they are often unprepared to deal with prognostic issues. This leaves caregivers frustrated, distressed and uncertain in their inability to explore future needs, as they are often not afforded opportunities to ensure they have the required information (Sze et al., 2006). Caregivers who may be present during appointments may be reluctant to raise their needs for fear of upsetting the patient, and seemingly undermining their feelings of independence (Sharpe, Butow, Smith, McConnell, & Clarke, 2005). Caregivers may refrain from seeking out or accepting additional support for fear of causing conflict between themselves and the patient. Caregivers may minimize their needs due to the assumption that their concerns are inevitable and cannot be met; they may decide to deny their needs rather than to appear to put their needs before those of the patient. Under these circumstances caregivers appear to respond to their situations in a reactive and dependent manner rather than feeling they were directing and influencing the caring experience (Scott et al., 2001). Various authors postulate that given caregivers' central role in patient care and the documented risks to their own health, opportunities need to be made available for caregivers to be better informed in order that they are able to make educated decisions about managing the physical, emotional and social aspects of their experience (Stajduhar, Martin et al., 2008; Hudson, 2003).

The fact that the patient and family may have very different needs and may choose not to discuss implications of a palliative diagnosis makes it difficult for clinicians to assess needs let alone be able to determine whose needs take priority. Typically, patients take precedence in healthcare, consequently health providers often underestimate caregivers' needs and lack of attention to caregivers results in continued unmet needs which further contributes to caregiver burden (Sharpe et al., 2005). Caregivers report occasionally being expected to update professional providers or gather information on their behalf. Some also describe feeling marginalized by members of the care team, either because information they had given providers was disregarded or because they were excluded from discussions about their spouse's care (Lohfeld, Brazil, & Willison, 2007). A qualitative systemic review by Docherty et al. (2008) found that communication between caregivers and health providers is a key issue in determining adequacy of information provision and caregiver understanding. Structured information punctuated by appropriate time allotted for discussion can reduce caregivers' anxiety

(Hudson, Quinn et al., 2008) and would reassure caregivers that their needs are legitimate (Soothill et al., 2003).

Barriers to information exchange are perpetuated when health care professionals have not ensured that caregivers have heard and understood the content of the information and are not provided with sufficient time to have questions clarified. Furthermore, caregivers often regard the physician as the most trusted source of information (Schubart et al., 2008), but resist asking too many questions in fear of offending. When caregivers are confronted with new practical, emotional, and existential issues many avoid talking about them. Different degrees of collusion, deception and avoidance, between patients and family caregivers contribute to the difficulty in assessing the need and development of informational and supportive strategies if caregivers and patients are restricting what they disclose. This conspiracy of silence is not restricted to family caregivers and patients but exists for health care professionals also. Clinicians may at times feel uncomfortable and avoid dealing with issues related to death and dying. This may occur because of health care professionals' own lack of preparedness to help others deal with this issue or alternatively, they may be reluctant to break the conspiracy of silence occurring between caregiver and patient. The outcome contributes to limited information for fear of imposing information on caregivers, which they may not be ready to receive. The literature shows, however, that caregivers need for information continues to be unmet (Hudson et al., 2004; Hudson, 2004).

Social support. Social support assists with positive adjustment, personal development and provides a buffer against the impact of stress. Social support includes information, instrumental, emotional, and esteem support (Hudson, 2003). As discussed previously, the support needs of informal caregivers vary with their stage of life, the length of time they have been a caregiver, and the acuity and intensity of the caregiving situation; the needs of those providing 24 hour care on a long term basis differ from the needs of those dealing with an unexpected, life threatening diagnosis (Ploeg, Biehler, Willison, Hutchison, & Blythe, 2001; Ergh et al., 2003). The strain on patients and caregivers has been well described in a number of qualitative studies suggesting a high level of supportive care needs (Sherwood, Given et al., 2004; Sherwood, Given, Doorenbos et al., 2004; Salander & Spetz, 2002; Wyness, Durity, & Durity, 2002; Salander, Bergenheim, & Herksson, 2000; Horowitz, Passik, & Malkin, 1996; Leavitt, Lamb, & Voss, 1996). There is evidence in the literature that caregivers without adequate social support are increasingly distressed with time elapsed since injury and the extent of supportive care needs having been shown to be predicted by the level of emotional distress (Janda et al., 2006). Contributing to caregiver emotional distress is the patients' unawareness of their own deficit and executive dysfunction. Ergh et al. (2003) found that across all levels of social support, increased neurobehavioral problems were associated with increased caregiver distress and reduced caregiver life satisfaction. Janda et al. (2006) found the level of distress noted in caregivers of PMBT in contrast to other caregiver populations provides evidence that supportive care services are needed for a large proportion of patients with a brain tumour and their caregivers.

Inadequate social support may translate to limited assistance with the caregiving burden. This includes not knowing how to navigate and access community services and resources and how to talk to health providers, particularly doctors. Unfortunately, the high demand on these caregivers also limits time to seek and engage in supportive social contexts further isolating caregivers from opportunities to develop supportive relationships. Given this scenario, it is not surprising that these caregivers would be the least satisfied with their lives (Ergh et al., 2003). Social support influences include having family and friends who were available to listen and provide non-judgmental, practical hands-on help or who kept in touch by telephone and emails. Unhelpful is the intrusive involvement of family members who were not providing primary care and in many cases little or no care and lacked realistic knowledge of the patient's illness progression, but disagreed with the decisions made on behalf of the patient by the primary caregiver. Another example relates to the breach in the caregiver's boundaries when others forged ahead with ideas or changes in patient regimens that were not wanted by the caregiver. Some caregivers felt abandoned by family and friends and were disappointed when their expectations for support were not met (Stajduhar, Martin et al., 2008).

There is consensus in the literature that support services are essential for family caregivers of patients with advanced disease and that their entitlement to better support from our health care system should be promoted by policies targeting this group (Schubart et al., 2008; Janda et al., 2006; Dumont et al., 2006; Aoun et al., 2005; Thomas & Morris, 2002; Ploeg et al., 2001). Social isolation of caregivers is depicted aptly by Tebb and Jivanjee (2000) as an outcome of prolonged caregiving but can also be a factor in caregiving responsibilities as seen in the brain tumour setting. Caregivers' lack of awareness of their isolation, their lack of knowledge about available supports and not being identified by health providers as needing support and assistance are critical impediments to needed social support. The psychosocial support needs of brain tumour family caregivers are reported to be greater than the general caregiver population, because there is often little time to adjust or adapt to the disease. The illness is intrusive, affecting virtually all aspects of life (Schubart et al., 2008) and the burden of care causing the greatest impact on quality of life (Janda, Steginga, Langbecker, Walker, & Eakin, 2007). Yet, the psychosocial burden of caregiving at the end of life is vastly underappreciated and is over shadowed by the fear of and increasing demands associated with the patients' increasing disability. The personal struggle of these caregivers often remains hidden from the outside and even from other family members.

While the findings suggest that caregivers may benefit from programs designed to assist them in seeking support to minimize their caregiving stress, resources may be limited (Kim, Schulz, & Carver, 2007). In fact, despite the intrinsic aim of palliative care that is meant to include the family in the care, the focus on patients remains at the exclusion of family due to the limits of available resources. Currently it is difficult within existing care models, for health care professionals to be expected to meet the needs of both patients and families. This impacts on information sharing regarding availability of services such as respite care. Hence, as the patient becomes progressively more disabled, relief from the demands of caregiving tends to be minimal. The lack of resource knowledge is documented to be the most common reason for non-use of needed services. Service based barriers also include lack of flexibility in service delivery.

To reduce the risk of compromising the caregiver's ability to care for the patient at home it is critical that support services be further improved to alleviate caregiver burden (Janda et al., 2007). The importance of monitoring, resourcing and enhancing caregiver access to social support is highlighted in the literature (Scott, 2001; Janda, Steginga et al., 2008) as a way to legitimate need for time off from caring responsibilities as well as potentiating the caregivers' ability to fulfill the role. However, caregivers have been found to carry out additional responsibilities alone assuming the burden of their roles without help although the need for help and respite care was obvious (Ergh et al., 2003). Caregivers who do not typically reach out for help include those who are isolated, culturally diverse, males and immigrants (Dobrof, Ebenstein, Dodd, & Epstein, 2006). These groups do not typically use available resource programs and are not typically represented in study samples. It is assumed that those with the most need typically do not participate in studies and very little is known about them (Janda et al., 2006). What seems to be apparent is that caring for a dying relative is usually very stressful, and no matter how much support is offered, it may not lessen the demanding nature of the role.

Self care. There is very little in the literature that focuses on self-care exclusively. The focus is on the importance of increasing caregiver mastery, which is associated with sense of control and linked to good preventative health behaviors by caregivers. Mastery decreases caregiver stress response (Sherwood, Given, Given et al., 2004) and can mitigate some adverse reactions (Doka, 2006). Keir (2007) found that stress reduction in the form of exercise and massage was preferred by the participants in his study, which focused on caregivers of brain tumour patients. These caregivers' profound levels of stress are similar to results of other research showing that caring for those with brain injuries and cognitive decline is stressful. This is consistent with King & Brassingtons' (1997) findings that showed that a significant proportion of older caregivers of both sexes are interested in improving their physical activity levels, especially through programs that do not require ongoing attendance at a class or group.

Teschendorf et al.'s (2007) qualitative study shows that loss of time due to caregiving responsibilities, impacts on caregiver ability to ensure self care, to manage their own medical care, or to get respite from the daily strain.

Finances and employment. Caregivers of persons with a brain tumour report high levels of stress associated with career sacrifices, monetary losses and workplace discrimination (Schubart et al., 2008). These issues are significant and overlap. How work influences stress in cancer caregiving, let alone in the brain tumour area, has received little research attention (Gaugler et al., 2008). Kim, Baker et al. (2006) examined the effect of caregivers' multiple roles on their psychological adjustment, such as being employed and taking care of minors in their household. This study found that although caregivers may benefit from being employed, the more social roles a caregiver carries out, the more likely the caregiver is to experience stress and negative affect. Consistent with existing literature, the multiple and changing roles that caregivers simultaneously carry out are likely to compete with each other in the context of the caregiver's limited psychological resources. Gaugler et al.'s (2008) review of qualitative and quantitative studies suggests that existing empirical results do not support such a conclusion and posits that employment may even "buffer" or protect caregivers against caregiver stress. Swanbergs' (2006) qualitative study identified workplace factors that inhibit or facilitate caregivers' ability to meet both work and caregiving responsibilities. The factors that facilitated reduction of stress in the caregiving experience included having workplace supports such as responsive supervisors and co-workers as well as flexible work hours. Although the primarily female sample was involved in caregiving on average for 18 months, this does not match with the typical brain tumour caregiving experience. Regardless of support, managing both caregiving and working outside the home was impossible and required reduction of work time or to leave the job completely.

Financial concerns include out of pocket expenses for home care supplies, transportation costs (parking), use of sick days and leave from work without pay; caregivers may also have to quit their jobs in order to meet patients' needs (Ramkumar & Elliott, 2010; Sherwood, Given, Schiffman et al., 2004; Hudson, 2006). Compassionate Care Benefits (CCB) as income replacement is limited to 6 weeks through Employment Insurance (EI) and do not fully replace employment salary. Current literature critiques the CCB and deems it inadequate as it marginalizes the disadvantaged who are typically represented by the unemployed and women (Flagler & Dong, 2010; Berg & Woods, 2009; Williams et al., 2011). Those who have either not paid into EI and do not have any insured benefits or savings must turn to Employment and Income Assistance (Welfare). This state controlled safety net, is very limited in its eligibility criteria and has associated with it significant social stigma.

Emotional needs. There is abundant research that demonstrates that taking on the task of caring for a dependent person comes at caregivers' personal cost and exposes them to risk for developing various physical and psychological problems such as depression and anxiety, reduced self esteem, feelings of isolation, mental and physical fatigue, guilt, resentment, anticipatory grief, anxiety and sleep deprivation (Berg & Woods, 2009; Lopez et al., 2007; Ergh et al., 2003; Hudson, 2003; Aoun et al., 2005). Coping, as a dimension related to caregiver needs is associated with feelings of control and competence, and helps to protect against exhaustion and psychological distress. The intensity of the burden experienced by the caregiver is intimately tied to his or her subjective evaluation of the availability of resources, as well as the process of constructing meaning to the accompanying experience (Dumont et al., 2006). Ironically, while the health care system's need to reduce health costs has been a driver in the shift of care to the community, that is, family, there is evidence of growing caregiver stress and the increased need for support services from the very system that off loaded care. Research findings are consistent in pointing to a relationship particularly between unmet needs and caregiver burden (Sharpe et al., 2005), which manifests in the continual addition of new tasks and the continual adaptation to new roles over time. The "hidden morbidity" in cancer, as it pertains to the spouse caregiver (Braun et al., 2007) is recognized as a serious issue requiring greater attention in order to mitigate debilitating distress (Dumont et al., 2006). As noted previously, caregivers should not be considered only as partners in caring but also as potential patients.

Caregivers report high levels of distress as compared with the general population (Janda et al., 2006; Khalili, 2007). Elevated anxiety and depressed moods in carers of brain tumour patients are comparable with those observed among other cancer populations (Janda et al., 2007) and Dumont et al. (2006) report that the psychological distress of family caregivers was markedly higher than among the general population. In their study, 40-60% of family caregivers who care for a loved one during the end of life experience demonstrated a high level of psychological distress especially as the patients' level of autonomy diminished. Almost 40% of the spouse caregivers reported depressive symptoms, a prevalence that is almost two-fold that of their ill partners; these results are concerning as other studies have also demonstrated that the caregiver's psychological morbidity was equal to or greater than the patients. These results are replicated findings of previous studies and show that subjective caregiving burden is more important than objective caregiving burden in predicting caregivers' depression. Subjective caregiving refers to the experience of caregivers' appraisal of their role as caregivers; objective caregiving burden refers to concrete care tasks, such as assistance with self-care, financial management, and medical and emotional care (Braun et al., 2007). Unique to Braun et al.'s study is the provision of information about the contribution of relational variables to spouse caregivers' depression. Marital dissatisfaction was found to be an important contributor to spouse caregiver depression since giving care requires being attuned to the partner's needs and interacting in intimate and difficult situations. In such circumstances, it may be fulfilling to give care to someone with whom the caregiver shares a satisfactory relationship (Braun et al., 2007; Sharpe et al., 2005).

Several studies have confirmed the existence of a strong relationship between caregivers' psychological distress and the patient's symptoms (Given et al., 2004; Schubart et al., 2008; Dumont et al., 2006; Stajduhar, Martin et al., 2008). Caregivers were better able to cope when the patient was "doing well" and psychological distress tended to increase along with the decline in patient's mobility status (Dumont et al., 2006). Therefore, targeting the reduction of patient symptoms is expected to reduce emotional distress in the caregiver and an increase in the caregiver's comfort with their role and ability to cope (Hudson et al., 2008; Glajchen et al., 2005). Many caregivers also commented that coping with caregiving was much easier when the patient was aware of and accepting of their illness, when the patient recognized the caregivers' contribution to their care and when the patient did not take the caregiver for granted. Being treated in a respectful manner motivated caregivers to continue providing care. Caregivers also appreciated when the dying person realized that the carer needed a break; some caregivers felt resentful that the patient did not understand what they were going through and grieved over the loss of the person that once was (Stajduhar, Martin et al., 2008).

The majority of caregiving research has been done in the area of dementia. This does not reflect an identical experience to caregivers in the cancer setting. In dementia, the caregiver role tends to be assumed gradually as changes to the care recipient's functional and neurological status typically occur slowly over many years. Caregivers, therefore, have more time to adapt to changes in the care situation. In the brain tumour setting, the caregiving role typically has a sudden onset where patient autonomy is acutely compromised (Dumont, Dumont, & Mongeau, 2008; Dumont, Turgeon et al., 2006; Aoun et al., 2005). In this situation caregivers may experience heightened stress responses, condensed into a shorter time span (Sherwood et al., 2008).

Although many studies focus on the negative implications associated with caregiving, there are abundant studies reporting on the benefits of taking care of family members who are ill (Folkman, 1997). Osse et al. (2006) report that 80% of the participants in their study found the caregiving task rewarding, resulting in increased positive feelings related to their role. Other recent caregiving studies have emphasized that gains and losses coexist in the caregiving relationship (Waldrop, 2006, 2007). Caregivers report feeling obligated to provide care but also wanted to contribute to a health care system that they perceived to be in need of help. They were able to recognize their limitations and could seek advice and help with caregiving early in the patients' disease trajectory and before they became overburdened. They realized that advance preparation was important if they were to continue to cope (Stajduhar, Martin et al., 2008). The group of caregivers who are described as hardy are more likely to use problem-focused and support-seeking coping that is adaptive, whereas non-hardy individuals are more likely to use avoidant coping. Stajduhar, Martin et al., (2008) did not use measures to assess these personality traits, but the caregivers' descriptions of their approach to life would suggest that these personality traits might have played a role in influencing the caregivers' ability to cope. Caregivers with higher self-efficacy report less depression and lower burden. Depression, anxiety, low self-esteem, helplessness and pessimistic thoughts are associated with a low sense of self-efficacy (Hudson, 2003).

The benefits of caregiving described in the literature include post-traumatic growth, improved sense of self-worth, and increased personal satisfaction (Kim & Given, 2008). Although a daunting process, to care for someone has been described qualitatively as an invitation to enter someone else's pain and suffering. The experience of caregiving can be viewed as a privilege to help relieve suffering and deliver hope; caregiving becomes a challenge along the path of life and loss (Rainer & McMurry, 2002). The benefits of the experience centre on having personal satisfaction knowing they made the patient more comfortable, realizing their own capabilities and having control within their own home (Hudson, 2006). Positive feelings about caregiving have also been associated with meaning making emerging from viewing the importance of final, shared times (Waldrop, 2007). Caregivers who received comprehensive and coordinated professional support felt positive about their caregiving experience and some went on to train as volunteers for palliative care, to repay some of the commitment shown to them (Aoun et al., 2005). The positive effect of caregiving has been shown to be associated as a buffer against overwhelming burden and traumatic grief (Hudson, 2006).

Complicated grief. The caregiver role impacts on caregivers' quality of life throughout the illness trajectory and has implications for the caregiver's response to bereavement; "grief is experienced throughout the context of life-threatening illness" (Doka, 2006, p. 205). Complicated bereavement is associated with extreme and debilitating reactions to loss that include symptoms of psychological trauma (Hudson, 2006). Tomarken et al. (2008) define complicated grief as a cluster of experiences that include separation distress, post-traumatic stress and an inability to cope with the loss of a loved one. Complicated grief has been further divided into anticipatory grief reactions and bereavement reactions. The strong relationship between complicated grief pre- and post-death illuminates the importance of studying pre-loss grief reactions. The more mental health professionals know about the risk factors of complicated grief pre-death, the more they can identify those at risk for post-death bereavement and offer appropriate symptom-focused treatment to aid in the management of pathological grief reactions. The limited research dealing with complicated grief pre-loss has focused primarily on middle-to older-aged samples. Some research has demonstrated that bereaved elderly individuals with higher levels of complicated grief were more at risk for mental and physical health problems than those with lower levels of complicated grief. Other research points to the importance of assessing younger caregivers due to their involvement in multiple roles and lack of experience with death and dying (Kim, Loscalzo et al., 2006). This evidence points to the importance of assessment by mental health professionals prior to the loss of a loved one which may help to protect bereaved individuals from future mental and physical morbidity.

The distinct features of caregiver grief are important components for targeting in social work practice with people who are caring for a terminally ill person. Tomarken et al. (2008) recommend that mental health professionals who work with caregivers should pay particular attention to pessimistic thinking and stressful life events, beyond the stress of the loved one's illness. Although their study did not reach significance, it contributes to little known knowledge about complicated grief experienced by caregivers pre-death. The researchers found the use of the Stressful Life Events Scale as having predictive value for the development of complicated grief pre-loss. Caregivers may not identify their distress as grief, especially while they are still engaged in caregiving responsibilities, but they may wonder what is happening and why they feel so sad and as though they are going crazy. Support and information is recognized to be essential in the process of facilitating the grieving process and the prevention of bereavement complications (Dumont, Dumont, & Mongeau, 2008; Doka, 2006; Rando, 1984); psycho-education "can help prevent cycles of blame, shame and guilt" (Rolland, 2005, p. 2588). Practitioners can help normalize these responses by educating caregivers about their responses to end-stage care, death and adaptation to loss (Waldrop, 2007). In addition, health care providers, typically social workers, can help caregivers understand that their experiences in providing end stage care may have long-term effects (for example, sensory experiences can trigger a flood of memories). Social workers in community based oncology or primary care clinics and hospitals can use these findings to justify making regular supportive and therapeutic contact with caregivers during the course of terminal illness and after the persons' death. This is supported in the National Association of Social Workers Standards for Social Work in end of life care (2004), which provides guidance for practitioners who encounter caregiving families in health care. This is fundamentally empowering work in helping grieving families to cope and regain some control.

Continuity of care. Continuity of care (COC) can be defined as "the way in which patients receiving care view it as being coherent and sequentially related. This aspect of care is the result of effective transfer of information, good interpersonal relationships, and efficient care coordination" (Dumont et al., 2005, p. 50). COC can be examined as an essential structural component of service delivery, and is discussed as such further on in this report. However, it can also be viewed as an implicit need of caregivers in that, where COC is minimal or non-existent, caregivers experience confusion and uncertainty about all aspects of their experience. In their attempt to fulfill the very fundamental aspects of their role, caregivers are often thwarted when they try to navigate through a medical system that often lacks coordination and sufficient health services and community resources (Stajduhar, Martin et al., 2008). Provider continuity, follow up care and respite services are known needs for caregivers (Lohfeld et al., 2007; Braun et al., 2007). These needs are simultaneously present in the setting where uncertainty regarding treatment goals and the future is consistent (Grbich, Parker, & Maddocks, 2001; Kristjanson, 2004; Aoun et al., 2005; Dumont et al., 2006). Fractured care (Dumont et al., 2005) is often linked to an excessive number of healthcare workers and lack of coordination across providers, which contributes to increasing workloads for caregivers. Explicit conversations between professional health providers, patients and caregivers is recommended to ensure awareness regarding what caregivers can expect from each team member (Speice et al., 2000) and community resources. Geographic location contributes to increased difficulties in securing what is expected from community resources. As well, the discrepancy between urban and rural support services requires more attention.

Understanding the factors that influence caregivers' abilities to cope with the caregiving role is an important step in informing front line health care providers of the burdens associated with caregiving in advanced disease. Anticipating problems that may arise is essential in the process of ameliorating burden and minimizing risk for complicated grief (Tomarken et al., 2008; Stajduhar, Martin et al., 2008). Consistency and availability of information through effective communication within multidisciplinary teams inclusive of patient and family is a benchmark for continuity of care.

Mediating factors: age, gender, multiple roles, health. The literature shows that young caregivers experienced higher psychological distress, especially as the death of their loved ones became imminent. It is thought that young caregivers may experience death as very traumatic increasing their vulnerability for psychological distress in their multiple roles. Caregivers who were employed and took care of children were likely to experience psychological strain and have difficulty in finding meaning from their new role as a cancer caregiver. This role is relatively new to the participants compared to other pre-existing roles such as being an employee or parent, and providing care to the patient requires meeting their multidimensional needs, including treatment monitoring, treatment-related symptom management, emotional and financial support, and assistance with personal and instrumental care (Kim, Baker et al., 2006). Tomarken et al.'s (2008) review shows that younger age was related to complicated grief pre-death and therefore a risk factor for complicated grief. The experience of complicated grief in the younger adult population (younger than 50 years old) is poorly represented while older participants (those over 60) are less likely to report unmet needs (Sharpe et al., 2005).

Caregiving is seen to be highly gendered (Berg &Woods, 2009; Baines et al., 1998) and consistent with other reports Dumont et al. (2006) show that women make up a clear majority of the cancer caregiving population and tend to report greater distress, anxiety, depression, and subjective stress when compared to their male counterparts (Gaugler et al., 2008). One possibility for this recurring empirical trend is that care recipients rely on female caregivers for more basic and intensive forms of care. This may be related to the fact that in addition to the many demands of caring for the patient, women also perform many household tasks, while juggling employment responsibilities, and child rearing. Lack of emotional support, perception of financial burden and loss of income through absence from work and insufficient support from ones' surrounding, has been shown to be weakly but positively related to psychological distress (Dumont et al., 2006; Stajduhar, Martin et al., 2008). Women who perceived themselves as lacking confidence and or competence in respect to caring for a loved one with cancer experience higher levels of distress than men. In contrast, with more males fulfilling the caregiver role that is not expected of them, they often report feeling good about themselves as a result (Kim et al., 2006a, 2006b). This may be because men may rely on other family members to provide this care even when assuming "primary" informal care responsibilities. Gaugler et al. (2008) emphasize the social and gendered context of informal long-term care and the importance of distinguishing the diverse and complex experiences of families providing care to a relative suffering from cancer. It is also noteworthy that it may be hard for younger carers to identify the source of stress in their life, as it can be multidimensional due to the multiple roles typically associated with younger households (Scott et al., 2001).

“Grief is stressful, and stress adversely affects health” (Doka, 2006, p. 207). “The effect of caring on caregiver’s health is a most important aspect of caregiver burden” (Sharpe et al., 2005, p. 112). It is clear that those carers who report a high level of need are those most at risk for poor caregiver health and reporting of poor health is significantly associated with a high level of psychological distress (Berg &Woods, 2009; Dumont et al., 2006). Providing care has been shown to have negative physical consequences for the caregiver such as altered immune function, hypertension, morbidity and poor overall physical health (Sherwood et al., 2008a, 2008b). This can be further exacerbated when caregivers have their own disability or chronic illness (Thomas & Morris, 2002). The risk for negative health outcomes has been shown to be present particularly in the setting where caregivers have limited social support (Ergh et al., 2003). Older spousal caregivers who experience stress from caregiving have been shown to be more likely to experience earlier mortality than non caregivers; the combination of loss, prolonged distress, physical demand of caregiving and biological vulnerabilities of older caregivers compromise their physiological functioning and increase their risk for physical health problems leading to increased mortality (Aoun et al., 2005; Dumont et al., 2008). Unrelenting fatigue in the caregiver has also been shown to increase the likelihood that the care recipient will be taken to hospital.

Program Structure

The second concept to be discussed is program structure. The dimensions included within this concept refer to the process of service delivery to patients and caregivers. I have found that collaboration, family centered care and continuity of care are important categories that impact this concept. The principle of collaboration has not typically been associated with the medical model of practice, meaning that patients and families are not typically consulted or regarded as experts. The World Health Organization's (2007) promotion of family-centered palliative care and the highlighted focus on advance care planning as a collaborative approach to care underpins the importance of the inclusion of caregivers in the PMBT disease site and the multidisciplinary approach to delivery of care. This begs for the need to approach practice in an inclusive and collaborative way (Morrison & Meier, 2004). There is a dearth of information in the literature relating to structured multidisciplinary neuro-oncology programs. There is little addressing active and aggressive treatment inclusive of assistance to patient and family in living fully with a life limiting illness (Tepper, 2003). The general focus of medical care in the literature is on clinical care of patients with specific disease entities and the brain tumour area receives similar attention. Since this disease entity is fairly rare and the sequelae unique, further exploration is justified to fill the gap to include multidisciplinary service provision to patients with primary malignant brain tumours and their caregivers. This part of the literature review examines the limited literature and serves as a springboard for my study.

Back et al. (2007) demonstrate quantitatively significant improvement in clinical outcomes in patients with a high grade glioma treated in a multidisciplinary tumour clinic. Their study delineates the team approach, which includes only medical personnel such as a neurosurgeon, radiation oncologist, neuro-oncologist, neuro-radiologist, and a clinical nurse specialist. Here the value of a multidisciplinary team approach is limited to medical care exclusively and with a scope of focus on patient length of survival as the valued outcome at the exclusion of quality of life for patient and family. The relevance of the findings is limited and reiterates that medical focus is disease oriented only.

Grisold, Oberndorfer, and Hitzenberger's (2006) editorial points to the development of multidisciplinary neuro-oncologic teams as a way to improve treatment quality and care for patients and caregivers noting that neuro-oncology is currently an interdisciplinary approach and that the "multisdisciplinary team is not confined to medical treatment only" (p. 329); the team includes medical specialists, specially trained nurses, psychologists, occupational therapists, speech therapists and social workers, neurorehabilitation and spiritual care. The importance of this editorial is in its' recognition of patient needs as well as the needs of their support network, which goes "much beyond medical treatment" (p. 329). The authors recognize, however, that the more inclusive multidisciplinary team attending to "the soft facts" of patients and carers will be the "mainstay" of future work apart from standards of medical treatment.

Tepper (2003) reported on the development and implementation of a pilot model of care at Duke University Medical Centre, an American setting, where comprehensive care was provided to individuals with malignant brain tumours and their families. This program is the only one found in current literature that addresses the PMBT population in terms of a formal service established to provide a family-focused program. The goals of what was called a Transitions Program aimed to ensure quality of life, inclusive of opportunities for advance-care planning, improvement of end-of-life care and improvement of patient care outcomes. Educational materials and access to psychosocial support and counseling was ensured through five key times during the illness continuum:

at diagnosis or time of entry to the brain tumour centre, at clinical or radiographic progression of disease, at hospice referral and immediately after the hospice referral and following the death of a patient. The program had formal protocols that ensured this type of care and the clinical social worker was central to the coordination and implementation of this standard of care.

The program's underlying value resides in the importance of education and psychosocial services as critical components in overall treatment planning for the patient and family throughout the illness trajectory. The program is designed to assist patients and families in preparing for the possibility of death, while supporting them as they cope with the illness. Tepper (2003) posits that protocols were created and implemented for each of the critical points along the trajectory without which psychosocial care and support would have been overlooked or dismissed. The outcome and process standards served to ensure access to comprehensive services to all patients and their caregivers. Tepper points to the need for continual programmatic re-evaluation in response to staffing changes, time constraints, resource constraints, provider limitations and differences in service delivery within the institution and in the community. All of this would resonate with anyone working in health care. Although the author highlights the importance of self-determination, she does not address cultural diversity or how to manage the unique needs of those who do not fit into standard care. Tepper's article is the only one found that addresses a structured program for neuro-oncology patients and can serve as a template for multidisciplinary care.

The Disease Site Group for Neuro-Oncology program at CancerCare MB, which is where I provide social work service, does not have Terms of Reference that delineate in precise terms disciplines required for provision of care. However, the lack of stringent guidelines serves to facilitate the creative discretion of the Chair, which has supported and promoted a multi-disciplinary approach to comprehensive care within the constraints of the general health care system for patients, caregivers and families.

Program structure is affected by and affects continuity of care (COC). COC is often at the heart of plans to improve health care delivery, as well as the subject of a growing number of empirical studies with patients, caregivers and physicians (Lohfeld et al., 2007). Given the increasingly fractured nature of care in North America, particularly for complex, chronic, or palliative care, understanding COC issues from the perspective of multiple stakeholders is important. COC interfaces well with the defining principles guiding family-centered care, which include:

> 1. People are treated with dignity and respect, 2. Healthcare providers communicate and share complete and unbiased information with patients and families in ways that are affirming and useful, 3. Patients and family members build on their strengths by participating in experiences that enhance control and independence and 4. Collaboration among patients, family members and providers occurs in policy and program development and professional education, and delivery of care (Kovacs, Bellin, & Fauri, 2006, p. 15).

The importance of good quality multidisciplinary care is defined in current literature by consistent communication amongst health care professionals, the care recipient and the caregiver (Scott et al., 2001; Schubart et al., 2008; Janda et al., 2006; Hudson, 2006). Palliative management of brain tumour patients requires a multidisciplinary approach performed by a well trained neuro-oncology team (Pace et al., 2009). Inadequate communication from health care professionals can result in conflicting information contributing to misunderstanding or uncertainty about treatment goals. This can potentially contribute to patient and family stress and limited confidence further complicating the delivery of timely care (Burns et al., 2007; Cagle & Kovacs, 2009). Lack of trust in health care providers can lead to detrimental consequences such as families choosing to ignore supportive services because what is offered will not be considered effective to meet their needs; inferior communication, poor provision of services and lack of emotional support does not instill confidence in caregivers (Hudson et al., 2004). As discussed previously, a hallmark of quality palliative care is consistent communication among health professionals and with the caregiver, referral to palliative care sooner in the disease trajectory and access to respite services (Hudson, 2006). This fits well with the current push for “effective information sharing” (Lohfeld et al., 2007, p. 124) all over Canada through better use of available technology such as electronic charts, single records, standardized referral criteria and on-going communication with family physicians to help promote provision of seamless complex care along the health care continuum.

Collaboration is advocated among professionals who participate in well functioning care teams, thus providing seamless complex care and effective case management (Lohfeld et al., 2007; Sohlberg, McLaughlin,Todis, Larsen, & Glang, 2001). These authors point to the growing literature, which recommends a tripartite framework involving the caregiver, care recipient and health professions. With the ever-growing body of literature on caregiver strain and burden, anything less is simply not enough (Lohfeld et al., 2007). Docherty et al. (2008) refers to this holistic approach as critical for information gathering and sharing. Collaboration with and inclusion of caregivers in the context of a brain tumour is particularly important in the setting of cognitive impairment and anticipated deteriorating sequelae (Sze et al., 2006). Here collaboration is regarded as a “process in which family expertise is acknowledged and used to direct selection, implementation, and evaluation of treatment plans. It denotes an equal partnership between professionals and members of the client’s support network” (Sohlberg et al., 2001, p. 498) particularly pertinent to the brain tumour population. Family centered care is an effective systems approach that incorporates the involvement of those upon whom the patient is dependent, namely the primary caregiver.

The relationships that are established among the patient, staff and caregiver (Hudson, 2006) contribute to what is referred to in the literature as relational continuity, crucial for seamless patient and family-centered care. Effective palliative care is not only multifocal (provided by several providers across disciplines and organizations), but addresses both the medical needs of the patients and the psychosocial/emotional needs of patients and their families. Clearly it is easier to address such concerns if there is minimal tension between providers, or between providers and patient/caregiver dyads (Lohfeld et al., 2007). A range of obstacles that can impede this process include the great many health care professionals involved in patient care, as well as the nature of the information that must be conveyed to patients and their care providers. Multiple health providers can make it difficult to create meaningful relationships among caregivers, patients, and family. However, when meaningful ties are established, the result is a number of important benefits: patients and family are more easily reassured less information ends up being duplicated and care is sequentially ordered (Dumont et al., 2005).

Enhancement of communication may need to involve caregivers independently of patients. The literature clearly shows that caregivers' perception of need is often different from those of the patient (Burns et al., 2007; Hudson, 2004*)* and caregivers are often reluctant to disclose issues with the patient present (Janda et al., 2008) for fear that attention to the caregiver will divert resources away from the patient. As well, caregivers do not typically initiate discussions about their needs unless asked (Walsh, Estrada, & Hogan, 2004). Incorporating routine family meetings at the start of care can provide the forum to discuss patients' and family members' needs and will demonstrate provider practice styles. These opportunities will also demonstrate the high regard given to the caregiver as a person and in the role (Rolland, 2005). In addition, family meetings conducted early in the care process may identify problematic family dynamics, giving the professional care team advance notice of potential conflicts. Often, family members need guidance about how to best support the patient through the care process, need clarity about treatment goals, expectations for roles and information sharing that can be used for conflict resolution (Speice et al., 2000).

Positive communication and authentic connection by health professionals with patients and their families develops over time and requires effective communication skills that include sensitivity and time (Burns et al., 2007; Lohfeld et al., 2007). Care cannot proceed successfully regarding the illness and treatment in the absence of effective interaction (Dumont et al., 2005). However, not all aspects of communication between provider and caregiver involve sharing information relevant to the patient's status or care (Lohfeld et al., 2007). Normal conversations about casual, day-to-day issues have been documented as being important to families, and serves as a reminder that caregivers and patients are more than just a role and a recipient of care (Sze et al., 2006). Clinicians need to promote an environment that is conducive to information exchange when providing supportive care. There should be privacy and minimal interruptions to allow for optimal communication but this is not easily done in hospitals or ambulatory care settings. The expanded role of the provider as willing to take time to talk and to listen would instill confidence in seriously ill individuals and their family caregivers all of whom would be more apt to feel cared for and cared about (Lohfeld et al., 2007; Taillibert et al., 2004).

Several authors make recommendations towards the improvement of service delivery and recognition of the value of a trusting relationship by the assignment of a dedicated member of the care team or case manager to oversee care and to ensure clarity and understanding (Janda et al., 2006; Burns et al., 2007). This is supported by Lohfeld et al. (2007) who refer to the continuity of care over time as being synonymous with provider continuity throughout an illness episode. Robb (2011) reports in an unpublished review that a case manager rarely provides direct clinical services and is "described as assessing client need, developing a service plan, arranging services, monitoring implementation, and evaluating effectiveness…within specific budgets" (p. 2). The consistent reference in the literature to the importance of interdisciplinary team-based care and provider continuity promotes a different approach from the medical model of a single provider and may be associated with case management that is broader in its scope of practice. This would ensure provision of identified services, transfer of information and be readily available to answer the principal questions of patients and caregivers, while offering support, reassurance and advocacy throughout the various phases of the disease process (Catt et al., 2008).

Much of the literature in the caregiver area is produced from a nursing perspective. It is not surprising then, that the clinical nurse specialist is often regarded to be the appropriate discipline for the role of case manager. Khalili (2007) promotes the idea that the nurse specialist can ensure the successful transition of the patient and family when medical treatment goals change. Grisold et al. (2006) promote a clinical nurse specialist whose provision of care is directly related to the systemic structures that enable medical service. This focus perpetuates a system that excludes multidisciplinary care. A number of reports in the literature, however, refer to the social worker as the appropriate discipline to absorb the role of case manager precisely because this fits with social work training which prepares us to view individuals in the larger context of their family and social environments making us highly qualified to model for other interdisciplinary formal caregivers the provision of family-centered care (Kovacs et al., 2006). As an advocate, the social worker is also able to identify current and anticipated issues and could serve to bridge the gap between health care providers and resources. Identifying and arranging appropriate services beginning at the time of diagnosis and throughout the course of the illness trajectory is a natural role. For example, accessing allied health services such as those of the neuropsychologist, is critical. The utility of this service provider is invaluable in identifying deficits and providing intervention to patients and caregivers to alleviate the burden of neurocognitive and neurobehavioral problems that arise in the setting of brain tumour patients (Schubart et al., 2008). Family-centered care is an espoused value within the scope of social work practice (Schubart et al., 2008;

Kovacs et al., 2006). Tepper (2003) refers to the social worker as likely to remain the one consistent staff member involved in the patient's and family's care throughout the illness.

In summary, the literature points to the necessity for case management in the broadest sense in order to ensure continuity of care. Case management does not typically include direct client service (Robb, 2011) but front line medical social work practice can in fact incorporate this task as a way to ensure continuity of care by bridging the various services that are involved throughout the brain tumour illness trajectory. The expansive scope of clinical social work which includes on-going counseling, advocacy and supportive intervention, can facilitate discussions related to disease process, decision making and caregiving role responsibilities. The "case manager" or "contact person" will advocate for respite care, will assist the caregiver to return to pretreatment responsibilities or to prepare for long term care, while providing support and referrals to resources to minimize social isolation, stigma and discrimination. The role focuses attention to the caregiver's own health, to reduce risk for compassion fatigue, anxiety and depression. Raising and addressing unspoken fears, and supporting caregivers through end of life passages, including clear decision making and preparation for death (Schubart et al., 2008; Janda et al., 2008; Cagle & Kovacs, 2009) is critically important since caregivers may be unaware they are experiencing grief and often need assistance to identify and integrate these normal responses to loss (Waldrop, 2007). The designated contact person could help deal with the emerging emotions, facilitate discussions between patient and carer and also answer medical and practical questions. This person would serve as a main contact if unexplained symptoms arose and could proactively facilitate with pertinent and timely information as is relevant in legal matters such as Power of Attorney and Will, preferably before treatment is initiated. Continuity of care ideally would extend beyond the end-of-life period for the patient as the post bereavement period has been shown to be a time that caregivers are often left alone (Rainer & McMurry, 2002; Grbich, et al., 2001).

Interventions Aimed at Caregivers

The third and final concept that is pertinent to this review is associated with interventions that are aimed at caregivers of individuals with PMBT. As discussed above, the identification of factors associated with unmet needs in caregivers is highlighted in the literature much more extensively than interventions to mediate needs. Interventions focusing on reducing the negative aspects of caregiving in the advanced cancer setting are limited (Aoun et al., 2005) and further development and evaluation of these is required in order to provide sufficient direction to inform appropriate interventions (Stajduhar, Martin et al., 2008). The vast majority of authors argue that strategies must be put in place to support family caregivers in order to minimize the burden placed on them and to mitigate the negative effect on patients' and caregivers' quality of life (Rabow et al., 2010; Lipsman et al., 2007; Hudson, 2004).

A growing body of research shows that when patients and families have a better understanding of their diagnosis and treatment, they are better able to cope with their illness and that improved coping strategies generally result in better adjustment to a cancer diagnosis and an enhanced quality of life (Schubart et al., 2008; Cagle & Kovacs 2009). This manifests as adjustment to stressful situations and the ability to overcome problems. It allows for more effective use of the health system and has the potential to result in less psychological distress. This premise is supported by alternative models of intervention represented by Hudson (2003), Sherwood et al. (2004) and Rolland (2005) and will be discussed later in this chapter. To date, however, there is a dearth of evidence-based supportive interventions within the palliative care domain (Hudson, 2003). Lipsman et al. (2007) and Rabow et al. (2010) add to the current literature that promotes supportive intervention to be initiated by front line clinicians and health care providers. One reason for the lack of interventions generally may stem from the belief that emotional distress is considered to be a normal response in context of terminal illness, therefore, not identified as requiring intervention (Grbich et al., 2001). However, there is strong evidence for the importance of identifying and monitoring caregiver needs, which ultimately may benefit patient care (Dumont et al., 2006). Interventions designed to facilitate access and use of available resources in the community, such as peer mentoring, respite care, and support groups may prove beneficial, as may interventions focused on engaging family resources to enhance caregivers' experiences of support (Ergh et al., 2003). Considering the risks for morbidity and mortality in caregivers of PMBT, it is incumbent upon the health care system to develop and implement strategies that would strengthen this subgroup of caregivers.

Targeted interventions are recommended for family caregivers based on their needs (Hudson, Hayman-White, Aranda, & Kristjanson, 2006; Hudson et al., 2008; National Comprehensive Cancer Network, 2008) and are recommended as an integral part of good palliative care, fully integrated to health policies for the terminally ill (Dumont et al., 2006). The delivery of targeted interventions may prove beneficial in minimizing the adverse impact of cancer on family by helping individuals maximize the positive experiences from this disruptive (Hudson, Aranda, & Hayman-White, 2005). The inclusion of family members in the delivery of psychosocial interventions is required at every phase particularly when caregivers take on tasks they were not trained to do. Intervention results show evidence of mitigated overwhelmed feelings, isolation, resentment, anger, depression and denial (Kim & Given, 2008).

What is suggestive in the literature is the utility of interventions that incorporate multiple rather than single approaches, as these have shown success in producing positive outcomes for caregivers (Hudson, 2004; Hudson et al., 2005); the range of strategies may be utilized as needs change over time (Scott et al., 2001; Janda et al., 2008). Interventions that emphasize education and information about medical treatment and disease processes, focus on improving problem-solving skills, and provide information. Embedded in this approach is psychological counseling and supports, which includes validation of caregivers' concerns (Lipsman et al., 2007). This appears to be successful in decreasing caregiving stress and improving the quality of caregiver life (Kim & Given, 2008; Cagle & Kovacs, 2009). The limited body of literature reflects evidence for the utility of various interventions with the intent to reduce the negative aspects of caregiving while also providing cost-effective allocation of resources (Aoun et al., 2005; Hudson et al., 2005).

Screening. As discussed previously, there is growing evidence in the literature that caregivers have needs of their own that are just as pressing as those of the patient's yet they remain underrepresented (Soothill et al., 2003). Screening is recognized as an important initial strategy for identifying risk and care needs of caregivers (Janda et al., 2008; Schumacher et al., 2008). Screening and assessment can overlap and both are recognized as intervention tools and as means for alleviating caregiver burden (Dumont et al., 2006; Hudson et al., 2005). However, the use of a definitive screening tool to identify caregivers at risk for lower levels of psychosocial functioning is not sufficiently developed and must be studied further in large samples (Hudson et al., 2006). Currently only patients seem to be surveyed routinely for emotional distress (Groff, 2011; Vodermaier & Linden, 2008).

The necessity for screening patients and caregivers together and apart, for the identification of psychosocial needs stems from the evidence that meeting psychosocial needs of informal caregivers, benefits both the patient and caregiver. The research conveyed in the literature shows that patients and caregivers have differing preferences and needs and that caregivers minimize their own needs in deference to the patients to avoid causing burden (Sharpe et al., 2005). Value based barriers, which invoke caregiver guilt, contribute to the difficulty caregivers experience in relinquishing the caregiver role to others and guilt about meeting their own needs. Caregivers do not want to put their needs/issues before the patient; they don’t want to be judged inadequate as caregivers, and often believe that concerns and distress in the role is inevitable and cannot be improved (Hudson et al., 2005). In their effort to protect the care recipient, the caregivers do not share their needs and consequently they receive less support from family and health professionals and risk experiencing increased burden (Sharpe et al., 2005; Hudson et al., 2004). Along with this scenario, patients will not raise needs of which they are unaware, which also contributes to the lack of attention given to caregivers. Caregivers do not want to bother health providers because they believe that these providers operate in a system where resources are limited and professionals’ time is constrained.

Caregivers often perceive their role as more tangential; hence, they may not feel that their needs for support and information are important or valid. The reticence to mention their own problems has been explained by caregivers as their issues not being 'bad enough' to bother the health care professionals (Hudson et al., 2004; Walsh et al., 2007). The routine use of a screening questionnaire could universalize needs and would help to prioritize services to those most at risk. The data generated would also be useful for resource planning and policy making.

Dumont, Fillion et al. (2008) developed a new 16 item tool to specifically assess family caregivers' burden during end-of-life care. This self-report questionnaire was systematically developed and validated through qualitative and quantitative methods. It is psychometrically sound and focuses on identifying caregivers at risk for burnout or psychological distress at the end-of-life and is meant to facilitate planning of assistance and support to this vulnerable group. The strength of this tool is in its ease of use while enabling clinicians to quickly identify caregivers at risk of manifesting severe psychological distress in palliative care. However, the authors do not comment on when in the "palliative care" continuum this tool should be used or how frequently. Although the authors recognize that the scale's cultural validity is limited to English and French speaking Canadian populations, this tool nevertheless is one that has gone beyond just English speaking participants. This tool is also specific to the context of palliative care and is therefore a relevant intervention tool for the PMBT caregiver.

Assessment. Recommendations for clinical practice through proactive and routine assessment, as a structured approach to family care, are well supported in the literature (Berg & Woods, 2009; Schumacher et al., 2008; Lipsman et al., 2007; Glajchen et al., 2005; Soothill et al., 2003; Chambers, Ryan, & Connor, 2001). Proactive assessment contributes to enhanced communication as it promotes understanding by providers of what type of information is needed and desired, as well as the timing and manner in which the family wants to receive it (Cagle & Kovacs, 2009). On-going assessment throughout the illness trajectory is seen as a proactive intervention intended to meet the changing needs and emotional state of patients and families, all of which change over the course of an illness (Schubart et al., 2008; Janda et al., 2006). Assessment for risk can also mitigate the current practice of provision of intervention as a reaction to crisis, seen by Harding & Higginson (2003), as rewarding failure. It is vitally important to understand the mindset of these patients and their caregivers in order to provide them with comprehensive and effective care (Lipsman et al., 2007).

As discussed previously, identifying and assessing the distinct features of caregiver grief is an important component in end-of-life care as it has significant implications for coping pre- and post-death (Waldrop, 2007)**.** Waldrop underscores the importance of both accurately assessing and effectively intervening with caregiver grief as a means to enhance quality of life by assisting caregivers to learn to live with the disease and its demands, giving meaning to the disease and its process, rather than allowing the disease to define the individuals' entire existence (Rainer, & McMurry, 2002). Health professionals need to know how to readily determine which caregivers are suffering significant psychosocial distress such as anxiety or depression given that these syndromes are frequently undiagnosed and undertreated (Hudson, 2006). The message in the literature is consistent regarding the warranted effort towards identifying family caregivers in greatest need of help over time (Hudson et al., 2006; Speice et al., 2000; Kristjanson, 2004).

The literature reiterates the importance for health care providers to be sensitive to the meaning that caregivers bring to the caregiver role based on their attachment orientation (Braun et al., 2007). Attention to relationships can be expedited through routine assessments. Those who live in distressed relationships experience more burden, as they tend to receive less support from the wider family (Sharpe et al., 2005). Emotionally charged relationships between patients and caregivers are unlikely to be affected positively by intervention from the health care team and indeed, the illness experience may exacerbate any preexisting relationship tensions (Stajduhar, Martin et al., 2008). The need to acknowledge the importance of couple relationships to the welfare of both spouse caregiver and patient while facing cancer cannot be ignored and interventions directed at couples should be developed and assimilated in routine practice (Braun et al., 2007). Discrepancy between patients and their caregivers may obstruct proper informed consent and complicate the delivery of effective care due to misunderstanding or uncertainty about treatment goals. As identified previously most caregivers, if given the opportunity would be willing to talk about issues specific to their needs and concerns.

The literature reveals that different interventions are required to match various needs that arise in different phases along the illness trajectory. Therefore, continuity of care throughout the illness trajectory must be promoted through intervention to ensure quality patient care and sustainability of caregivers. The research in the area of caregivers of cancer patients highlights the diversity of need and the importance of recognizing that the illness trajectory is dynamic and changing thus requiring on-going assessments and varying interventions over time. Strategies for determining caregivers at risk of psychosocial distress are a priority and without research initiatives in this area, interventions may not be specifically directed at those who need them most (Hudson, Hayman-White et al., 2006). Hudson (2004) critiques the limitations and underdevelopment of intervention studies citing the lack of control groups as well as a lack in comprehensive theoretical or conceptual frameworks. Studies are limited by their sample biases and typically use only English speaking, high functioning participants, whose preexisting psychosocial characteristics were not known (Hudson et al., 2004; Hudson et al., 2008; Hudson et al., 2005).

Stajudhar, Martin et al.'s (2008) work suggests that an individualized approach to assessing the coping abilities of caregivers already in the community would assist in predicting how they might cope with home-based caregiving. With this information, healthcare providers would be better able to determine the type and amount of health services needed to help caregivers who wish to continue providing home care and would alert them to potential problems that caregivers might have. Osse et al. (2006) caution that needs assessments cause expectations in caregivers. There is a fear that clinicians would not be able to respond adequately to the needs for care that a structured needs assessment might uncover and this may support the complacency regarding screening and assessment. Along with assessment then, it is important to identify barriers that may confront health care professionals in order that provision of supportive care comes to fruition (Hudson et al., 2004).

Individual. Very few specific interventions addressing caregiver strain and burden in oncology or end-of-life were found in the literature. It is possible that these are not reported. Individual intervention opportunities can result from routine assessments by practitioners or by caregiver self-referrals. The need for provision of information and education for patient and family is identified as the most prevalent issue and has been discussed earlier in this chapter. It warrants repeating that caregivers should be offered a variety of supportive information tools in the form of face-to-face intervention, written materials, videotapes and audiotapes (Lipsman et al., 2007; Keir, 2007; Hudson et al., 2005).

A compelling article by Cagle and Kovacs (2009) posits that provision of education is not only a useful intervention frequently used by social workers but also an empowering and complex one. This work conceptualizes education as an applicable intervention across the acute, chronic or terminal practice settings. Cagle and Kovacs' focus on end-of-life is relevant to this discussion and dovetails significantly with family-centered care. The complexity of the intervention includes cultural variation, cognitive status, health literacy, patient and family expectations, emotional responses and practitioner bias along with the reality of smaller families, and belief that life can be prolonged in institutions via scientifically based care (Kovacs et al., 2006). The assessment of family must be individualized and caregiver preference could ensure that the right form of information matches with the need. The treatment modalities used include crisis intervention, brief and solution focused therapy, cognitive-behavioral therapy, and relaxation techniques to name a few. The intervention is theory based in guiding practice and includes the involvement of various health care providers. Cagle and Kovacs (2009) do not provide evidence for efficacy in use of the above modalities. Lipsman et al., (2007) make a strong argument for the importance of clinicians to acknowledge the uniqueness of the disease and that concerns specific to this disease be validated as specific to the brain tumour experience. These authors strongly recommend that assurance be given that additional supports will be available as needed and significant support is iterated as a referral to social work to deal with the psychosocial consequences of the disease.

Recommendations for written information tools are found in the literature but few family- specific resources are available. Most education tools are written for patients and the effectiveness of these interventions remains unmeasured (Hudson et al., 2005). Family caregivers need their own educational materials that incorporate problem solving strategies, how to care for their relatives, how to maintain their own health and how to deal with bereavement. Videotapes or audiotapes specifically guiding caregivers confronted with life threatening cancer are limited. One example is a psycho-educational intervention, which consisted of a caregiver guidebook, and audiotape, which was used to complement the visiting nurse interactions (Hudson et al., 2005). The guidebook aimed to provide easy access to written information related to typical aspects of caring for a dying person and the audiotape featured reflections from carers and incorporated self-care strategies and a structured relaxation exercise. This intervention resembles that of Cameron, Shin, Williams, and Stewart (2004), which promoted a brief problem-solving intervention for caregivers of individuals with advanced cancer, also in the form of a detailed home care guide. Typically, however, the dearth of quality and quantity of supportive information aids leave health care professionals with little to offer caregivers beyond the spoken word (Hudson et al., 2004). Cagle and Kovacs (2009) make a compelling argument for education as a powerful intervention using the 'spoken word'; Keir (2007) and others concur that caregivers prefer face-to-face intervention, particularly in relation to stress reduction.

Individual interventions that integrate emotional and concrete support are strongly legitimized by findings suggesting that different interventions are required at different points on the illness trajectory (Janda et al., 2008). This paradigm promotes the shift of cancer services that focus on 'universal' needs to the 'personal' and 'situational' needs that might only concern a minority (Soothill et al., 2003). It is recommended then, that the effectiveness of strategies with individual caregivers should be examined at different time periods. I see single system design as an accessible approach to such an evaluation (Hudson, 2004; Bloom, Fischer, & Orme, 2006) and can be used throughout the caregiving and bereavement period. One-to-one information provision and contact was found to be a useful influence in caregiver coping and well-being. Caregiver needs addressed earlier in this chapter, identified the limited literature focusing on caregiver self-care. Keirs' (2007) self-report questionnaire of caregivers of brain tumour patients found that caregivers were interested in learning strategies for stress reduction that involved concrete and practical strategies. Ninety Percent of his 60 participants preferred this intervention to be provided at home. Massage and exercise were highlighted as useful techniques that were familiar to the participants and could easily be adapted to the specific needs and abilities of the caregiver.

Effectiveness of one-to-one modalities that focus on reframing caregiver thinking about the caregiver situation is under debate. Research suggests that personality traits remain predominantly stable throughout one's life. Therefore, it is questionable whether reframing interventions, which encourage caregivers to change their perception and to think positively, might in fact, have a detrimental effect on those caregivers already challenged by the demands of caregiving (Stajduhar, Martin et al., 2008). It is thought that caregivers may benefit from interventions designed to assist them in acknowledging that the changes in their life are due to their loved one's cancer and affirming the value of their caregiver role (Kim et al., 2007). On the other hand, Cognitive-Behavioral Theory (CBT) has been particularly influential in anxiety and depression, where its effectiveness is well validated, namely in mental health services (Payne, 2005). Also, reframing can acknowledge society's under evaluation of the caregiver role. Hudson (2004) recommends that targeting primary caregivers in the first instance may be more realistic than focusing on the whole family. However, individual therapeutic intervention can also do much to inform and teach family and friends about the ways in which they can help support the caregiver.

'Minimal Therapist Contact' is another example of a one-to-one individualized intervention (MTC) developed by Lopez et al., (2007). This psychotherapeutic stress management program was tested on long-term caregivers and met research requirements for treatment efficacy. The program included regular meetings with a therapist along with phone contacts, audiovisual material, and use of manuals. This kind of format may be especially appropriate for caregivers who are unable to find time to attend regular therapy, which is a frequent reason for high dropout rates in on-going therapeutic interventions. Utility may apply to short-term caregivers as seen in the brain tumour population. Hudson's (2004) review of supportive interventions concludes that psycho-educational approaches directed toward individual primary family caregivers are more effective than groups in that service is targeted to the most vulnerable. Psycho-educational interventions are delivered on a one-to-one basis and have shown their capacity to decrease caregiver burden, and to increase caregiver quality of life and knowledge of patient symptoms. Engaging in counseling that helps with ‘sense making’ as a way to process the illness and its consequences also provides some sense of control (Schubart, 2008; Hudson et al., 2005). This is well supported by Cagle and Kovacs (2009) but one can not overlook the fact that the intervention requires the ‘buy in’ by caregivers and is not acceptable by all, it is also time consuming and costly (Harding & Higginson, 2003).

Walsh, Estrada et al., (2004) describe a qualitative study of an individual telephone support program for primary caregivers of seriously ill cancer patients as a useful outreach tool for caregivers during stressful times. This tool has not been previously used in this population but has gained acceptance as a method to reach a number of other vulnerable groups, with the aim to assist with knowledge deficits and communication difficulties between caregivers and the patient and caregivers and health professionals. The intervention consisted of 5-20 minute calls, every second week for 10 weeks. The calls offered information and support resources. The study included both English and Hispanic speaking caregivers; cultural issues were not explored and 69% of the caregivers were women. The rate of study completion was 84%, indicating that the intervention was helpful and qualitative data revealed caregivers’ appreciation and receptivity for having “at least one interested person…who would inquire frequently about their situation and could be reached for assistance” (p. 186). The participants were able to reflect about the preference for the one-to-one format afforded by the telephone. As noted previously, caregivers in this study indicated that the researcher's question regarding caregiver need was the necessary prompt that motivated caregivers to share their experience; they would not have disclosed concerns otherwise. Despite the receptivity to participate in the study and knowing they could call for assistance, the participants did not phone. The relevance here points to what is consistently found in the literature. Many caregivers do not feel entitled to utilize services and do not intentionally indicate need. This study demonstrates the utility of the telephone as a useful adjunct to home visits, particularly when families live in rural locales, where support programs are typically less abundant. This intervention can be considered important enough as a tool to provide sufficient guidance and education to eliminate home visits by health care providers or delay or reduce ambulatory clinic visits by patient and family. Clearly a requirement for this intervention is a telephone.

The use of the telephone as a platform for outreach and delivery of care to a large population is addressed in Hutchison, Steginga, and Dunn's (2006) tiered community based psychosocial intervention. This model addresses barriers to access such as geography, ill health, and cost and is very detailed, thus being accessible to duplication in various community settings. The intervention integrates screening and assessment to determine the degree of distress, which then determines the required services and sectors. This framework does not speak to those caregivers who do not self-identify or are not assessed by any health provider. This model is highly reliant on screening and assessment, not yet embedded in the current health care system but may serve to address the growing numbers of patients and caregivers in the community. This intervention would require resource commitment by the health care system but might save some resources as well.

Group intervention. Intervention for caregivers in the form of groups is primarily focused on psycho-educational groups. These supportive education groups are increasingly promoted and justified in the literature as an integral part of cancer care where shared information and experiences reduce isolation, foster hope, strengthen coping skill, validate perceptions and feelings and generally normalize experience (Leavitt et al., 1996). In this context individuals interact with others who have gone through or are going through a similar experience (Hudson, 2004; Kim, Baker et al., 2006). Qualitative and quantitative studies have demonstrated that the sharing of information in a group format assists in demystifying the role, allows in the development of realistic expectations and could increase positive perceptions of the caregiver role. This finding is important as these perceptions may well act as a buffer against negative psychological factors influencing caregivers' experience (Hudson et al., 2008). This has also shown to result in the need for fewer resources (Sze et al., 2006).

An example of group intervention in the form of a three session education program for home based caregivers showed its effectiveness in meeting the information needs of caregivers while also enhancing their competence and preparedness for the role (Hudson et al., 2008). The program is demonstrated as being "applicable and accessible" (p. 277) allowing participants the opportunity to ask questions and acquire knowledge. The limitations of this study reflects those of many in the literature namely the use of different facilitators, absence of a control group, small sample size coupled with poor data collection in time 2 and 3 and no knowledge and skill testing done pre and post intervention. No independent observer was used to ensure adherence to intervention protocol, nor were the caregivers a homogeneous group with regards to the stage of advanced disease experienced by the care recipient. Non-English speaking caregivers were excluded from the study and comprehensive cost/benefit analysis was not undertaken. The course evaluations were developed by the research team specifically for this study and did not undergo rigorous psychometric testing. The qualitative nature of acquiring caregiver perception was, however, relevant and useful. The limited number of sessions could be seen as a strength in that the group conceivably would be more accessible to some who are unable to commit to being away from their caregiving responsibility for more than a few sessions and at any great distance from home. Nevertheless, this time limited program also experienced attrition.

Cashman et al.'s (2007) evaluation of an educational program for the caregivers of persons diagnosed with a malignant glioma is directly applicable to my interest. A structured educational program multidisciplinary in expertise, developed in response to caregiver feedback through a needs assessment was provided for 24 participants. Knowledge was assessed before, immediately following and four to six weeks following the program; quantitative and qualitative measures were used for data collection. Two educational program sessions took place for two consecutive half-days at the hospital campus. Parking cost was covered by the study, childcare was available as was supervision for patients in separate rooms in the facility. These authors found statistically significant improvement of knowledge from baseline testing, demonstrating effective knowledge transfer (recall of the information). The clear strength in this study is reflected by the accessibility of this program (no exclusion criteria for participants) and everything possible was taken care of to ensure that the caregivers could attend without having to worry about their loved one. As well, the development of the program content was directly related to a needs assessment and included brain tumour biology, treatments, symptom and side effect management, safety in the home, the role of palliative care, understanding and coping with cognitive changes, and obtaining psychosocial support. The presentation was provided by the investigators and included a neuro-oncologist, advanced practice nurse, palliative physician, occupational therapist, social worker and neuropsychologist. This program provided a question and answer period, group discussion and informal interaction of participants.

Patients were required to provide written informed consent for his or her caregiver to participate. This may have represented an obstacle for those caregivers who might have participated but could not if their care recipient did not agree. In the brain tumour population that could be a significant obstacle for all the reasons discussed previously, none more significant than the common response by caregivers that their needs are not as significant as the patients as well as the real possibility that due to cognitive impairment, the patient could easily not have the insight to recognize the value in having the caregiver participate in such an educational opportunity. Another important limitation, points to the well educated 80% female sample. Although no exclusion criteria were stipulated, care recipients needed to be mobile in order to receive care on the premises for the duration of the program. The authors recognize the limitation that those most in need likely did not participate but they do not acknowledge the risk for sample desirability in their involvement in collecting the evaluations of the program. Nevertheless, the significant strength of this program is embedded in the attention given to promoting caregiver competence in the role as well as the opportunity to deal with the reality of the life-limiting outcome of the disease.

Psycho-educational support groups can serve as a forum for the delivery of education and input by multi-disciplinary staff already involved in the delivery of care, thus requiring minimal extra resources (Hudson et al., 2008). While the literature sufficiently justifies the need for supportive educational interventions, it also highlights the importance of having skilled and experienced group facilitation that provides a safe and informal atmosphere, with capacity for the sessions to be guided by the needs of the participants while still ensuring the delivery of the key components of each session (Hudson et al., 2008). It remains, however, that few supportive palliative-stage family interventions have been conducted, rigorously evaluated or reported in the literature (Hudson, 2004). Hudsons' work has been extensive in the area of family caregivers and recommends that priority should be given to the development and testing of psycho-educational interventions directed toward individual primary family caregivers. His review shows that despite the limited number of individual interventions, these seem to be more successful than group programs, which gives credibility to qualitative evidence. Paucity of intervention research coupled with poor design and the limitations of many of the studies including small samples, lack of diversity in sample, self selected nature of the samples generally point to selection bias and social desirability which may also affect caregivers' responses thus limiting transferability and generalizability. The participating caregivers may suggest that these samples are better adjusted and healthier than might be found in the caregiving population at large (Dobrof et al., 2006). This is also demonstrated by Cameron et al.'s (2004), brief problem-solving intervention which showed potential benefit for caregivers in increasing confidence and positive problem solving with a sample that likely included relatively good problem solvers at baseline. The reality, however, is that those who would most benefit from the intervention, are not likely to participate in studies, a point highlighted by Hudson (2004) and others.

Conceptual Models Supporting Family Centered Care

Three conceptual models support the importance of focusing care around the family system. These models strongly influenced my study, and served as a framework for the conclusions that I have drawn. The first model is Rolland's Family-System Illness model (2005) (see Appendix I), which is a systemic approach to chronic illness and disabilities, grounded in the strength-oriented resilience perspective. The resilience framework stems from ecological and developmental contexts and "situates each family in relation to its particular challenges, constraints, and resources" (Walsh, 1996, p. 1). How a family deals with challenges is crucial for individual and family recovery and the processes used vary and differ. "Relational resilience involves organizational patterns, communication and problem-solving processes, community resources, and affirming belief systems. Of particular importance is a narrative coherence that assists members in making meaning of their crisis experience and builds collaboration, competence, and confidence in surmounting family challenges" (Walsh, 1996, p. 1). This perspective is a competency-based, strength-oriented paradigm, which fits well in the work associated with a life limiting illness like PMBT; it supports the focus on what can be done, as opposed to what is hopeless. The underlying premise is that "all families have the potential for resilience…there are many pathways in resilience" (Walsh, 1996, p. 6).

This concept builds on Lazarus and Folkman's (1984) stress, coping and adaptation and will be discussed below.

Rolland (2005) uses the Family System-Illness model as a psychological map to address the "stresses and uncertainties of cancer" (p. 2584). This is an integrative psychosocial framework that provides a set of terms and common language that attends to the longitudinal, psychosocial pattern of a health condition within a multigenerational, life cycle, and belief system context. This can facilitate collaborative, effective coping and adaptation, thereby enhancing the quality of life for families affected by cancer; "in building family resilience, we strengthen the family as a functional unit and enable the family to foster resilience in all its members" (Walsh, 1996, p. 2). The importance of a systemic assessment is underscored in this theory (Walsh, 2006). The complexity over time requires varied coping strategies to meet different challenges as they emerge. At each developmental stage there is a shifting balance between stressful events that heighten vulnerability and protective mechanisms that enhance resilience; "crisis and challenge, become a tension and organizing principle for a coherent life story… hence the importance of narrative coherence in making sense of disruptive experiences" (Walsh, 1996, p. 4). "How a family confronts and manages a disruptive experience, buffers stress, effectively reorganizes, and moves forward with life will influence immediate and long-term adaptation for all family members and for the family unit" (Walsh, 1996, p. 5).

Rolland's (2005) framework is a comprehensive way to organize thinking about many complex interactions between the biologic illness, family, individual family members, and professionals involved in providing care. This model accommodates the changing interactions between the various parts of the 'system' over the course of the illness and the changing seasons of the life cycle. The focus is not only on the impact of disease on the family, but on how health providers can intervene. Rolland, therefore, upholds clinical responsibility through questions that acknowledge multigenerational legacies of illness, loss and crisis, health beliefs and the family's sense of mastery in facing illness; issues that are also critical for exploration as they have implications for treatment compliance incorporate the family's beliefs regarding the cause of illness along with ethnic, religious and cultural beliefs. The role of clinicians is to collaboratively help families define attainable objectives to achieve quality of life, through creative problem solving. The model provides an opportunity for the health care team to learn about and support the patient and family along their continuum of illness.

The second and third conceptual models are Hudson's (2003) (see Appendix J) and Sherwood et al. (2004) (see Appendix K) both of which are based in Lazarus and Folkman's (1984) transactional stress and coping theory. This theory informs various frameworks in the literature and has been widely used and advocated in family caregiver research. While interventions are aimed at reducing levels of stress, the focus, however, remains on the individual. Lazarus and Folkman (1984) define psychological stress as "a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well being" (p. 21).

The transactional model of stress and coping incorporates cognitive appraisal and coping, as critical mediators of stressful person-environment association. The cognitive appraisal involves the evaluation by the individual of whether an encounter with the environment is relevant to his or her well-being. The primary appraisal determines if the nature of this encounter is likely to be benign, beneficial, harmful, or a challenge. This decision is formulated through a range of personality characteristics including goals, commitments, values, and beliefs. Secondary appraisal involves the person identifying, what, if anything can be done to overcome the situation, minimize harm, or increase the likelihood of benefit.

Coping relates to the individual's cognitive and behavioral efforts to manage, reduce, minimize, master, or tolerate the internal and external demands of the person-environment transaction that is appraised as taxing or exceeding the person's resources. Problem-focused coping is directed at managing or altering the problem causing the distress, and used when conditions are appraised as amenable to change. Emotion-focused coping is directed at regulating emotional response to the problem. This is likely to occur where there has been an appraisal that nothing can be done to modify harmful, threatening, or challenging environmental conditions. These processes are not always conscious and readily accessible (Hudson, 2003) but since "cognitive appraisal rests on the individual's subjective interpretation of a transaction, it is phenomenological" (Lazarus & Folkman, 1984, p. 46)

Hudson's (2003) framework is relevant to caregivers of PMBT as it provides health care professionals and researchers with a conceptual model for examining individual caregiver needs and to inform intervention development for enhancing care for caregivers of palliative patients. It does not presuppose that certain events in an individual's life must necessarily be viewed as stressful; rather the individual evaluates an issue in relation to his or her own resources and commitments. Commitment is defined as an expression of what is important to the person, what has meaning for him or her and underlies "the choices people make or are prepared to make to maintain valued ideals and/or to achieve desired goals" (p. 56). It is the subjective understanding of events and not their objective features that best determine stress. Therefore the reaction to the stressful event relies on the relationship between the demands and resources as perceived by the person and the appraisal process is regarded as a dynamic one, and its utility in intervention development is relevant (Hudson, 2003).

Hudson's (2003) model was developed based on Lazarus and Folkman (1984) and Folkman's (1997) modification. He maintains that an appraisal of the caregiving situation in positive terms is likely to be influenced by the caregiver's perception of control over his/her environment, a sense of support and a perception that they have the necessary skills to confront problematic situations. A caregiver who can find a sense of purpose or meaning associated with their experience is less likely to be overburdened. This model serves as a vehicle for examining individual caregiver needs to lessen the negative implications of care giving, by considering variables that act as moderators and/or mediators when health providers design supportive caregiver interventions. These mediators include: preparedness, mastery, competence, self-efficacy, anxiety, depression and psychological distress, social support, information, rewards, meaningfulness, positive emotions, optimism, mutuality, respite, cultural factors, caregiver burden and health, choice and commitment, patient's disease status, level of dependency, and duration of illness, caregiver age, gender, and socio-demographic status (Hudson, 2003).

Sherwood et al.'s (2004) conceptual model is also based on Lazarus and Folkman's Theory of Stress and Coping but focuses specifically on the caregiver of a person with PMBT; the model specifically highlights the complexity of such a diagnosis. This caregiver group is identified as unique in its experience because of its' associated risk for a negative-stress response arising from the care provision for someone who may suffer from both a short and terminal illness as well as having potential cognitive and neuropsychological and neuropsychiatric sequela. The conceptual model was developed to provide a tool for identifying factors that place caregivers of persons with PMBT at risk for negative consequences and to design interventions to improve caregiver health. The model is used to isolate care demands and to identify resources that can decrease the negative consequences of meeting these demands. In this model the stimulus event that initiates the caregiver's stress response is the care recipient's diagnosis which is typically sudden and traumatic, and associated with severe morbidity and mortality. The caregiver's stress response to the diagnosis and subsequent care situation is determined by the number and type of care demands that are present in the primary appraisal, as well as by the resources that are available to meet those demands.

The first stage in the caregiver's stress response is to perform a primary appraisal of care demands. This includes assessment of the nature of the demands that are placed on the caregiver; the factors included here are the cell type, stage of disease, location and treatment of the tumour. The most obvious effect of tumour status on care demands is its influence on the care recipient's neurological status, which is defined as the care recipient's functional and cognitive status and the presence or absence of neuropsychiatric symptoms.

During the secondary appraisal, the caregiver considers the resources that are available to meet care demands. Resources can be both external and internal and will influence the caregiver's stress response to the care situation. External resources are factors that are not endogenous to the caregiver (not a personality trait) and can include education; learning how to deal with difficult care recipient behaviors, how to provide assistance, how to communicate with the care recipient and with healthcare team, and learning effective coping strategies. Personnel resources include professional and family/friends. Financial resources involve comparing household income, with the cost of daily living and out of pocket expenses, transportation, sick days and non-reimbursed time off for the caregiver. Support resources include social support/family and friends, spiritual support, and professional support (counselors). Although support resources can be used to decrease the stress involved in meeting the demands of the care situation, the situation itself may dictate the caregiver's access to support resources. The care recipient's behavior may limit the dyad's social interaction; availability of social supports may be more limited as neurocognitive and neuropsychiatric symptoms increase.

Internal resources are emotional and physical traits of the caregiver and can include mastery, which is defined as the amount of control that a person feels regarding the forces that are impinging upon him/her. Sense of control associated with mastery has been linked to good preventive health behaviors on the part of caregivers. This impacts physical health, emotional health and self-efficacy. The caregiver's physical health has a direct effect on his /her functional ability to meet the patient's demands. Emotional health (caregiver depression, anxiety, and optimism) will have an impact on stress response to the care situation. Caregivers who are emotionally distressed may exhibit a more negative stress response to providing care. It has been noted that caregiver's emotional health during the care situation predicted whether the caregiver's depressive symptoms would improve or not after the care recipient had died. Emotional health is required to deal with oncological issues as well as neurological sequelae, such as changes in cognition and neuropsychiatric symptoms. Both of these require both the functional ability to perform physical tasks and the emotional health to contend with the potential decline and loss of the care recipient.

The caregiver's perception of the stressfulness of the care situation is manifested as the caregiver's stress response. The response can range from low to high stress and may be manifested as an emotional or physical response to providing care. The emotional stress response is categorized as either a specific emotional reaction manifesting in depression or anxiety or as global emotional reaction. The latter involves caregiver burden or strain resulting from an imbalance of care demands relative to caregivers' personal time, social roles, physical and emotional states, financial resources and formal care resources given the other multiple roles they fulfill. Poor cognitive function has a significant negative impact on the caregiver's emotional health, regardless of the care recipient's physical problems. The caregiver's level of depression and anxiety may predict the caregiver's long-term emotional response to providing care. Caregiver's stress response may also be exhibited in decreased overall physical health, exhaustion and increased risk for mortality.

Different combinations of disabilities will have varying effects on care demands and will require the identification of different resources to meet care demands. Caregiver resources can develop as a positive consequence from the care situation itself, which may help to mediate the stress response; caregivers may feel a closer relationship to the patient and those rewards and feelings of satisfaction may co-exist with negative care demands and help to buffer some of the negative consequences of providing care. Care demands are dependent upon multiple factors; a change in any factor within the primary or secondary appraisal may alter the caregiver's stress response. The availability of resources may also change during the disease trajectory. The continuous feedback loop in the model illustrates the dynamic nature of the care situation in which constant reappraisal of the primary and secondary factors of the care situation dictate a varying stress response. Interventions should be targeted at those caregivers whose care situation includes stress-related factors and should emphasize utilization of those resources found to be helpful in decreasing the stress response.

Hudsons' (2003) and Sherwood et al.'s (2004) frameworks focus on intervention development as it pertains to the caregiver's stress and coping variables; these are similar to Rolland as they seek the best adaptation for a particular individual in a particular environment, adaptive challenges are viewed contextually, similar to the ecological perspective and share core elements such as hope and optimism (Walsh, 1996, p. 9). Rolland's (2005) framework, however, enlarges the umbrella within which health care providers are responsible to actively engage in ensuring that needs of patients and families are explored and intervention are targeted to their unique needs along the continuum individually and as a family. Resilience is seen as relevant in understanding family influences in health and the course of illness (Walsh, 1996), going beyond problem solving by preparing families for future challenges, helping families to "find *coherence within complexity*…helping families build competence and confidence" (Walsh 1996, p. 10-11).

Closing Comments on the Literature Review

Research pertaining to caregiver needs and interventions aimed at caregivers is fraught with a number of methodological difficulties such as recruitment of participants (patients and caregivers), rapidly changing clinical situations making stability of research conditions difficult, high attrition rates, as well as ethical dilemmas associated with gate keeping behaviors exercised by professionals (Dumont et al., 2006; Aoun et al., 2005). As well, studies utilizing only one measurement and data collection at only one point in time do not adequately reflect the experience of caregivers whose needs shift and change over time (Osse et al., 2006; Stajduhar, Martin et al., 2008). Generally, studies in this area reflect samples, which are heavily weighted with English speaking Caucasian women as participants, and with the affluent and educated (Kim, Loscalzo et al., 2006). Studies looking at participants' depression are limited by the researchers' inability to control for participants' depression before the cancer diagnosis and typically, the sample's knowledge and skills are not formally assessed before the intervention. As well, cost benefit analysis is typically not done and comparison of study results is difficult due to the different criteria used in different locales. An example of this is Dumont et al.'s (2006) palliative care study, which was conducted in Quebec; less than 10% of end-of-life patients in other parts of Canada have access to similar palliative care programs. In Manitoba, brain tumour patients and their caregivers live with the sequelae of palliative disease, but are denied access to many palliative care resources while the patient continues to receive chemotherapy. Literature pertaining to structured neuro-oncology programs was limited to one article by Tepper (2003).

What is profoundly resonant throughout the literature is the importance of systemic commitment to a consistently high level of health care and the urgent need for evidence-based practice. A substantial number of studies have identified caregivers' needs but further development and evaluation of research based interventions focused on reducing negative aspects of caregiving are required (Hudson, 2004; Dobrof et al., 2006). The importance of this cannot be overstated due to the expectation that caregivers provide the care that has shifted from institutional settings. It is critical that intervention programs within community-based services target informal caregivers to ensure their sustainability in the role and to ensure improved and enhanced quality of life (Kim, Baker et al., 2006). The prevalence of caregivers cannot support complacency and lack of focus on interventions for this group based on the belief that emotional distress is considered to be a normal response in context of terminal illness and therefore, not identified as requiring intervention (Grbich et al., 2001). The complex breadth involved in the delivery of comprehensive advanced cancer care demands for health care professionals to be better trained has been identified. Formal health care providers must be skillful and able to confidently assess, evaluate and meet caregiver support needs. Skilled practitioners are essential in every facet of advanced disease (Morrison & Meier, 2008; Hudson et al., 2008), not only for patients, but also for the caregivers upon whom the system relies. Conventional training has traditionally focused on the importance of patient education while the importance of caregiver needs has received minimal attention. This tradition in health care is changing and requires the role of health care professionals to evolve as well.

Issues and tensions persist and challenge professional practice. What I am referring to is the social value of self-reliance and independence in the setting where caregivers not only are untrained but also by virtue of performing the role, are placed at risk. The degree to which unmet needs or limited support contribute to caregiver burden remains unclear and may continue to be underestimated. Given the central role of caregivers in our society, education as an intervention at the general community level is needed to promote the social value of caregiving and an awareness of the demands and impact of the role (Aoun et al., 2005). The development of educational programs for employers and employees to make workplaces more caregiver-friendly is particularly relevant in the Canadian context; broad-based public education strategies to encourage better understanding of death and dying should also be promoted. Developing policies to provide income security and employment protection for those who care for terminally ill family members is imperative. Policy changes are needed for more flexible employment arrangements to reduce work conflict and give caregivers, particularly women, more options in combining paid employment and caregiving. The new Canadian legislation entitled Compassionate Care Benefit is a step forward in ensuring that caregivers will be able to take temporary leave to support a family member at the end of life (Dumont et al., 2006). However, because family caregivers are not typically part of policy discussions, the limitations on their ability to provide care and their need for training and support are not usually considered when decisions are made about how to deliver care or save money. Caregivers remain isolated as they negotiate an increasingly complex and fragmented system and are left to find whatever help they can by whatever means they can (Arno et al., 1999). It is recommended that engaging family members at the design state of intervention through the use of focus group interviews would be valuable (Hudson, 2004). Designing or evaluating health care delivery programs requires patient and family perspectives; this fits well with the mandate of family-centered palliative care (Lohfeld et al., 2007) and qualitative studies can be a useful vehicle for such inclusion where family members can accurately describe the challenges they face and provide ideas about the help they desire (Teschendorf et al., 2007).

This literature review explored the area of caregivers of PMBT and the importance of meeting their needs in a proactive way is undisputed. In this setting caregivers come to the attention of health care providers during an acute onset of illness and the opportunity to enhance the quality of life for the caregiver and the care recipient is immediate and imperative. There is very little evidence in the literature of multidisciplinary approaches to the provision of comprehensive care in this setting. Rollands' (2005) Family Systems-Illness Model, which advocates for family focused, collaborative intervention, is an exception and provided the undergirding to the qualitative thesis study that surveyed social workers in ambulatory neuro-oncology programs in Canadian centres.

Chapter 3: Methodology

Approach

The qualitative multi case study design was identified as being the most appropriate methodology for examining several cases that share a common phenomenon, namely ambulatory neuro-oncology service, referred to as a “quintain” (Stake, 2006, p. 6). This approach permitted an in-depth inductive empirical inquiry (Patton, 2002; Morse & Field, 1995; Stake, 1995; Yin, 2009) into the research question: “how are the needs of caregivers of primary brain tumour patients met through structured ambulatory neuro-oncology programs in Canadian centres?” This question has not been addressed in the literature and the growing number of caregivers supports the relevance of this examination. This study focused on the “experience of real cases operating in real situations” (Stake, 2006, p. 3). The research examined programs through the perspectives of social workers’ and one psychologist’s subjective meaning and experience regarding programs in which they provide service (Creswell, 2007). One or more study participants represented every province but Quebec and New Brunswick.

Each psychosocial clinician represented a case, “a specific entity” (Stake, 2006, p. 2), “a primary unit of analysis” (Yin, 2009, p. 29). Each case, as part of “a bounded system” (Stake, 1995, p. 2) provided comprehensive, systematic, and in-depth information about psychosocial practice within the ambulatory program that provided medical care to brain tumour patients and their caregivers. This qualitative approach embraces “ the idea of multiple realities” (Creswell, 2007, p. 16) thus allowing others’ experience to be heard and to be validated, by virtue of participating in a study asking for their thoughts and using their words in the final report.

I utilized a semi-structured telephone interview to capture each clinician's "real-life phenomenon" (Yin, 2009, p. 32), to reflect their experience. The understanding of each case contributed to the overall understanding of the quintain, thus allowing me to go "beyond the case" (Stake, 2006, p. 8) to get an understanding of the Canadian experience. This qualitative approach was appropriate for the exploration of processes and activities in different programs across Canada and illuminated the kind of service caregivers are receiving.

Data Collection Strategy

The strategy used to collect data was an in-depth semi-structured taped telephone interview. This was in compliance with the requirements of the expectations of the Faculty of Social Work, the Faculty of Graduate Studies and the University of Manitoba Psychology/Sociology Research Ethics Board. Each conversation lasted approximately one hour. As the researcher, I was the only interviewer and I used interview guides (see Appendices E and F) consisting of open-ended questions and probes that were used to elicit additional information. The participants were encouraged to speak freely and to describe in their own words, what their thoughts and experiences were pertaining to provision of service to caregivers. The development of interview questions evolved from a review of the literature, and from my own experience as a neuro-oncology social worker and from discussion with my advisor. A Table of Concepts of Operationalization (see Appendix G) was a helpful tool to organize the extensive body of available literature regarding what was already known. While the recorder was on, I jotted down notes in order to ensure that I would be able to capture the essence of the interview should the recording fail. With the exception of one respondent who elected to respond in writing to the interview guide, study participants were interviewed by telephone using the protocol described below.

The interview process was used as an opportunity for gathering new findings and as recommended by Stake (1995), my aim was to thoroughly understand the cases and to see how the people being studied, see the “issues from the inside… *emic issues”* (p. 20); when the prepared questions were not sufficient as new issues became apparent, new questions were incorporated in subsequent interviews (p. 9). I aimed to hear the lived experience of psychosocial colleagues while setting my own experience aside; this in and of itself, was a challenge as it was a different approach to “hearing and responding” than is exercised in a clinical counseling session, where intervention is the objective.

Immediately after each interview, I used field notes to record my experience, interpretive commentary and the disruptions or distractions, if any. These notes helped me to recall details I might have otherwise forgotten. I also kept a personal log as a back up to data storage. I welcomed any other sources of information, such as brochures and other documents that pertain to the various programs offered. These would have contributed to triangulation of the data. However, no such additional material was forwarded to me. All telephone interviews were professionally transcribed except for three, which I transcribed in order to acquire experience in the process of transforming raw audible data into the written form. This experience provided me with a significant appreciation for the skill required in transcribing. To ensure confidentiality, all programs (participants) were assigned an identifying professional designation and number (eg. SW1, SW2, PSY13…, P11, P14) which was used for reference, as such, in all reports. Respondents’ comments are included throughout the report to illustrate key points and their comments appear in italics. The participant number and page of transcription are provided for reference.

A paper file was kept for each data source (participant) and this file was stored in a locked drawer.

Sampling and Recruitment

A purposeful maximal non-probabilistic sampling strategy was implemented. I recruited a sample of eleven medical social workers and one psychologist who participated in direct psychosocial services in various ambulatory oncology centres across Canada. The recruitment involved telephone contacts with all the service sites and organizations listed in Appendix F to ascertain the location where brain tumour patients were treated. This was followed by telephone contact directly to the social workers working in these locations. If potential participants indicated interest in being interviewed, I faxed them a Letter of Recruitment (see Appendix B). This invitation to participate was followed up by a phone call initiated to answer questions and to confirm interest (see Appendices C and D). A consent form (see Appendix A) was faxed once a potential participant indicated interest in participating, at which point a time for an interview was scheduled. The signed consent forms were faxed back to me prior to the scheduled interview.

The constitution of the final sample consisted of all interested social workers and one psychologist in various cancer centres. Recruitment also included the Executive Director of the Brain Tumour Foundation of Canada as well as one other member of the staff of this national organization. Their contribution provided a more global perspective, which offered another source for cross-validation of information; “for accuracy and alternative explanations" (Stake, 1995, p. 107). The BTFC is a national, not-for-profit organization dedicated to reaching every Canadian affected by a brain tumour through support, education, information, and research (BTFC Newsletter, 2009).

Data Analysis Method

The process of data analysis began with the preparation and organization of the collected data for "constrained viewing of the case" (Stake, 2006, p. 6). The raw data was condensed and organized, classified and edited into a manageable and accessible coding scheme and descriptive typologies (Patton, 2002). The discovery of patterns and themes in the data was an inductive process inscribed in the shared experience of the sample. The themes and interpretations that emerged, addressed the original research problem adhering to what Patton (2002) advises: "purpose guides analysis" (p 434); interpretation, although subjective, contributed to analysis and synthesis (Stake, 1995) that involved the understanding of how the cases were linked, what characteristics were shared in common and what were the differences.

The epistemological orientation of this study was constructivist and underpinned by "the belief that knowledge is constructed" (Stake, 1995, p. 99). This multiple case study provided an opportunity for in-depth study of multiple perspectives, experiences and interpretations within a bounded system (Creswell, 2007). The participants were encouraged to speak about the phenomenon associated with meeting caregiver needs (Creswell, 2007; Stewart & Mickunas, 1990) and the meaning the experience had for them. In keeping with the various research methodologies that case study draws from, my curiosity, interest in learning and setting aside presumptions as best I could, I attempted to promote "subjective openness" (Moustakas, 1994, p. 25). This process was in keeping with the orientation of qualitative inquiry (Stake, 1995) and helped to guide, organize and to define alternative explanations to be examined in the case study analysis (Yin, 2009). This approach was previously highlighted by Stake (1995) who saw the case study as relying on two strategic ways for reaching new meanings about cases, direct interpretation of the individual instance and through aggregation of instances "until something can be said about them as a class" (p. 74). While the literature review and the theoretical orientation guided the interview questions, the analytic time was used to identify the most pertinent data while setting the rest aside; "the case and key issues need to be kept in focus. The search for meaning, through the analysis, should roam out and return to those foci over and over" (p. 84-85).

A first reading of the verbatim transcript was done immediately after receipt of the transcript. This was to get a general sense of the information and to reflect on its overall meaning (Creswell, 2003). This provided an opportunity to begin writing my impressions of the interview and included ideas raised, tone, general impression and thoughts. General impressions were written in the margins of the printed transcription. This was followed by more readings of the transcripts and by the beginning development of coding which was the formal process of organizing the material into categories. This analysis was used to reduce the large amount of qualitative data to core consistencies and meanings (Patton, 2002). This inductive process involved identifying, coding, categorizing, classifying, and labeling the primary patterns in the data that represented "the indigenous categories that people interviewed have created to make sense of their world? What are practices they engage in that can be understood only within their worldview" (Patton, 2002, p. 454). In this process, redundancies were sorted out and the case record was organized for ready access topically.

The category system was analyzed for convergence (what things fit together, recurred and revealed patterns that were sorted into categories) and divergence (data that did not fit) (Patton, 2002). Color-coding significant statements completed the classification of the statements and categorization of patterns. This process helped me to develop terms that described inductively generated categories using the actual language of the participants "called an *in vivo* term" (Patton, 2002, p. 192). Some topics were expected, since they were drawn from the research questions and served as a template for the analysis. I was open in the analysis for codes that were surprising since it was anticipated that patterns would emerge from the analysis as emic issues, "important to the actors themselves" (p. 78). I also looked for codes that addressed a larger theoretical perspective (Creswell, 2003). The analytical process was an on-going process that evolved after each interview and was "a matter of giving meaning to first impressions as well as to final compilations" (Stake, 1995, p. 71). The significant statements and categories were then aggregated by cutting and pasting into pre-determined theme folders referred to by Patton (2002) as sensitizing concepts. The categories represent the data in a way that facilitates the "reader's understanding of the world under study" (Patton, 2002, p. 457).

The number of cases in this study is 14 and was determined by the responses to my invitation to participate. My intent was to recruit representation from every province and as noted previously, all provinces are represented but New Brunswick and Quebec. In order to ensure readability, I have made every effort to make sure that the report is concise and coherent in its organization, representing the cases by focusing on the most salient issues that show how the phenomenon of care to caregivers appears in different contexts. The intent is to provide the reader the opportunity for "vicarious experience" (Stake, 1995, p. 86). By providing "thick description and experiential understanding" (Stake, 1995, p. 43) the *multiple realities* reported, preserve the different and even contradictory views" (Stake, 1995, p. 12). The introductory chapter describes and introduces the topic and builds a foundation with a rationale and purpose for the study. It also allows me to locate myself in relation to the topic. The literature review and theoretical alternatives provide a background to what knowledge exists. This is followed by the methodology undertaken, the findings, discussion and recommendations.

The discussion addresses the findings and deepens the understanding of the studied phenomenon. For example, the discussion is used to show the inconsistency between what is presented in the literature versus what is observed in current practice. This evidence can be effectively used for informing policy and problem solving in future action research.

Accuracy of information was difficult to ensure as I was limited to speaking with only one participant in all but two cases and I did not have access to other sources such as other members of the health care team, in order to check, (triangulate) the information that was given. Initially, I had hoped to use the reports of the Executive Director of the BTFC for triangulation purposes, but during the interview process, I realized that the knowledge of the BTFC is limited primarily to the BTFCs' geographic location and its' current projects. I did have the opportunity to have one colleague as well as my advisor, review my writing throughout the process and to check my interpretations. This provided opportunity to be clearer and to ensure that what I wanted to convey, was in fact, done. My awareness of time constraints confirmed by the sample during the actual interviews discouraged me from re-contacting the participants for further clarifications.

The qualitative design was a very appropriate methodology as it served to empower those who participated by sharing their voice and insights. The intent of the written project was to document the voices and ideas of the participants and to reflect their eloquent thoughts using their words and insights along with a comparison with the literature. The analysis is intended to be meaningful, reachable and accessible by providing interpretation about the specific contexts with a focus on the common phenomenon. The purpose of this project is to have the account "resonate with people" (Creswell, 2003, p. 196). Since this is a thesis project, my objective is to meet the requirements of my thesis committee but also to have a useful document to share with colleagues in oncology social work, particularly those interested in the care of caregivers of brain tumour patients. The report therefore intends to provide information that will be easily assimilated with both type of readers' existing knowledge. This is in keeping with the constructivist approach, which supports the epistemological position that "when knowledge is being constructed, no two observers construct it exactly the same way" (Stake, 2006, p. 37). As a qualitative researcher I was interested in diversity of perception, representing the multiple realities within which people experience their life and work. With my experience in a specialized ambulatory neuro-oncology program I was able to include my own personal perspective in the interpretation (Stake, 1995, p. 135) along with my knowledge, experience and judgment (Patton, 2002), and I was also able to speculate about meanings, and make qualified conjectures about the significance of the data.

Strengths and Limitations

My study has several strengths and limitations. I view my experience and participation in program development as a strength that has influenced the delivery of care to brain tumour patients in Manitoba and has influenced how I interpreted the data. The subjectivity that is inherent in my interpretation can be viewed as a strength and as a limitation. Every effort was made to ensure objective receipt of respondents' data, but I acknowledge that it is not possible to assume objectivity nor is it necessarily desirable in a qualitative study just as generalizability is not the goal in this design. Choosing to study this topic from a qualitative perspective allows for the data collection and analysis to be processed through my own interpretive lens while giving voice to the participants' experience and interpretations. The "real business of case study is particularization, not generalization" (Stake, 1995, p. 40).

The significant strength in this study and report is that it allows for "lessons learned" (Creswell, 2007, p. 75) rather than objective findings, and the information that was gathered is intended for use by clinicians, service managers and health policy analysts in the field of neuro-oncology. The evidence taken from the case studies shows how uniformity and /or disparity characterize the quintain (Stake 2006, p. 40). The results of the study serve to enrich the literature while informing new questions that require further enquiry. The case study provided an opportunity to emphasize the sample uniqueness and the important and relevant knowledge shared by the participants. It is highly personal and interpersonal and demonstrated how in-depth interviewing as qualitative inquiry “opens up what is inside people” (Patton, 2002, p. 407). The inquiry demonstrated the depth and breadth of the issues identified by the study participants as it relates to their experience with caregivers, and enriched and deepened what the literature has shown, further confirming that the issue of caregivers is not only a private, family issue but also a public, and social one (Patton, 2002).

An important limitation worthy of mentioning is selection bias. Only those programs that could be identified and located, and only those with representatives who were willing to participate, were included in the study. Although an effort was made to include all provincial programs, no representation was acquired from Quebec or New Brunswick. As well, some brain tumour programs were likely omitted from the study because they simply could not be found. An attempt was made to use the BTFC as a clearinghouse for all programs, but it is evident to me now that this national organization does not have the overall connection to all health care programs across the country. Although most respondents utilize written resources and refer to BTFC support groups, not all respondents are known to this national organization, nor do the respondents recognize the BTFC as an adjunct to their services and resources.

The inclusion of the BTFC representatives was intended for triangulation purposes. However, it became clear that for the most part, the organization is constrained by their affiliations to programs that promote volunteer peer support groups that are known to the BTFC. There are brain tumour services in Canada that are not affiliated with the BTFC; it is difficult to know the number and location. The national aspect of the organization’s mission remains focused on research that ultimately benefits the global brain tumour population. However, details associated with specific jurisdictional differences still elude the organization and therefore could not be relied upon for accuracy.

The interview guides were developed to assist in ensuring that there would be consistency in the interview process, from one respondent to the next and to minimize my bias. Effort was made to solicit information that would allow for comparing and contrasting as well as to promote the opportunity to hear about unique aspects associated with the represented programs. It is recognized that time availability had a considerable influence on the extent to which conversations were time limited and my focus was on gathering salient data. I recognize that the quality of inquiry improved with every interview. I was constrained by my awareness that interview skills for research purposes are distinctly different from interview skills I use in clinical practice with the aim of intervention. A related limitation was the significant time constraint that was mentioned by participants. As well, soliciting information and probing could have been explored in more depth had time not been a factor. Contacting participants for clarification did not seem to be an option due to verbalized time limitations.

Another limitation of the study is that the data was uncorroborated as I only interviewed the psychosocial clinicians. Each respondent shared their unique experience vis a vis the program with which they were affiliated. Programs were found to be different and could not be compared in detail. This is the nature and richness of qualitative inquiry.

Interviewing medical social workers in various oncology programs was satisfying and inspiring. This opportunity helped to identify colleagues' experience and approaches to care with caregivers and serves to provide for a better understanding of what is actually happening in health care as it pertains to service delivery to caregivers of PMBT, a vulnerable and important sub-group of caregivers. The constructivist view underlying this case study is intended to provide readers with “good raw material for their own generalizing” (Stake, 1995, p. 102). This is in support of the belief that “knowledge is constructed rather than discovered” (Stake, 1995, p. 99). As noted earlier, this knowledge may be useful in policy and program development and implementation.

Chapter 4: Presentation of Findings

This study intended to capture the way that services to caregivers of primary malignant brain tumour patients are provided across the Canada. The context of understanding is set through the lens of eleven social workers and one psychologist who worked in various cancer care facilities. Two representatives of the Brain Tumour Foundation of Canada added their perspectives to the study.

This chapter will include a description of the study sample. It also provides an overview of respondents' views about current service delivery to people with PMBT and their caregivers; how psychosocial services are accessed and what psychosocial intervention includes. This chapter also reflects the respondents' perceptions regarding the vital role of caregivers of PMBT patients and the caregivers' specific needs for information, professional services, finances, social and emotional support as well as respite and self care needs. The chapter concludes with findings associated with the inherent challenges in the clinical setting which include the recognition of this subset of caregivers, the difficulties associated with geographic disparities vis a vis available services and limited cancer treatment centre and community resources. This is followed with respondents' recommendations for system and service improvements.

The eloquently articulated large amount of data that was collected as part of this study was difficult to reduce, as it was rich and complex. Data that illustrates key findings will be presented in italics and is attributed to individual respondents using a numbering system that includes reference to the participant's abbreviated discipline and number as well as the page of the data transcript.

Study Sample

Twelve professionals, whose assignments include service to brain tumour patients, were interviewed, eleven of whom were social workers and one of whom was a psychologist. The Executive Director and the Information Specialist of the Brain Tumour Foundation of Canada provided additional information. To maintain the confidentiality of these two individuals, detailed information about them is not provided. The rich data they provided was used to support the interpretation of the findings.

Participants represented nine cancer treatment facilities from Alberta, Saskatchewan, Ontario, British Columbia, Nova Scotia, Newfoundland and Prince Edward Island. The Yukon, Nunavat and Yellowknife are served by neurosurgical and cancer programs which are centralized in major southern cities in the above-mentioned provinces. Representatives from New Brunswick and Quebec were not included despite my effort to locate participants.

Table I provides an overview of the participants' profiles and experience. Of the twelve clinicians, nine were women and three were men. Half of the respondents were MSW credentialed, five had BSW degrees and one was a PhD in Psychology. Experience in the respondent cohort ranged from two to thirty years. One third (4) of the clinicians were specifically assigned to neuro-oncology work (neuro-onc), also referred to as tumour-site specific clinics; three of these were MSW credentialed and one held a PhD. The remaining two thirds (8) had general oncology caseloads that included patients with brain tumours and other forms of cancer. These clinicians are referred to as having a "generic" oncology affiliation. Of the eight generic clinicians, three were BSW credentialed and five had MSW degrees. Most clinicians provided outpatient service exclusively; two MSW credentialed clinicians were able to provide service to both inpatient and outpatient facilities. Notable with regards to the level of knowledge and special interest in caregivers was Participant #3, MSW credentialed and generic in practice. This was due to previous extensive work with this group. As well, participants #9 and 13 represent a model of care in one cancer centre that seems unique in the country where instrumental intervention was provided by a BSW social worker and the clinical counseling aspect of intervention was provided by an MSW or PhD credentialed professional; in this tumour site it was a PhD.

Table 1: Description of Participants

Participant Number	Gender	Degree	Years in Practice	Years in Oncology	Clinical Service Affiliation
SW1	M	MSW		8	Generic Onc
SW2	F	MSW	16	3	Generic Onc
SW3	F	MSW	10 *	0	Generic Onc
SW4	F	MSW	30	3	Generic Onc
SW5	F	MSW		18	Neuro-Onc
SW6	M	BSW		4	Generic Onc
SW7	F	BSW	4.5	0	Generic Onc
SW8	F	MSW	20	7	Generic Onc
SW9	F	BSW	4	0	Generic-Onc
SW10	F	MSW	20	2	Neuro-Onc 1/3 caseload
SW12	F	MSW	11	8.5	Neuro-Onc In-patient & out-patient
PSY13	M	PhD Psychology		20	Neuro-Onc In-patient & out-patient
P11	F	**	N/A	N/A	N/A
P14	F	***	N/A	N/A	N/A

* Participant #3 had previous work with caregivers in another organization
** Executive Director, Brain Tumour Foundation of Canada
*** Information Specialist, Brain Tumour Foundation of Canada

Setting the Stage

A primary malignant brain tumour (PMBT) is a complex illness. The diagnosis of PMBT raises special issues for patients and their caregivers, which are essential for professionals to understand if they are to be effective. For this reason, respondents were asked to provide detail on how well they understood this tumour site. Two thirds of the respondents provided in-depth responses that suggested they were keenly aware of the complexity of this tumour site, while one third were less insightful. The majority of respondents was aware of the dire outcome of a high grade malignant tumour such as glioblastoma and knew that this disease is variable in regards to the impairments experienced by patients. There was an understanding that the debilitating sequelae can be very dramatic and quick and that the individual's independence can diminish as a result. Social workers who specialize in the brain tumour area seemed to have a broader understanding of the illness. This was illustrated by their acknowledgement of the impact of the illness on caregivers and the importance of caregivers' involvement in the care of the brain tumour patient:

A lot of our patients are quite…impaired from the beginning. And a lot of the work that you do is more with helping the families cope and adjust (SW5, 23-25), *it's not a really common…diagnosis* (SW5, 39). *You have to work in the area to really get it* (SW5, 363).

Two respondents highlighted an important finding further demonstrating their understanding of the variability in disease manifestation. This finding refers to the discordance between the patient's normal and well appearance and their masked impairment:

I look normal, I seem normal…yet my partner or the grocery store clerk or my adult children or my cousins or brothers or sisters or whatever…they don't have an understanding that I just really can't manage (SW4, 666-670).

Almost 60% of respondents demonstrated awareness that the illness is concurrently acute and palliative. The rest of the sample revealed gradations of knowledge in their responses. The majority acknowledged that due to treatment advances, the prognosis has lengthened over time and when the initial crisis is over the illness continues in a chronic state until it progresses further; while the palliative disease outcome is predictable, its course remains variable. For some patients, the impact is immediate causing dramatic and observable deficits, while for others the debilitation reveals itself subtly over time. This variability was also noted in reference to the palliative nature of this illness:

> *And they tend to be longer stay patients at palliative care because the decline tends to be a bit slower. And they're still pretty ambulatory by the time they get there. So they don't fit the typical patient in palliative care* (SW1, 287-291).

It was acknowledged that the complexity of the illness can be very challenging and confusing in instances where patients live with "stable disease," (i.e. their existing disease is not in a growth phase). These patients are referred to as 'survivors' and one respondent noted that the uncertainty of how to live as a survivor impacts patients and families in a unique way. The patient experience as a "survivor" was poignantly described by this respondent:

> *What do you do when you return to life and you are a survivor of a disease like that, knowing by the way that this thing is going to come back .... Everybody tells you that this thing is going to come back one day. You're not going to get away with this.... you can't be sitting twiddling your thumbs* (PSY13, 778-784).

Service Delivery to Brain Tumour Patients

All respondents across Canada seemed to be aware of the crisis oriented entry of brain tumour patients into the health care system. Typically the patient is taken to a hospital Emergency Room (ER) following a dramatic medical event. The usual scenario in the ER includes a scan, which reveals the tumour; a neurosurgical procedure follows. As one participant described: *holy cow, let's get you admitted. Do neurosurgery. Do a resection. And welcome to your whirlwind tour of brain cancer* (SW3, 212-214). Once a biopsy or resection is done, the neurosurgeon refers the patient to a regional ambulatory cancer treatment centre for radiation and/or chemotherapy (in pill form) in conjunction with regular medical follow-up. In many cases, the process unfolds in a very quick manner beginning as a rule and in most cases, with a very short hospitalization; surgical results are usually unavailable before discharge from hospital;

> *often times they have not received the path [pathology] results before they come for their first visit ... I'd say a lot of times they're getting their path results from us on their first visit* (SW5, 77-85).

Following the neurosurgery procedure which takes place in a hospital inpatient service, brain tumour treatment is uniformly delivered in ambulatory centralized health care centres only. Cancer centres are mandated to provide cancer care to all patients in each province; brain tumour patients are referred by a neurosurgeon in the inpatient service for the next phase of brain tumour treatment, which includes radiation and concurrent chemotherapy that is provided in the outpatient ambulatory cancer clinic. Radiation is centralized to a limited number of urban locations typically associated with a neurosurgery hospital program. The cancer treatment centre's mandate oversees care to a vast catchment area and therefore, includes urban and rural patients:

> *It's an ambulatory outpatient clinic attached to the hospital... our patients are all ambulatory and seen on an outpatient basis* (SW1, 7-10)*…we have a provincial mandate…and we are the only site in our province for radiation treatment so anybody across the province has to come here* (SW1, 472-477).

The standard of care includes an appointment with the radiation oncologist but the results of the surgery must be available in order for a treatment plan to be set in motion.

So from that first visit, usually people are booked into a planning appointment within a week. Sometimes we do it same day, depending on the nature of the tumour and if they're coming from quite a distance, we try to consolidate appointments as much as we can… So treatment would normally start within two weeks of that first visit. And hopefully within 3 to 4 weeks of the time of surgery (SW5, 111-121).

An important issue raised by respondents relates to the waiting time between the neurosurgery procedure and the actual appointment with the oncologist.

I think that the delay between diagnosis and treatment or diagnosis and the initial consultation with medical or radiation oncology is agonizing for people. There's nothing there to assist them (SW3, 472-476).

In response to this concerning gap and delay in care, some centres across Canada have developed a 'Patient Access Coordinator' or 'Patient Navigator' position. This role is meant to address the associated anxiety and information requirements of patients and families waiting for further health care in the cancer clinic. As one interviewee describes,

Our Patient Access Coordinator also… provides support services for patients while they're waiting. If the patient's feeling anxious or the family member's anxious… they have a contact number in the cancer centre to actually to talk to somebody (SW6, 560-565).

The professional affiliation of the patient navigator varies and in three facilities this role was filled by a nurse; in one, it was a social worker:

Initially they wanted a nurse to do that job as a Patient Access Coordinator and …a big part of it is providing that psycho-social support until they get a doctor and then they will be assigned that doctor's social worker. So there was a big push to maintain it as a social work position (SW7, 228-233).

Inpatient and outpatient service is provided by different systems. Typically, the inpatient social workers do not follow patients once they are discharged from hospital.

Some crossover into inpatient stay and…we would sometimes follow them if they get admitted but, for the most part, we do see people, families, patients and families as an outpatient basis (SW1, 10-13).

Ambulatory service providers work almost exclusively in the outpatient settings, separate from the hospital system; each service provider is accountable to their respective, inpatient vs. outpatient, organizational structures. Most clinicians reported that *we are connected to a hospital but…I work strictly with the outpatient side* (SW5, 70-71). One clinician represented the minority in the respondent cohort, and routinely supported *patients and caregivers living with malignant brain tumours in both the outpatient and inpatient setting* (SW12, 6-8). The division of services into inpatient and outpatient areas leads to fractured care as multiple providers deliver services, and communication between the inpatient and outpatient services does not seem apparent.

Cancer centres were organized in various ways. Four centres delivered care to brain tumour patients through specific tumour site clinics specializing in the central nervous system. Three others were organized according to the specialty of affiliated physicians, such as radiation oncologists, medical oncologists and surgical oncologists; the social workers in these centres were assigned to follow the physician's practice; *once they know who the physician is, [the patient is] given the social worker's business card* (SW7, 111-112). In five other instances caseloads were evenly distributed through an equitable division of incoming referrals that were sent to a centralized social work office or department. Brain tumour patients, when not followed through brain tumour specific clinics, were typically included within the general oncology population: *we are a very small department. And we are generalists. We don't have specific … tumour group* (SW4, 190-192). In one setting where brain tumour patients were seen in a tumour specific clinic, instrumental intervention was separate from clinical counseling; the former was served by BSW's who had a generic practice; the clinical counseling was delivered by

MSW's or in the case of brain tumour patients, by a psychologist who was assigned to the central nervous system tumour site. Brain tumour patients were not targeted as a unique client group in most Canadian centres and structured neuro-oncology programs were not the norm. This was aptly described as *nothing [no specialized team/program] unique to or specific to neuroncology* (SW1, 167-168). Targeted psychosocial intervention in most centres was limited to referrals to psychosocial clinicians within the treatment facility; case finding and routine involvement of psychosocial clinicians in the represented facilities was not normative practice.

Team. The team approach to care seemed to be a standard across the country with

> *a minimum ... of... a nurse and an oncologist and…maybe licensed practical nurse that will see the patient as well as the radiation therapist that will work with the patient* (SW4, 277-281).

Team membership varied and impacted available brain tumour services. In many instances the "team" was defined as a multidisciplinary group composed of the collection of disciplines that were available to be called upon. These included:

> *oncologists…nursing, radiation therapists…nutrition….that probably makes up the majority of the members. But …for each patient that we see, I shouldn't say it's team specific. But certainly at rounds, or…on a case by case basis, if we need to pull a team together, we certainly would* (SW2, 113-119).

Perceptively one generic respondent described the "team" approach as:

> *Quite a stovepipe type set-up. It's much more hospital like set-up even though it's an out-patient clinic where disciplines were kind of parallel to each other but where it's kind of challenging to achieve some kind of integration* (SW4, 287-291).

In one facility the psychosocial team was described as consisting of a:

> *clinical nurse specialist, social workers, psychologists, psychiatrists, spiritual care providers…we can have someone referred to PT [physiotherapy] or OT [occupational*

therapy] if they need it…so there is quite a care team around people in the cancer centre. It's sort of contained (SW3, 280-285).

Team membership seemed to be determined by the facility size and organizational structure which also impacted the extent to which discipline roles overlap, for example *we have a nurse practitioner too who does an awful lot of...patient counseling and support* (SW8, 949-951). Team size has evolved and increased over time; this is a reflection of the increase in patient numbers and complexity.

> *We have now the neuro-oncologist that's here so the numbers have increased. I think patients' life prognosis has lengthened so you're involved in longer period of time. Not significantly longer, but longer. But I also think their needs have grown* (SW5, 936-940).

The interdisciplinary approach to care was more apparent in settings where brain tumour patients were medically followed in specific tumour site clinics but also only after a referral was made to social work, not typically at an initial patient visit. Notably, neuropsychological service was not a core or affiliated resource in any program and was not routinely accessed.

Philosophy of the program. In the brain tumour setting, it was widely acknowledged by specialized front line social workers that the involvement of caregivers is necessary from the initial appointment and with every intervention.

> *It depends a lot on the patient….. if people are arriving and they're able to self direct their care… we try to maintain…a philosophy of patient focused care but I think that the difference within CNS compared to my other site groups is that there really is a need to have the caregivers, you know, on board right away.* (SW5, 188-194).

However, the programs primarily were patient focused and patient driven. Patient focus is a prioritized objective in health care across the country. This global mission manifests in the interventions and processes that take place in each facility and program. It can be argued that patient screening drives the health care system. Caregivers were routinely excluded from patient screening. Another illustration of the patient focused nature of the system was the requirement for patient consent in order to involve family members in the care: *As you might expect of course [intervention] is all consent based* (SW1, 48).

Although medical services to brain tumour patients were mandated in every provincial jurisdiction, targeted service to caregivers was not mandated. Respondents described cancer centre programs as being open to patients and caregivers, however, maintaining confidentiality limited services to caregivers;

And well it's sort of the convention in the facility. And there is kind of legal structures about, you know, client confidentiality and all of the other as well. Right. So it's ..., actually quite a complicated situation (SW4, 659-675).

Although caregivers were generally underserved and mandated programs targeting caregivers of brain tumour patients were virtually non existent, there was effort to provide some service as illustrated by the following comment:

Our program is called Patient and Family Support. And so we very much identify the family as part of that patient ... group. [we are] limited in terms of confidentiality. We get the permission of the patient ... to be engaged outside of them, outside of them with the family member but there's not usually a problem with that (SW5, 795-801).

One setting in which existing infrastructure afforded a comprehensive service that promoted autonomous clinician practice that included the family alongside the patient demonstrated another notable exception. This approach appeared to be normative to this setting where every clinic is tumour-site-specific with interdisciplinary teams specifically assigned.

The doctors and the nurses, I'll tell you, they're, they're right on board. If ...a couple's coming in… they ask them like how are you coping? It's not just about the patient. How are you, caregiver? Hubby how are you coping with this? How are things running at home? Who's taking care of the kids?... Are you able to continue work? Are you able to *take time for resting* (SW9, 419-426)**;** *caregivers here are important. And, like I say, it's, it's that whole family unit* (SW9, 745-746).

Another exception seemed to be associated with one clinician's past professional experience and particular interest in the caregiver population. This social worker's understanding of caregiver need was directly influenced by previous work, which seemed to profoundly impact current practice with brain tumour patients and caregivers.

Since I've been here, there's been a huge emphasis on caregivers (SW3, 364-365).

Program attention to diversity. Canada is a diverse country and brain tumours do not discriminate (Wen & Kesari, 2008). Most respondents saw their setting as diverse and sensitive to diversity. Some respondents described population diversity in their particular catchment areas and linked that to program attention to this issue: *It's not an overly cultural diverse area here [province]… so our boundaries I guess aren't stretched that much* (SW8, 559-561). Another respondent associated questions pertaining to the diversity of service as primarily applying to aboriginal clients, and reported that service to these clients was infrequent: *Not a whole lot. But we do see them from time to time…population based, especially from [location] tend to be Inuit or Innu* (SW1, 628-631). In this case, alternative providers, such as Aboriginal Friendship Centres, were used instead of professionally trained interpreters. Another view articulated the perception that diversity did not have a significant impact on services: *it's clearly not that big of an issue. If I've been here that long and I've never had to use an interpreter* (SW2, 427-435). While most respondents reported that cultural sensitivity existed in their work environment they did not identify any special needs or complexity associated with service delivery to diverse groups.

Although the term "diversity" includes differences in cultural backgrounds, for a majority of respondents, their primary understanding of diversity was limited to diversity of language. Diversity was, therefore, narrowly defined and seemed to be associated with language barriers only. For these respondents, the primary service issue pertained to the use of interpreters: *Yes. We have access to interpreters [province] Health Services…. I mean we work with a lot of them* (SW9, 1076-1084). Other facilities used another approach: *we do have a list of interpreters… from employees* (SW6, 487-488). Finally others used family members:

We don't get a whole lot of people that come in here that can't speak English. So I know there have been some but…I haven't dealt directly with them…[they] had children…family members who…accompanied them and can… understand (SW7, 668-674).

The difficulty inherent in the use of translation services as it applies specifically to psychological issues was highlighted by one clinician:

It's not my favorite type of work, because, you know I don't see it as futile, I just see it as very difficult, in terms of establishing the clinical rapport that you need to do psychotherapy and exchanging about private matters with the translator between the two of you, you know. And of course ideally you would need a translator who would have a sense of psychological issues, psychological problems … a sense of the nuances of psychological work and those translators are unheard of you know. They are rare as hens teeth, really (SW13, 875-883).

Interpretation and assumptions related to cultural preferences and stereotypical norms seemed to be a widely used approach that rationalized the way care was provided:

Now that I'm thinking about it… there are some people who don't want their community to know that they have cancer. And that runs of course through all my site groups that it's almost a source of shame to them…so that they sort of handcuff themselves in terms of what kind of support you can access from the community because they don't want the community involved in … in their family business (SW5, 633-640).

The assumptions about what constitutes family support also contributed to how respondents utilized and followed policies associated with service provision. Routinely, the non-use of professional interpreters was prevalent in treatment centres even though policies were in place to ensure maintenance of an approved standard:

We have limited resources in terms of interpreters...our practice and our policy is not to use family as interpreters. Usually it's staff... there's a staff list within [hospital]. We have 4,000 staff. So there's quite an extensive list. And so you can usually try to find somebody, especially if you have some warning that will come. That is someone not known to family but you know, employed by the hospital, and has had, you know, some training. Not a lot but some training in how to give, how to do… translation (SW5, 568-591).

In addition to language diversity, respondents appeared to have stereotypical attitudes that attributed diversity to the family structures and traditions of patients and caregivers from different cultural groups:

With those populations, the caregiver issues are so different because they've got really good support through family (SW9, 1099-1101) and *different cultures are so much better off because they do really truly support…each other* (SW9, 1129-1130).

Respondents seemed satisfied with their understanding of cultural diversity. However, some were aware that there were deficiencies both in providers' understanding of diversity and in the service response to these cultural differences. Three respondents verbalized awareness of the possibility that service delivery to diverse populations may highlight systemic neglect, represented by the following: *Or maybe, I don't know, maybe there's a gap that we're missing, right. I'm not quite sure* (SW10, 364-365). One respondent acknowledged lack of cultural sensitivity and its impact on appropriate care:

Yea, there is cultural diversity…I know that it is a big issue in this hospital… in general. I don't feel, for my own experiences that ... kin networks from the [Ethnic group name] community are recognized, because white folks just don't tend to understand a community caring for someone. (SW3, 593-598).

Program attention to gender. Most respondents denied that specific gender differences were instrumental in influencing the way health care services were provided. In fact, no unique needs were identified in relation to gender differences and most respondents did not allude to gender issues even when directly asked a question that used the term 'gender'; *I don't think there's been any real big [gender] issues around caregiving* (SW1, 530-531).

Many respondents simply reiterated the commonly held perceptions about women and men. Women are expected to provide care, know how to do so possibly to their detriment, and are known to defer to their husbands' need for independence; *there's that perception that caregiving is more of a natural…would come more naturally to women than to men* (SW1, 523-528). Another respondent poignantly expressed the recognition of the pressure associated with the expectation on women to provide care at all costs, although no reference to a specific intervention was mentioned:

> *And I've also had situations where inter-generationally, I mean the wife was telling me, well my family expects me to…care for him and if I was going to put him some place else or take time away…they would think I wasn't doing my job well* (SW10, 227-237).

While caregiving is assumed to be a 'natural' function for women, men are not expected to provide care and are affirmed when accepting the role of caregiver and its inherent difficulties. Notably, one respondent identified the connection made and attention and support given when the health care provider personally identifies with the life circumstances of the patient and family:

> *One of our physicians tends to really connect with young male caregivers. ... Just, I think, because it's a similar age and he can relate. People with kids his age. You certainly get the sense that he's… certainly more involved, more connected, more informed and more involved in knowing what's happening in those situations and certainly more of an advocate… than if, you know, an 80-year-old wife …. Those ones are a bit more, dealt with from a distance* (SW5, 438-447).

Current Services to Caregivers

Patient and caregiver screening. Respondents described the importance of screening and assessing patients and caregivers who may be in need of psychosocial intervention, and collectively made three important points. First, the initial assessment was of the patient, and was most often done by a front-line nurse as part of the nursing assessment. Standardized tools were not used to screen or assess patients: *I don't think any of our sites have screening tools…we don't use it [Edmonton Symptom Assessment Score] in CNS [central nervous system] clinic* (SW5, 805-809). Second, the assessment rarely involved psychosocial staff members as information gatherers, and psychosocial staff members were rarely present when the patient's diagnosis was disclosed. Third, the focus of the initial assessment was on the patient only and caregivers' needs were not addressed.

With respect to the limited use of standardized measures, the only tool that was mentioned by name was the Edmonton Symptom Assessment Score (ESAS), which specifically targets issues such as pain, appetite, mood and mobility that the clinic nurse can immediately incorporate into his or her nursing assessment. One respondent referred to a newly expanded version of the ESAS, which includes a psychosocial problem checklist that was in the beginning phase of being piloted in various settings across the country. Generally, however, a limited number of formal screening efforts were identified as being in use in the oncology patient population; none addressed psychosocial variables; and none was developed specifically for the brain tumour patient or their caregivers. One respondent mentioned the inclusion in the oncology nursing assessment of a form that asked about the need for services such as nutrition, social work, spiritual health, and specifically requested by patients.

With respect to the second point, the nursing profession plays a central role in the initial assessment of the patient, producing the initial illness focused history. Disclosure of diagnosis usually takes place in the cancer treatment centre. Most respondents indicated that they were not often present at disclosure of diagnosis and only *occasionally I might be invited in* (SW10, 279-280). Notably, one respondent was routinely present for the disclosure and had an appreciation for the significance of being part of this event as it has implications for the kind of psychosocial work that follows*: I'd say probably 75% of the time. Yea, I'm lucky. It makes such a difference to the role that you can establish I find* (SW5, 126-131).

Notable as well is the finding that only one quarter of the respondents highlighted the importance of having a point person who was able to provide direction and support throughout the trajectory of the illness. These respondents worked in tumour specific clinics.

> *I think one part that I like about my role is that I am the one continuous person because when people first start treatment, they're… usually being followed, by the radiation oncology team. And then when they finish with the radiation, they're usually moved over to the neuro oncology team. So the doctor changes. The nurse changes. The advanced practice nurse becomes involved. But I remain the one constant. And I think that's something that's…valuable within the team because I have that history with them. And also they…still [have] that connection with me …when they move on to another care team* (SW5, 385-402).

The generic practitioners, on the other hand, were not able to have this kind of contact.

The complexity of how to assist caregivers seemed to be profoundly concerning to study participants who were directly associated with brain tumour clinics. This was illustrated by one clinician:

> *To facilitate the involvement of the caregiver…to really…support the caregiver coming to medical appointments, having sufficient information, knowing about the services and accessing the services to the best of their ability…other than that…find problems early, in my experience, makes a difference. One of the things that is not done through screening but I think is important is also in terms of asking people if they have antecedents of emotional disorders…If you have a person who has a history of depression, a history of anxiety disorders, a history of alcohol, drug abuse… then you can sometimes intervene*

earlier in terms of preventing problems that can snowball… And result in situations of complicated grief… the one thing that can prevent…is a more thorough assessment at the front line of both the patient and the spousal caregiver and making sure that people receive psychosocial assistance when they need (SW13, 364-381).

Early assessment is viewed to be an important intervention approach,

[I] try to help the patient sort of identify who those key people are (SW5, 214-215). *But that's why I try to meet all the new patients because I can't rely that they're going to, that the same alarms that go off for me will go off for [attending physician]* (SW5, 1068-1070).

This service provision was directly affected by the specialized knowledge of clinicians assigned to brain tumour clinics. Early intervention was recognized by them as imperative for timely service delivery allowing on-going sensitivity to changes experienced at key stages and throughout the illness trajectory and beyond.

I might be working with somebody. .. and then their prognosis has changed … and then my involvement might be a little bit different in terms of, you know, we already have a rapport developed so that's a bit easier to explore, *end of life* (SW10, 284-295).

The specialized respondents were aware that although health care services generally were primarily focused on patients, not caregivers, they utilized their more autonomous roles, by virtue of their specialized assignment to provide more responsive intervention to caregivers.

Referrals for psychosocial intervention. Psychosocial service was typically provided in response to referrals made by front- line health care providers such as nurses and doctors or by family members themselves.

The oncologists and the nurses are well versed in what we offer and provide. So, you know, the majority of referrals… are coming from probably nursing here at the centre. … nursing, radiation, radiation nurses maybe. I mean they're the ones having the direct contact with the patient and identifying the issues (SW2, 83-89).

Many respondents believed that the referrals were the result of anxiety on the part of the care providers to crisis-oriented issues that had implications for compliance with recommended medical treatment. Respondents questioned timeliness of referrals and some expressed an interest in being involved automatically instead of during a crisis.

> *Like if a patient comes in … as a new patient, that should be an automatic referral to us. I think … to me the feeling is there's still some feeling that we are not, as social workers, are not a primary thought or almost a secondary thought. And in situations like that we're not necessarily thought of until it's a crisis or until, you know, there's no more treatment available, OK, well we better phone the social worker to make a referral to palliative care or whatever* (SW7, 511-519).

One respondent expressed cautious confidence in the current referral process saying: *definitely I wouldn't say we're reaching everyone but hopefully we're reaching the people who really need it* (SW8, 607-616). Notably it was another respondent's perception that patients are *triaged based really on [nurses and/or oncologists] workload* (SW4, 184-192). Specific generic clinicians did not raise or address concerns associated with caregiver issues or needs at the initial patient entry into the brain tumour service.

Four respondents were specifically assigned to brain tumour clinics. Through their day-to-day association in this clinic they seemed able to become involved with patients and families at an earlier stage than those generic practitioners who worked with brain tumour patients who were medically followed within the general oncology population.

> *We try to anticipate knowing that things are going to get worse and build in the supports rather than try to find supports after the fact (*SW5, 739-750)*…they try to get me involved even if the patient's still well if we know that things are progressing in anticipation that the caregiver needs are going to increase and we need to start looking at what they have available to them. Who they have available to them… How they're coping now* (SW5, 758-763).

> *Sometimes I can sit with a patient up to 45 minutes during their first visit at the (Agency) in the out patient clinic because they are already having a difficult time… with the events that they must deal with* (PSY13, 115-118).

In contrast, in most settings where generic practice was the norm, caregivers would need to self-refer in order to avail themselves of intervention: *I don't think we just swoop in. We try to treat people like anyone else and ...sometimes wait for them to self identify* (SW8, 589-592). Many respondents seemed to replicate the usual systemic expectation that patient and family would self-refer if they had concerns or issues. This finding is consistent across the Canadian landscape.

> *After their last treatment for rad onc [radiation oncology] they are given the social worker's number too so that if there is any, you know, concerns, I guess it sort of would be left up to… the patient or their family to contact* (SW6, 320-323).

Psychosocial service provision:

Intervention approaches. All respondents referred to salient components of psychosocial intervention such as practical and emotional support, education, training and resource counseling. However, these components were offered in different combinations, and each component was defined in different ways. The variability of intervention is represented below and illustrates the involvement of clinicians by their descriptions of service. The first is a generic clinician:

> *What we would offer is… counseling to a varying degree. So counselling, supportive counselling or whatever type of counselling I guess is required or whatever is referred to us….* (SW2, 47-62).

Another respondent was more detailed in the delineation of social work practice and although generic, reported a special interest in caregivers generally, and so seemed to routinely include them as illustrated:

> *I do everything from helping with practical resources, like transportation, Canada pension applications, things like that all the way through to one-on-one counseling with patients, their families and their caregivers* (SW3, 94-108).

The approaches used varied in intensity and frequency and included crisis intervention, individual and family counseling, and in some cases, bereavement counseling. Caregivers were regarded as having access to intervention and were recognized as a priority in this tumour setting, particularly in relation to ensuring that patient treatment would be facilitated.

Intervention approaches ranging from practical to emotional were provided to varying degrees. For example, assessment of finances and drug coverage/insurance to ensure ability to acquire medications was considered to be a routine intervention and a 'foot in the door,' thus rationalizing on-going service that was described as *the extra kind of TLC [tender loving care] maybe to get them through treatment but not necessarily anything ...formal* (SW8, 346-348). Involvement due to the funding issues associated with the current chemotherapy regimen was typically routine practice;

> *Usually I'm involved because…funding for Temadol [chemotherapy drug] can be an issue..the Temadol almost gives the in…it kind of justifies that I can follow them along…through the treatment. But …it's…nothing formal* (SW8, 352- 366).

A unique service model was described by one participant (PSY#13). Here the psychosocial approach was available through two distinct services, with the resource and instrumental intervention provided by a BSW credentialed generalist social worker while the clinical counseling intervention was provided by an MSW or PhD credentialed psychosocial clinician. This model was described as providing equal attention to the emotional and psychological needs of both patient and caregiver. This clinician argued that acknowledging and including the caregiver is the most important intervention in and of itself; this is eloquently illustrated:

> *the first and probably one of the most important psychosocial intervention[s] for the family…the medical doctor may not even talk about anything psychosocial but the way*

> *information is delivered, the way that attention is paid, the way that people are acknowledged…can make a huge difference in terms of how things are going to evolve over time…acknowledge the presence of the caregiver…talk to the caregiver, hear what the caregiver has to say and give the caregiver…the time to express some of their concerns. Only that can bring a major improvement to the situation* (PSY13, 625-640).

The variation in psychosocial approaches seemed to be associated with the organizational structure, whether services were provided according to the treatment received (chemotherapy, radiation therapy) or whether services were delivered through specific tumour sites (brain, breast, lung etc.).

Aside from financial issues associated with medication costs, intervention was also considered for income replacement, travel and accommodation: *If it's a daily treatment like radiation, they stay next door. So we provide a lot of facilitating of that or getting them money to do that* (SW7, 460-463). Only one model had infrastructure within the centre that provided travel support to families; *that fund is being used…for out of town patients…for travel* (SW9, 556-558). And only one facility actually had free accommodation for patients and their caregivers.

***Links with community resources**.* Three quarters of participants reported that significant effort was placed into linking clients with existing publicly funded, not for profit, community resources such as centralized equipment pools, provincial home care services, respite services, and specialized 'end of life' programs in order to meet identified needs. Services were provincially and jurisdictionally variable in regards to accessibility. Rural patients and families did not have access to the same breadth of services that were available in urban settings. Almost half of the respondents referred their clients to the Brain Tumour Foundation of Canada (BTFC) for their Annual

Information Days which were offered in three urban centres. Respondents also accessed BTFC volunteer, peer-led support groups which operated in various cities across Canada.

what I have encouraged, very, very much over the past half a dozen years is that we've had a very good support group, probably one of the best functioning support groups we have here in (the City) is a group for brain tumour patients and their family… supported by the… Brain Tumour Foundation of Canada (PSY13, 246-268).

The volunteer led support groups offered opportunities for caregivers to meet separately from patients. Unfortunately, their availability was dependent on the participant numbers and available facilitators.

Referrals to the Canadian Cancer Society (CCS) were also made.

The CCS … *offers a buddy system. So you can call them and hook up with someone. But they can be across the country … they will hook up caregivers too* (SW3, 1232-1236).

Respondents did not recognize any resources other than BTFC as offering specific services to caregivers of brain tumour patients. This concurs with the Executive Directors' description of the evolving mission of this advocacy organization:

The mission of the Brain Tumour Foundation of Canada... has evolved since the organization started. From focusing on research specifically, to find a cure, to providing information and support to people who are in the journey of having a brain tumour. And over time…the introduction of support groups and the Handbook, and all the information that we have we've realized the key role that the caregiver has in the life of a brain tumour patient. .. many of our programs and services are more… caregiver focused than even patient focused at times …its mission is to support everyone affected by a brain tumour (SW11, 13-28).

Generally resources in the community that addressed caregiver needs were profoundly limited if in existence at all. The creativity and advocacy illustrated by one specialized social worker can only point to the immense effort required to provide service to families:

I manipulate… it's recorded, right? I... use home care a lot. I mean we'll create a role because through our home care program, if you're receiving...professional service, OT/PT, nursing, then they become eligible for a drug card. So if all else fails, I will *manufacture a role for an occupational therapist or a nurse to go into the home* (SW5, 1212-1218).

The expectation that community services be available to support patients seemed to be a common experience articulated by respondents. Having resources within the treatment centre did not appear to be an expectation, therefore, *if people need… more than we can provide, then we do have to refer to… community based partners and services* (SW8, 707-709). However, it was not a certainty that resources would be available and in most cases they were described as limited; and *it is sort of a one-off and then…we'll try, I guess try to refer to the community… try to link them to supports in the community* (SW6, 627-631).

Grief counseling. Counseling that addresses the losses incurred due to the brain tumour illness is an essential intervention. It includes educating caregivers about their responses to their experience and promotes adaptation (Waldrop, 2007). The specialized clinicians in this study revealed insight and awareness that demonstrated their understanding of the importance of loss, as it pertains to the patient and caregiver in the primary malignant brain tumour setting;

> *There's so much grief before they're actually gone. And not to be too off color, one of our nurses suggested having a group for… for spouses who's, who are ready for their patients, for their loved ones to die because there is such a common theme of people who just felt that this was going on too long and they just want it to be done* (SW5, 356-361).

This disease impacts patient and family in a dramatic way from the acute phase of the initial diagnosis right through the illness trajectory. Patients and caregivers immediately experience loss that is associated with their employment as well as their public and private roles and responsibilities, to name a few. Respondents who had access to both patients and caregivers on a more routine basis seemed to have a better understanding of the importance of incorporating grief counseling into the intervention provided to caregivers whenever it was needed. In contrast two generic practitioners with different views stated: *I guess we do grief counseling here too when, you know, if needed* (SW6, 360-362) and

> *I find that their needs are so strong while they're going through with it that there's regular contact. But once the person has passed and… they're trying to readjust, it seems like they… tend to do it more within their families* (SW1, 418-422).

Support groups and psycho-educational groups. Group work as an intervention was variously opinioned by the study participants with no real consensus about utility, focus and value; most groups were noted to be primarily patient focused. Groups took different forms and covered a range of topics that embraced an educational and support agenda. Group work was described as conducted on a weekly or monthly basis. Some psycho-educational groups were conducted over a number of sessions. Certain groups were primarily for peer support (for patients exclusively) while others were psycho-educational and welcomed patients, caregivers, families and friends. The topics addressed included patient orientation to the cancer agency, as well as to the cancer experience; coping strategies, stress reduction and relaxation techniques, information associated with chemotherapy and radiotherapy, and how to communicate with the health care team. Groups were not always offered due to limited agency resources: *I think the psycho-educational format is very beneficial… The only problem here is the time to get it done. Our case loads are huge* (SW3, 833-841). In contrast, ambivalence related to the value of groups was demonstrated by another clinical perspective:

> *I just think that the self, the personal care, your personal needs are so intense at the time that, I mean, support groups work well when you're able to give and take. But.. in… my experience, that people's needs are so intense…and they're so subject to… the horror*

> *stories and sad stories of other patients that they can be very detrimental* (SW1, 456-462).

Only half the respondents seemed to value support groups as a useful intervention for caregivers. Generic respondents referred to generalized caregiver groups that had been attempted *but without a lot of success* (SW1, 794-796), and iterated that the groups *weren't well attended* (SW8, 747-751). In contrast, specialized clinicians were more specific in their analysis and mentioned that caregiver issues were vastly different from patients' concerns and therefore, meeting along side patients did not meet caregiver unique needs:

> *We did have a support group that we tried to divide between patients and caregivers about, since their concerns are always a bit different than the patients themselves but that …wasn't able to be maintained just due to staffing* (SW5, 221-226).

Generally, the value attributed to groups was associated with the opportunity for information sharing, skill development, coping strategies and social support for those experiencing a similar health crisis. It was notable that specialized clinicians recognized the unique value of caregiver support groups:

> *I find that support groups do a great job for caregivers…talk to caregivers, get a sense of where things are at … a support group is a great adjunct … as far as caregivers are concerned* (SW13, 644-649).

There were no mandated group programs in cancer treatment centres targeting caregivers of brain tumour patients.

Needs of Caregivers of PMBT Patients

The vital role of caregivers. The needs of caregivers cannot be addressed without highlighting the intensely significant role that the caregivers have with patients with this tumour. Respondents acknowledged, albeit to various degrees, that in this disease site, the health care system requires the immediate involvement of the caregiver.

This was the case even though caregivers were not formally recognized in the health care system.

Because we all know that caregivers are under an enormous amount of pressure. And that they are under recognized, under served, and really oppressed by the fact that they're not recognized… And not offered the supports within the community that they need. I mean they save the Canadian health care system 5 billion dollars a year but there's nothing for them. Nothing to help them in that role (SW3, 401-407)

The expectation for caregiver involvement surfaced at diagnosis and lasted throughout the duration of the treatment and illness trajectory, as noted by one respondent: *The difference within CNS [central nervous system] compared to my other site groups is that there really is a need to have the caregivers …on board right away,* (SW5, 191-194). The caregiver role was recognized to fill a gap in the health care system; it was needed in lieu of formal caregiver services (the public health care system) and often prevented patient hospitalization and /or institutionalization as eloquently noted:

They're filling a huge role. If there wasn't a caregiver to provide what they're providing, there would have to be a paid care provider or the person would have to be in hospital or in long term care facility. (SW3, 758-761).

The respondents delineated the role of caregiving. It was recognized as practical, time-consuming work, constantly changing in breadth and burden. The role was described as complex and requiring problem solving skills as well as creative management of limited resources *Oftentimes… it's the time and the energy that's involved in caring for somebody with a, with a disease that's affecting them cognitively and affecting them behaviorally…. It's an ongoing supervisory supportive… you're just always on, on call, And it can be a 24/7 type of on call* (SW5, 298-310). *One of the differences in caregiving for somebody with a brain tumour is that there is just the constancy of the role. And it's very hard to juggle the other things in one's world that have to get some priority at some point* (SW5, 455-459).

The respondents delineated the role of caregiving. It was recognized as practical, time-consuming work, constantly changing in breadth and burden. The role was

described as complex and requiring problem solving skills as well as creative management of limited resources

> *The caregiver is expected to fill so many roles. And we're not just talking the health care role. We're talking accountant… chief cook and bottle washer… Transportation person. family mediator. All kinds of things. Lawyer…* (SW3, 766-770).

The role included individualized patient care and advocacy by the caregiver on behalf of the patient. Respondents understood that the health care system relied on and expected caregivers to facilitate patient attendance at all clinic appointments. There was also an understood demand that the caregiver take full responsibility for ensuring that the patient was transported to treatment appointments which occurs on a daily basis over a lengthy period of time:

> *all of the different stresses that go along with this… it's quite a grind to get someone here for every day of the week, 6 days a week* (SW8, 513-516) *that first 6 weeks is quite onerous.* (SW8, 639).

Finally, participants noted that companionship and supervision when relocating to access treatment was an assumed caregiver responsibility.

The emotional aspect of caregiving was not addressed or represented to the same extent as the physical demands. This seemed to mirror the focus on instrumental interventions by health care providers generally, where attention was given to immediate and practical matters, as opposed to existential and emotional concerns that would be associated with a life threatening, incurable illness that impacts the whole family. Respondents who were specifically assigned to the tumour site noted that the caregiver must actively participate as a decision maker balancing risk management with risk reduction. The caregiver acts as a protector, overseer and custodian of the patient. The actively complex involvement and caregiver responsibility extends to all aspects in the brain tumour sequelae. One who is exceptionally knowledgeable about caregivers stated:

> *The caregiver has to be able to adapt to a lot of different circumstances, a lot of different people, a lot of different information. And they also end up charged with making a lot of huge decisions, especially when it comes to an advanced diagnosis and it comes to end of life care and decision-making and things like that* (SW3, 737-742).

This same respondent noted, very perceptively:

> *They don't recognize that they're caregivers, number one. They don't self identify because nobody's told them that what they do is caregiving and it's important…. So I think they kind of roll along OK for a little while. They deal with it… in relation to who it is that they're caring for. So if it's a partner, spouse… friend, family member, what have you. And then as things become increasingly more demanding on them, I think that their role changes, they change, their view on things change and they require different supports along the way* (SW3, 720-730).

With intensive past experience with caregivers this respondent further noted that caregivers don't see this role as being one of choice or one that has distinct parameters. They fall into it by virtue of proximity. Sometimes this fact is completely at odds with the nature of the pre-illness relationship between the patient and the person with whom they are living.

> *There probably is that old school expectation that the person who lives in the house with the person who's ill is going to care for them… And if that's the spouse, that's their duty. … It's just kind of the held assumption that … if you're married to someone or you're partnered up with someone and they become ill, you're going to look after them, even though we know that some caregivers, and I hate it when they use the term loved ones, you know, oh your loved one needs you. Well, you know what, the guy might have beat the shit out of her every day for the last 20 years of their marriage. She probably doesn't love him but now she's stuck with this… So there's that assumption* (SW3, 559-577).

The passion demonstrated by this respondent translated into targeted interventions that the clinician tried to provide to caregivers routinely.

Similarly to the spousal expectations, the role of caregiver is automatically assumed as a parental responsibility in situations where the patient lives alone or does not have a partner. This scenario was noted by a couple of respondents who showed awareness of this and pointed to potential difficulties associated with the disruption of normal developmental milestones.

I actually met an individual yesterday; he's 42 and has to return to his parents' home because he can't. He's lived on his own for many, many years. Can't live independently any more. And has needed to return home. And so not only the burden to himself but also to his parents who have to now, you know, care for, provide basic care to a 42-year-old … his parents are aging. His mom's 65, his father's 70… So it's really tricky (SW10, 53-70).

Specific needs of caregivers. Respondents identified a number of specific needs experienced by these caregivers. Half of the clinical practitioners identified caregiver needs as becoming more burdensome as they fluctuate; changing and increasing in demand over time.

I think [needs] absolutely change over time. And…you know, I think there's stages. I think… initially people are… sort of hit with a change… to go from not being a caregiver to being maybe….And again so individualized, I mean, depending on the level of care required (SW2, 444-449).

However, it is also recognized that there are stable periods during the illness course, when it is possible for the patient and caregiver to achieve

a period of fairly good quality of life and normalcy… throughout the treatment that they can almost get back to some kind of a normal routine of functioning (SW5, 720-723).

Respondents speculated that caregivers seem to benefit from intervention at key times along the illness trajectory; initially at diagnosis, during treatment, at recurrence, and when the patient is transitioned to the palliative stage. The uncertain course and overall requirement for the caregiver to be vigilant was noted to be variable and contributed to caregiver burnout.

As people become…more palliative, their needs, as patient's needs increase, the caregiver's needs increase. And I think for CNS [central nervous system], the caregivers tire way sooner just because… it starts sometimes from the beginning of the diagnosis *and for the next 18 months they're on…high alert and everything changes. So I think they burn out a lot sooner than other caregivers* (SW5, 726-733).

Information and professional resources. The need for information and professional resources was identified by half of the respondents. These respondents recognized the importance of information about the nature of the illness and its effect on patient personality and behaviour. *What happens in the frontal lobe… I think that's something that people aren't always prepared for. And they don't often get any support with* (SW3, 1183-1185).

Study participants identified caregivers as requiring assistance with coping as well as referrals for practical assistance with income, accommodation and transportation. Information regarding family dynamics and impact on relationships was highlighted by some of the respondents:

There is a pesal of different needs. For some people, when there are young families …their main concern is that their children are going to be affected … there is the relational, marriage issues… and generally speaking, if the marriage wasn't good prior to the diagnosis especially with the impact that a brain tumour can have on a patient … in terms of memory problems sometimes emotional disreglation, or difficulty managing certain behaviours, the marital difficulties increase (SW13, 179-204).

Financial. More than half of the respondents spoke about the enormity of the financial burden that besets families and many of the issues were discussed above. The financial burden usually stems from the reduction in income of the patient and /or caregiver and the heightened expenses associated with travel, accommodation for out-of-town families, and other out-of-pocket expenses.

They need financial assistance big time because many, many times it's not just the person who's ill who's not able to work, the caregiver stays home to look after them and usually their expenses increase during this period of time due to transportation issues, medication issue, all kinds of different things. … So the financial piece is huge as well (SW3, 416-435).

The Employment Insurance Compassionate Benefit and EI Disability Benefit are available as income replacement programs through the Federal Government. The benefits provide 6 and up to 15 weeks of financial support respectively; however, these programs were criticized by almost half of the respondents in reference to eligibility criteria thus rendering the benefit as inadequate at best and inaccessible at worst:

I think… on a… global… government level. I mean to identify caregiving as much more, …valued. The 6 weeks of compassionate care benefits just doesn't… just doesn't, not even a drop in the bucket. I mean for patients who need that kind of ongoing support for far more than 6 weeks, you know, their last 6 weeks of life. They need it sometimes for the last 6 months of life. And I think that's just not recognized and the caregiving role isn't formally recognized as such an important one. So people, on that level, it would be nice if they were to expand the EI benefits that are available to caregivers… People who've left work for caregiving purposes (SW5, 969-995).

The caregiver was described as having to keep working or relying on unpaid leave, as permitted by his/her employer or union agreements. Some provincial jurisdictions were described as having financial assistance programs but these were few, difficult to access and inadequate. It is relevant to mention that caregivers not only had the burden of their role but also had to contend with employers who did not fully understand the parameters of the income replacement programs and at times served to be additional obstacles for families.

Had to get stress leave from work to be home with him… with her husband. Her employer was a little reluctant to sign off on a compassionate 6-week leave so she ended up going to her doctor and getting a certificate for herself to be off on stress leave for an indefinite period of time. So it, you know, again it's all these hoops you have to go through to get the time that you need. I mean I think the 6-week compassionate care program doesn't work well for brain patients (SW1, 367-378).

Social and emotional support. Three quarters of respondents acknowledged that caregivers needed formal (professional) support. Some caregivers had the ability to reach out:

> *the needs of cargivers themselves, I find, is just to have had that connection to one person they can call at a moment's notice and use him as a resource to help find: "well where can I go to get this", or " what do I do next" , or "what can I expect to happen next"?* (SW1, 269-273).

There are caregivers who have more difficulty reaching out:

> *She wanted to see me but she didn't. She was petrified that she would see me because seeing me would then allow her to show her fear and her emotion and, you know, that's everybody fights off, right* (SW7, 1256-1265).

Relevant was caregiver reluctance to seek help and time constraints precluding them from seeking formal support:

> *They don't give themselves necessarily permission to….make that a priority to…come in for support. They're happy to talk when they're here already because they have to be …with the patient. But…it's not easy for them to get support outside of that clinic time either* (SW5, 1190-1196).

Caregivers were also seen to be in need of informal help from their social networks: *caregivers feel isolated at times;[their] usual support network can be threatened,* (SW12, 55-60); social network support might be withdrawn and basically become unavailable over time, leaving caregivers isolated and responsible for all care. Perceptive respondents noted that caregivers *need support of other caregivers* (SW3, 422) who understand the emotional drain associated with this illness.

Three quarters of study participants appreciated that caregiving burden and anxiety are associated with one's ability to provide appropriate care. The respondents articulated the relationship between emotional trauma associated with loss and grief, and the risk for burnout.

The needs of the caregivers, mostly in the emotional area particularly for caregivers of malignant brain tumour patients, a lot of people have problems with depression, anxiety, fear of the future and of course dealing with uncertainty (SW13, 153-170).

The respondents saw a connection to increased anxiety and burnout for caregivers coping alone over a long period of time with responsibility for a myriad of issues that included management of symptoms, having to ensure medications were correctly doled out and overseeing activities of daily living for the patient.

Family members find themselves managing symptoms, medication and performing adls [activities of daily living] for patient. This contributes to the extraordinary stress experienced by families in addition to emotional impact of illness (SW12, 106-110).

The anxiety was associated with not knowing how long the care would be required, and could be exacerbated with the subtext of already experiencing the loss of the person that once was and anticipatory loss through death of that individual. This was further complicated if relational issues pre-existed for the patient and caregiver.

I'm feeling like I'm being abused because I know that with the brain tumour he's changing so much and I can't afford to leave him with the children. .., he's not the man I married and sometimes there's days, many days that I'm, I don't love him because I didn't sign up for this. And, and I can't go on (SW9, 816-821).

As well, caregivers were described as caught in very difficult situations such as being socially isolated while at the same time being criticized for not doing enough by the very social contacts that stay away.

And I am carrying a heavy load and, yea, and his parents don't give a rat's ass that I'm carrying this heavy load. They never say anything to me. They still complain that the house is dirty, you know (SW9, 899-902).

Half of the respondents spoke to the issue that loss and / or grief is a component of the caregiving experience. The illness transforms what once was an able bodied individual to one who is dependent and impaired. This requires caregiver commitment to mental and physical work, as well as intense emotional effort.

The respondents agreed that caregiver needs go unmet and are overshadowed by the responsibility of caregiving. This puts them at risk for becoming patients themselves;

You know, sometimes I actually have more concern for the caregivers than I do for the patients. ... Absolute concern for burn-out. You know it's a fulltime job (SW2, 224-227).

Respite and self care. Respondents articulated that caregivers' ability to attend to their own needs is linked to the availability of respite support. Respite resources were regarded as an essential component to caregiver health, but were described as scarce and difficult to access across Canada. In some jurisdictions there seemed to be programmatic increases of respite support, targeted specifically at the end of life.

A…model that we're using here…it's targeted towards…well the last 28 days of life as much as anybody can predict that….they do use a performance scale to kind of measure that but…that's a service whereby all supportive care needs for the patient can be provided in their home at no cost….so that has alleviated the need to kind of push people into palliative care (SW1, 302-309).

Respondents also observed that caregiver ambivalence or reluctance to relinquish any aspect of care responsibility also interferes with self care;

It's often a lengthy, stressful… time for people… And again with, with some of them being resistant to… take extra time to…care for themselves because they…are stuck caregiving and often times feel stuck… then that is definitely a challenge of just having the time… to do other things (SW2, 553-559).

This contributes to the confounding issue related to the balance caregivers must maintain between caregiving and self-care;

I find that most caregivers… really do feel like they want to be the primary care provider and can manage without having to call in… professional home support services. So you're trying to balance that against their own self care needs which is difficult… caregivers realize that they have limited time with the person they love and so they want to spend all the time with them and do everything they can with them for the most part (SW1, 347-356).

Respondents speculated that caregivers *put their own needs completely in the background* (SW4, 427-428), and that they postpone or neglect self-care, which can negatively impact caregiver quality of life: *They need respite big time. They never get a break* (SW3, 421).

Practice Challenges

Respondents identified specific practice challenges that they encounter in their work. These professional challenges significantly impact service and interventions to patients and caregivers.

Recognizing caregivers of brain tumour patients. Recognizing and acknowledging the reliance the health care system has on caregivers is a significant issue. Those respondents who had a clinical practice that is focused on the brain tumour group and the respondent whose previous experience included working with caregivers, articulated a better understanding of how important the caregiver is in this tumour site; *caregivers are valued* (SW3, 545). These respondents noted that the system should acknowledge the caregiver and his/her essential role right from the beginning of the families' involvement with the system.

> *I think the first thing that needs to be done in order to improve services to caregivers [that] is of major importance [is] that the medical staff and if when called upon, [and] the psychosocial staff acknowledge the presence of the caregiver, when the caregiver is there, the spouse or caregiver, acknowledge the presence, talk to the caregiver, hear what the caregiver has to say and give the caregiver… the time to express some of their concerns.* (PSY13, 632-638).

Geography. Health care disparities are acutely noticeable in the case of rural care recipients; *you know… if you're rural, once you leave the city, there's not a whole lot of supports out there for you* (SW6, 470-472). Brain tumour treatment is limited to radiation centres, which are centralized in large cities; patients must travel to these centres to access targeted brain tumour intervention, so *any kind of resections [neurosurgery] or potential resections or biopsies, things like that. People will have* *already had to make a trip [away from home community]* (SW8, 282-284). Medical follow up and the possibility for psychosocial support and intervention is in many cases exclusively limited to the active radiation treatment period, which, is typically 6 weeks. Respondents did not speak about or refer to communication with colleagues in other locations, nor did they mention transfer of clients or referrals for psychosocial intervention closer to home. This speaks to the dearth of service in non-urban settings, as well as the limited, albeit intensive psychosocial intervention that cannot continue once patient and caregiver return to their home community. Practitioners focused exclusively on services in their place of work, in the city.

Geographically… we… don't have…the long-term… personal contact that we could if they were living close to us here. I mean we see them for a few short weeks and they're gone. So the ability to do any kind of… real good supportive follow-up is not there (SW1, 915-921).

Limited cancer centre resources. Respondents reported that the growing number of patients, chronicity of illness and prolonged survivorship of brain tumour patients has increased workload for all health care providers**.** The whole system is under additional strain as a consequence of successful treatments that have contributed to prolonged life. None of the respondents mentioned the shift of treatments and care that has occurred from hospitals to the treatment centre and community.

I want to emphasize…survivorship…in this group is definitely up and coming…the treatments are getting better slowly….[this] means…one set of issues for the patients but also another set of issues for the caregivers (PSY13, 892-900).

This shift has impacted the interventions available to patients and families due to time constraints, *my challenges are just the fact that, … again, you would like to be able to maybe do more or get at their issues more. But… just maybe timing and resources don't allow that* (SW8, 799-802). Clinicians are limited by workload and time, as are caregivers due to their responsibilities for the patients' needs. Intervention can only be provided during clinic time*, we're always playing beat the clock... you don't have that much time to spend* (SW9, 1491-1492) and *it's not necessarily that you don't have time, it's always that you feel that there's always more you could do (*SW7, 1074-1076). Home visits and creative scheduling is less possible.

Perhaps as a function of the limited resources available in cancer centres, program development, implementation of new initiatives, and the use or development of screening tools for caregivers were all non-existent. This left practitioners to feel that interventions were insufficient or inadequate and may not address those at highest risk.

In the brain tumour setting, where brain function has significant consequences on patient and caregiver quality of life, the lack of neuro-psychological testing and routine provision of intervention to caregivers to mitigate cognitive deficits and impairment, seemed to be uniformly absent across the country.

> *That's a bit of a bone of contention here. We don't have a psychologist employed within our centre itself. We do have ...I guess, the psychologist in the hospital or at a rehab centre here as part of our [name of program] but it's not direct access.* (SW1, 148-152)*... particularly with the neuro oncology stuff that there's certainly big gaps here. And issues that are unique to that diagnosis when it comes to caregiving* (SW1, 1031-1035).

Neuro-psychology services were described as vital to the understanding of the patient but as importantly, the caregiver's understanding, regarding the implication of changes and deficits on day-to-day matters. The neuro-psychology service did not seem to be integrated within cancer centres' intervention plans and was not routinely accessed;

> *neuro-cognitive rehab is a real big gap ... here .... Even if people simply had information ... as well as their caregiver, would know...your memory is fine but you just really have trouble processing information. So if you need to learn something new, these are the steps you should take or you won't remember it, right... Even that kind of thing would be, ... a major improvement to the quality of life people have, It's just not available… I do*

> *think there is actually huge potential to provide a really much better and much more integrated service to this population* (SW4, 856-979).

When referrals were made, the waiting period for such a service was about one year.

Interdisciplinary teamwork. The health care team approach is a concept in health care that has been established as a principle but participants' responses suggest it still requires adherence and consistent integration into day-to-day practice. The lack of consistent use of and variable approach to teamwork reflected by the data shows the exclusion of social work from initial contact of the patient with the treatment centre resulting in untimely referrals for psychosocial services. Another clinician's pointed perspective reveals the exclusion of caregivers from the official team and the consequent denial of service;

> *A lot of times just getting caregivers to identify themselves as having needs. They spend so much time worrying about the person that they're caring for. And a lot of times, you know, they see nursing in clinic or the doctors and the doctors whip in and they whip out and they say, how's everything going? And everybody puts on a brave face because they just want to get their information and nobody stops to really ask... how are you doing with all this? It's more how's the patient doing. It's very convenient not to ask because then we don't have to address it and spend money on it in the health care system* (SW3, 1120-1142).

As well, referrals for psychosocial intervention were triaged and determined by front-line nurses who represent the most common profession in health care across Canada. As was discussed earlier, the triaging process reflects the nursing professions' discipline preferences and individual biases and does not adequately address psychosocial distress or caregiver needs.

Limited and difficult access to community resources. Three quarters of respondents commented on the dearth of community resources such as respite. Community services associated with addressing patient needs were described as being not well publicized, with long waiting lists and not routinely accessed; as well, different jurisdictions had different services and varying access criteria.

I think that it's always a frustration that the continuing care system available to the public here is ... it's very full. And it takes a long time to get stuff in place.… Someone's physical abilities may decline extremely quickly and the caregiver has increasing amounts of care to give physically, emotionally to the person… And continuing care is saying, well you qualify for all this stuff but, you know, we can't put it into place because there's nobody to do it. You're on a waiting list. (SW3, 1070-1078).

This scarcity of services was particularly pronounced in rural communities; *and often home care workers are not even always available. And because we have such remote areas around the province, that sometimes becomes a barrier* (SW2, 655-657).

We can't even get a consistent person in half the time through our system… I work with the home care provider to try to get at least [the] same person in repeatedly to try to develop a rapport and a level of trust with the patient. And, you know, it just, everything is… you know, made a little more difficult. Like every transition, every change (SW5, 1375-1382).

Respondents commented not only on inadequate services but also on complicated access due to systemic fracture and disjointed services.

It is a struggle. It is a struggle. The [palliative care program is] very reluctant sometimes to take patients with brain tumours because they think they're going to be there for such a long period of time and…and more difficult to manage (SW1, 296-299).

There seemed to be a need to manipulate the system to gain access to existing resources and services not only for patients but also for caregivers. *Yea. So there's that challenge just in terms of working the system to get what, what your patient needs* (SW5, 1227-1228). It made being an advocate for clients, impossible at worst and very limited at best.

Recommendations

This subsection reports on the recommendations provided by participants in response to specific interview questions.

Raising awareness. One third of participants reiterated the importance of raising awareness about the importance of the caregiver role in the health care sector and the community. In addition, these respondents felt strongly that caregivers should be adequately resourced and should be provided with the information and support they require

> *I think that… there's just so many things the caregivers need. And I think the number one thing is generate awareness and recognition of what they do and provide … just the basic foundations of support for people which is the emotional support* (SW3, 930-943)

> *I don't think there is enough support there to, to teach caregivers … what they may need to… the tools that they may need* (SW6, 341-344).

Financial resources. As was mentioned earlier, caregivers and families were described as experiencing significant financial burden as a result of the disease. Alleviating the significant financial burden of caregivers and families was consistently recommended. Treatment centre infrastructure that would include services and facilities to support the medical treatment, such as significantly subsidized accommodation and assistance with travel expenses, would reduce the profound burden experienced by rural families. Clinicians working in facilities that had financial and lodging support emphasized the benefits of these services.

Increasing community resources. Respondents noted that increases and enhancements in community services for patients would in fact alleviate caregiver burden that would allow for more universal access to services such as respite and home care. This could also contribute to the reduction of stigma associated with service use.

Practice guidelines. Most respondents spoke about the need for practice guidelines that include mandatory inclusion of caregivers in the assessment process as part of comprehensive health care delivery in the brain tumour setting;

> *a social work office, we need to be putting in a best practice around… you know, 6 months later do a follow-up to, or offer a support group in particular for caregivers* (SW1, 1109-1112);

> *Especially for CNS tumours, ideally there would be an automatic referral of all new diagnoses. And I think that … there would be some degree of screening for caregivers. And then there would be follow-up maybe after 6 months. Not just with the patient* (SW4, 793-798).

There was recognition by these respondents of the importance of providing best practice service to caregivers alongside patients. This would serve to ensure equitable and consistent service, thus mitigating against discrepant practices across programs and jurisdictions with resource and organizational support.

> *[W]hen we see CNS patients here, it's inevitable we're going to be seeing a caregiver as well. Like we don't, we don't just meet with the patient… If that was put into a practice guideline … maybe just to make that clear* (SW10, 768-772).

> *[Practice guidelines] would probably be helpful for someone like myself because sometimes, you know, you fly by the seat of your pants really for lack of a better word. Yea. I mean, you know… if there's something I should be doing or I'm missing to be doing then, yea, it's always good to have a concrete reminder somewhere* (SW8, 771-780).

Practice guidelines would target high-risk individuals, thus ensuring those who needed service, would indeed, receive service.

Building collegial connections. Research participants felt that building connections with colleagues who work in similar settings and having similar work responsibilities would reduce isolation of service providers, supporting the development of evidenced based practice guidelines and their implementation. The positive response I received for recruitment for this study was an indication of the importance of the connection with colleagues and the support for contributing towards evidence based social work.

"I appreciate you doing this research. Thank you so much. It's so valuable and important and I hope it leads to good things for caregivers" (SW3, 1328-1332).

Developing connections between specialized neuro-oncology social workers and psychosocial practitioners across the country including remote areas would also contribute to the sharing of specialized knowledge. In this way clients would in fact have the potential benefit of services closer to home and targeted services would not be exclusive to urban centres.

Summary

The above findings are a compilation of the rich data that was generously shared with me by the study respondents. These findings illustrate the multiple and complex needs of caregivers of patients with malignant brain tumours. The data that is presented in this section is discussed in the following chapter which links the findings to the body of literature that is available and allows us to develop some tentative conclusions about these caregivers and the cancer care system.

Chapter 5: Discussion and Conclusions

My interest in studying how the needs of caregivers were met through neuro-oncology programs arose from my professional experience as a front line social worker in a specialized brain tumour clinic. Through my work at the clinic, I became keenly aware of the co-existing tensions between a health care system that provides technologically advanced and cutting edge interventions, and the limited resources available to support the growing number of cancer survivors generally, and brain tumour patients specifically. This situation has resulted in a heavy reliance on caregivers of brain tumour patients who provide their support to these high needs patients at no immediate cost to the health care system but at a great cost to themselves.

As was discussed in the literature review, the knowledge base associated with the PMBT disease is mostly limited to scientific research that informs medical treatment. The disease-focused literature is limited on the matter of comprehensive neuro-oncology services to brain tumour patients and their families, and specifically on services that include psychosocial intervention. The dearth in the literature mirrors the limited resources available to this caregiver group. The literature that promotes family systems interventions and that which focuses on caregivers generally tells a different story. In this chapter, the reality of clinical practice, as described by the respondents from cancer care centres across Canada, is examined in the context of literature that advocates for an integrative model of practice and for attention to caregivers' needs. Recommendations and conclusions are provided at the end of this chapter.

Caregiver needs. The literature provides ample evidence that demonstrates the needs of caregivers (Sharpe, et al., 2005; Kim & Given, 2008) and the dire consequences to caregivers if their needs are not targeted and addressed (Berg & Woods, 2009; Janda et al., 2006; Ergh et al., 2003; Sherwood et al., 2004; Salander & Spetz, 2002; Wyness, 2002; Salander et al., 2000; Horowitz, 1996; Leavitt, 1996; Stajduhar, Martin et al., 2008). The clinician respondents appeared to have a good understanding of the role of caregiving and the complex demands associated with it. They acknowledged many caregiver needs including the need for information and professional resources, assistance with financial matters, the need for social and emotional support, as well as respite. Respondents also seemed aware of the fact that caregiver needs change over the course of the illness trajectory. Only some of the respondents were able to identify the more subtle needs of caregivers such as the need to be informed regarding the discordance between a patient's normal and well appearance and their masked impairment. Other caregiver issues that were largely identified by specialized clinicians included the need for social support to mitigate the impact of burnout, and the need for skill development and self care. It appeared that clinicians who specialized in neuro-oncology practice or who had a particular interest in caregivers were more able to appreciate the nuanced issues that distinguished caregivers of brain tumour patients. As an example, one specialized clinician commented on the pre-illness state of the relationship between the caregiver and patient as being an important factor to consider when assessing for the caregivers' ability to sustain the required effort in the caregiving role.

The unique features that distinguished caregivers' needs were not always noted. There was consistent and limited attention to gender and diversity. With respect to gender differences, the literature provides evidence that demonstrates that caregiving is a highly gendered issue (Berg & Woods, 2009; Baines et al., 1998) and that women make up a clear majority of the cancer caregiving population (Dumont et al., 2006). In addition, they tend to report greater distress, anxiety, depression and subjective stress when compared to their male counterparts (Gaugler et al., 2008; Dumont et al., 2006; Stajduhar, Martin, et al., 2008). The literature shows that men report feeling good about themselves as a result of caregiving (Kim, Loscalzo et al., 2006), even if they rely on other family members to provide the hands-on care, while still regarding themselves as being the "primary" caregiver. One respondent highlighted the positive regard given by a male physician to young male caregivers with young children; female caregivers with multiple roles are simply taken for granted. It is simply assumed that caregivers, particularly women, will take on their expected role, no matter the cost. The cost is typically to women's well being (Dumont et al., 2006; Stajduhar, Martin et al., 2008). Given the fact that caregiving is a highly gendered issue and that brain tumour incidence rates are reported to be higher among males than females (Wen & Kesari, 2008), it was interesting to note the lack of attention to this matter on the part of the respondents.

The literature speaks to the issue of younger households and the possibility that it may be difficult for younger caregivers to identify the source of their stress as it can be multidimensional due to the multiple roles associated with these households (Scott et al., 2001). Respondents, for the most part, did not mention the special challenges associated with age, family developmental stage and family composition; nor did they note special challenges associated with cultural diversity. When asked about diversity, it was defined by respondents in the narrowest sense in terms of language differences. The response to "cultural diversity" was to focus on the need for interpreters and the needs of families from different cultures who were not able to speak English were not always addressed through professional interpreters. Alternately, caregivers who were able to speak the language of the dominant culture were sometimes saddled with the responsibility of language interpretation in addition to other burdens of care.

Only three clinicians mentioned that diverse populations were underserved; two were specialized and one had a special interest in caregivers. The inconsistent practice of using professional interpreters, and the incorporation of stereotypical assumptions related to how certain cultures meet needs within their own family constellation, lifestyle and social network can bias decision making in favor of expedience and at the cost of lowered standard of care. This practice rationalizes formal systemic neglect and is in direct contradiction with the mandates that facilities are assigned to by the provinces. Notably, the only example describing a specialized brain tumour clinic is Tepper (2003) and it is silent regarding the issue of diversity.

Caregiver needs are multi-dimensional and change over time. Without a clear and comprehensive sense of caregiver needs, it is difficult if not impossible to develop and deliver services that meet those needs. In fact, the literature refers to caregivers as "the hidden patients" (Kristjanson, 2004) or the "other cancer survivors" (Golant & Hoskins, 2008), and supports the perspective that caregivers tend to have more unmet needs than patients (Soothill et al, 2003).

The System Response

Patient centered care. At the most fundamental level, the Canadian health care system is organized around patient care, providing diagnostic and treatment services to people who fall ill. Respondents described this "bare bones" system and the role of the psychosocial professional who is limited by the bias towards patient centered care, and has patient autonomy as the single most important standard that must be upheld. The most cogent illustrations of this bias came from comments made by respondents who were not permitted to become involved with patients until they were invited to do so and were not allowed to provide services to caregivers without patient consent. In most cases, respondents could only play an active role in treatment teams if the organization had identified the contribution of psychosocial interventions to team functioning, or had structurally incorporated multidisciplinary tumour specific clinics into their centres.

The alternative in the literature which recommends collaboration among the health care professionals, the patient and caregivers, is holistic and family centered and particularly important in the brain tumour setting (Lohfeld et al., 2007; Sohlberg et al., 2001; Docherty et al., 2008; Sze et al., 2006; Hudson, 2006). When patient consent is the main priority, caregiver needs are less likely to be identified, are untargeted and under-served by programs. Patient focused care and patient autonomy in this situation blurs the systems' responsibility to proactively inform caregivers of potential impairments over the course of the illness trajectory. This approach leaves families to struggle as they wade through the experience floundering and tripping over obstacles that could be proactively identified and mitigated for families. The current practice of upholding patient autonomy at all costs, defies and contradicts what is evidenced in the literature, namely that brain tumour illness is a palliative disease and a family disease and should be inclusive of family as the unit of overall care (WHO, 2007). The focus on patient autonomy was evident in my findings, and appeared to severely limit the development of comprehensive services for caregivers. The patient centered approach has been adopted by the disciplines of Nursing and Medicine, representatives of which played a major role in assessing patient needs. This initial frame of reference created a lens through which interventions were formulated. This discipline-based bias raises concerns since psychosocial issues heavily impact this group of caregivers; without targeted knowledge and specific tumour site insight from a psychosocial perspective, needs and issues are overlooked. Financial concerns are a case in point. Assistance with the costs of accommodation, travel, and drug costs, and income replacement are of significant concerns to many caregivers. These issues are considered to be in the domain of the psychosocial professional; are not attended to by the medical disciplines and consequently may or may not be adequately addressed.

Three models of care represented by Rolland (2005), Hudson (2003) and Sherwood et al. (2004) serve to challenge the patient-centered care model in the brain tumour arena. Rolland (2005) identifies the importance of systemic responsibility for the over all care and inclusion of caregivers, citing this as a crucial component of health care delivery. Hudson (2003) also points to the systemic responsibility for incorporating caregiver focused services into models of care. Sherwood et al. (2004) present a perspective that focuses specifically on the caregiver alongside the PMBT patient, challenging the patient focused model of care.

Argument for specialization. Sherwood et al.'s (2004) model implicitly supports the need to examine the way in which services are structured in terms of the availability, or lack thereof, of specialized services that can attend to the needs of both brain tumour patients and their caregivers. These services would offer psychosocial interventions that reflect knowledge held by specialist professionals who have a clear understanding of the illness and its effects on patients and their loved ones. Sherwood et al.'s (2004) model illustrates the importance of knowing the distinct features of the illness and its variable complexity in order to be able to address the needs of the patient and caregiver. It incorporates assessment of caregiver needs at key points in the illness as a routine part of practice. The model best represents the approach that not only provides a guideline for ensuring intervention is appropriately delivered, but it assumes understanding of the illness, its complexity and its changes over time. Critical to this model is the importance of well-resourced and comprehensive specialized programs. The specialized clinicians represent agencies that have dedicated infrastructure that supports a more specialized approach.

The literature is silent regarding specialized brain tumour clinics except for Tepper's (2003) study that describes a multidisciplinary approach to care. For the most part, literature in the area of PMBT mostly speaks to scientific research that informs medical treatment; very few articles focus on the impact of brain tumours on caregivers. The importance and relevance of psychosocial care is more recently reported in the literature as a prerequisite for appropriate and timely intervention (Lipsman et al., 2007). The findings provided examples from both generic and specialized clinicians that demonstrated that having knowledge about the devastating disease may not necessarily translate into practice; however, it is clear that organizational structure, mission and policy regarding delivery of care contribute significantly to the way service is delivered and to the extent clinician autonomy can be exercised.

System fragmentation. The impact of fragmentation in the health care system was described and identified by the study cohort as posing a risk to caregivers. This risk is mirrored in the literature showing the isolation of caregivers as they negotiate an increasingly complex and fragmented system; they are left to find whatever help they can by whatever means possible (Arno et al., 1999). There are many points at which system fragmentation has a deleterious effect on patients and caregivers. PMBT is a palliative illness, but the palliative component of the health care system is not only physically situated away from the acute ambulatory treatment setting, but is also organizationally separate from cancer treatment centres. As well, the criteria for eligibility make caregiver access to palliative care support services difficult at best. Notably, the practice of linking clients with palliative care programs whenever possible in order to access more services for the caregiver seems to be prevalent across the country. The continuum of care from acute to palliative is fragmented and services are delivered in a “piecemeal” way, augmenting the risk of caregivers falling between the cracks.

The disjointed services along the treatment trajectory are disconnected by virtue of disrupted or non-existent communication amongst the practitioners involved; there is no case manager to oversee care throughout the treatment trajectory. To begin with, inpatient and outpatient services are separate and health care providers are accountable to different organizations with varying policies. Although it was noted in the study that only specialized clinicians can actually provide service seamlessly, their movement to and from the ambulatory treatment centre and hospital, was not the norm. The lack of communication between inpatient services and outpatient programs was an example of disrupted and discontinuous service, which, seemed to begin at the very start of the illness trajectory and continued throughout. In fact, it is not assumed from the interviews conducted that psychosocial service was in fact available or provided in the hospital for the brain tumour patient, let alone the caregiver.

The literature speaks loudly about the importance of collaboration and communication, not only between health care practitioners but also with the patient and family in the process of unfolding treatment (Speice et al., 2000). Openly discussing treatment goals and knowing what to expect from available service providers is key to empowering caregivers. The literature is pointed in connecting discontinuous care, insufficient health care services and limited community resources as contributing factors to caregiver confusion and increasing burden (Stajduhar, Martin et al., 2008; Lohfeld et al., 2007; Braun et al., 2007; Grbich, 2001; Kristjanson, 2004; Aoun et al., 2005; Dumont et al., 2006).

Another example of fragmentation is illustrated by the fact that most brain tumour patients are provided care through treatment centres that incorporate brain tumour patients within the general oncology population. In this regard, caregivers are not targeted for service at all as their special needs are not prioritized for attention. The current approach makes it more difficult for families to establish rapport with care providers anywhere along the illness and treatment trajectory. Timely and appropriately varied interventions are less likely to be initiated and provided.

Rural and urban disparities also point to fragmentation as patients and their caregivers are required to relocate in order to receive active treatment. This includes disparities in communities' ability to diagnose PMBTs as the required technology and human expertise across the country rests in large urban centres. Psychosocial expertise specific to the brain tumour specialty is also associated with large urban centres and is available to different degrees depending on the priorities in treatment facilities. To counteract fragmentation in care given the fractured nature of services, especially between rural and urban settings, it can be extrapolated from the literature that speaks to the importance of communication amongst health care professionals that proactive information sharing between urban and rural colleagues is a recommended approach (Scott et al., 2001; Schubart et al., 2008; Janda et al., 2006; Hudson, 2006; Lohfeld et al., 2007). This would reduce isolation of practitioners who practice in rural communities and have a generic responsibility for patients who return to their home communities once treatment is initiated. Reciprocal communication between rural and urban practitioners would enhance and strengthen knowledge and expertise between various involved disciplines and would more likely ensure that caregivers, who are identified for intervention, might be more likely to receive it. The ideal situation would ensure that the intervention provided or needs identified would not hinge on, and be limited to, the patient and caregivers' proximity to a cancer treatment centre.

The various forms of fragmentation of care described above contrast with the continuity of care model that is promoted in the Canadian literature (Wilson, Birch, Thomas, Justice, & MacLeod, 2008; Lohfeld et al., 2007). In fact, most respondents did not mention this fragmentation as an obstacle to be overcome, but instead seemed to accept the status quo within which they worked. The model promoting continuity of care in the current literature promotes a contemporary approach that is responsive to caregivers throughout the illness trajectory.

However, the specialized respondents did endorse a "point person" or case manager who would follow patients and caregivers throughout the illness trajectory. The literature describes the case manager as being dedicated to overseeing seamless care and ensuring clarity and understanding (Janda et al., 2006; Burns et al., 2007; Lohfeld et al., 2007), facilitating the acquisition of instrumental resources and providing psychosocial intervention at key points in the illness including identifying and integrating normal responses to loss, before, during and after death (Waldrop, 2007). This role was identified but not without the dilemma that is experienced by all clinicians, namely the limited time available for providing the care that is needed, including a supportive presence which is associated with building rapport with caregivers. This involves normal discourse on a casual basis as well as communication and provision of targeted care (Sze et al., 2006; Burns et al., 2007; Lohfeld et al., 2007), which impacts on whether families feel cared for and cared about (Lohfeld et al., 2007; Taillibert et al., 2004). The organizational priorities however, typically focus on medical intervention primarily and target treatment related issues specifically, thus limiting professional autonomy.

In summary, the literature points to the necessity for innovative and broadened case management in order to ensure continuity of care. Case management does not typically include direct client service (Robb, 2011) but front line medical social work practice can in fact incorporate this task as a way to ensure continuity of care by bridging the various services that are involved throughout the brain tumour illness trajectory. The expansive scope of clinical social work which includes on-going counseling, advocacy and supportive intervention, can facilitate discussions related to disease process, decision making and caregiving role responsibilities. The “case manager” or “contact person” can advocate through this role, for respite care, will assist the caregiver to return to pretreatment responsibilities or to prepare for long term care, while providing support and referrals to resources to minimize social isolation, stigma and discrimination. The role focuses attention to the caregiver’s own health, to reduce risk for compassion fatigue, anxiety and depression. Raising and addressing unspoken fears, and supporting caregivers through end of life passages, including clear decision making and preparation for death (Schubart et al., 2008; Janda et al., 2008; Cagle & Kovacs, 2009) is critically important since caregivers may be unaware they are experiencing grief and often need assistance to identify and integrate these normal responses to loss (Waldrop, 2007). The designated contact person could help deal with the emerging emotions, could facilitate discussions between patient and carer and could also answer medical and practical questions. This person would serve as a main contact if unexplained symptoms arose and can proactively guide in pertinent time sensitive information as is relevant in legal matters such as Power of Attorney and Will, preferably before treatment is initiated. Continuity of care would ideally extend beyond the end-of-life period for the patient (Rainer & McMurry, 2002). The post bereavement period has been shown to be a time that caregivers are left alone (Grbich et al., 2001).

I have had the experience of being in the broadened "contact person" role as described above, which has allowed me to provide seamless availability to patients, and caregivers from diagnosis in hospital throughout medical follow up in ambulatory care, in the emergency room of a hospital, during the palliative phase and beyond. With my professional experience along with the evidence reflected in the literature, I believe that the integration of case management with psychosocial clinical care as delineated above would enhance program structure and comprehensive delivery of care.

Team. All the respondents represent multidisciplinary settings that vary in membership, but are primarily comprised of medical practitioners; this is in compliance with Accreditation Canada (2010) which is a not-for-profit, independent organization that provides health organizations with an external peer review to assess the quality of their services based on research and evidence-based standards of excellence. The normative definition of “team” by respondents illustrated a delineation of various disciplines that are available to provide service when consulted, but follows the organizational acquiescence to the physician dominated team approach to oncology care. The extent of their involvement seems to be associated with whether treatment centres are generic in nature or provide specific care to brain tumour patients in specialized neuro-oncology clinics. None of the respondents referred to family members or primary caregivers as members of the health care team despite the expectations that they carry out the actual caregiving. This represents the normative view that diminishes family expertise and disregards emotional, spiritual and practical needs associated with the goals of patients. As well, psychosocial clinicians were not described as typically present when the disclosure of the diagnosis was given. This reflects the limited interdisciplinary team approach and the diminished importance or even the relevance assigned to psychosocial involvement in the overall care of patient and family.

While there is a dearth of literature regarding neuro-oncology programs specifically, Tepper (2003) is the only article found that describes an existing multidisciplinary neuro-oncology program where seamless, collaborative and family focused care is offered consistently throughout the illness trajectory, thus ensuring interdisciplinary and continuous care. This model demonstrates the importance of having a specialized and trained neuro-oncology team (Pace et al., 2009) where medical care is “not confined to medical treatment only” (Grisold et al., 2006, p. 329). This approach gives credence to both the person with the illness and the support system impacted by the illness.

There is a strong body of literature that promotes collaborative interdisciplinary work (Rabow et al,. 2010; WHO, 2007; Morrison & Meier, 2004; Schubart et al., 2008; Janda et al., 2006; Hudson, 2006) and the discrepancy between what is promoted in the literature as progressive health care and what is in fact the norm in the health care system, is noteworthy. A case in point is the lack of integrated neuro-psychological testing that could provide all team members with an understanding of the patient's cognitive strengths and deficits thus informing patients and caregivers about realistic expectations regarding improvements in patient communication. The test results can also be used in targeted cognitive rehabilitation. Respondents did not mention neuropsychological testing as an intervention although they knew that this subspecialty service could be accessed occasionally, albeit with difficulty. The inclusion of neuro-psychology services is only mentioned in a descriptive study of a psycho-educational program for caregivers of brain tumour patients (Cashman et al., 2007). The exclusion of this service represents a significant limitation to comprehensive intervention to both patients and caregivers and reveals the system as primarily medically oriented.

The literature shows that available information and consistent communication among health care professionals, the care recipient and the caregiver is important and results in good quality multidisciplinary care (Pace et al., 2009; Scott et al., 2001; Schubart et al., 2008; Janda et al., 2006; Hudson, 2006). Furthermore, a well-trained neuro-oncology multidisciplinary team inclusive of patient and family is a benchmark for continuity of care. Conversely, inadequate communication from health care professionals can result in conflicting information thus contributing to misunderstanding or uncertainty about treatment goals. This can potentially add to caregiver stress and limited confidence and trust (Burns et al., 2007; Cagel & Kovacs, 2009). Poor communication can also lead to detrimental consequences such as families choosing to ignore supportive services due to reduced credibility and feelings that what is offered will not be considered effective to meet their needs. A knowledgeable team is a proactive one; providing timely intervention based on what is professionally known can go a long way in mitigating risk to caregivers.

Interventions for Caregivers

The services that are offered to caregivers are primarily practical and instrumental in nature, and include interventions that range from those that are evidence-based to those labeled as 'tender loving care' or 'tlc'. The interventions are generally selected on the basis of caregiver referral, which are made by non-psychosocial practitioners who decide whether a referral is appropriate. Even those respondents representing the four specialized locations rely on referrals from other professionals before initiating interventions, and all too often, caregivers are expected to self-refer to access the services they need. To understand why other professionals refer caregivers for assistance with practical matters, it should be noted that the emotional and physical aspects of caregiving often go unnoticed and unsupported (Schubart et al., 2008; Soothill et al., 2003). Current practice relies not only on referral but on crisis referrals for situational "emergencies" which have the potential to affect patient treatment. This seemed to be most predominant in settings where generic attention to brain tumour patients was the norm. The facilities that provided more specialized services demonstrated a broader understanding by clinicians and embedded in their programs are more opportunities for addressing emotional needs such as grief, self-care, burnout and social support. For the most part however, psychosocial intervention was not described by most respondents as a core service that was routinely included in the roster of PMBT services available from cancer clinics.

In terms of self-referral, it was frequently noted by respondents that caregivers have the option of referring themselves for services. It can be argued that the reliance on self referral leaves the family caregiver as invisible. The Executive Director of the BTFC confirmed this and added that caregivers do not raise issues in the presence of patients in order not to draw attention from the patients to themselves. This concurs with the literature that recognizes that caregivers will only speak openly if they are invited to do so independently of the patient (Walsh et al., 2004). The lack of opportunity to openly share their concerns, fears, and needs puts them at more risk for their own physical and emotional health. An approach that is limited to self-referral only serves to keep care caregivers silenced and negates their right and opportunity for attention.

Screening and assessment. Screening and assessment as interventions are well supported in the literature as part of structured, targeted and comprehensive approaches to family care (Berg & Woods, 2009; Schumacher et al., 2008; Glajchen et al., 2005; Soothill et al., 2003; Chambers et al., 2001; Cagle & Kovacs, 2009; Rolland, 2005). In addition, they are supported by the Standards for Social Work in the end of life care (NASW, 2004), which provides fundamentally empowering guidance for practitioners. Screening and assessment demonstrate to caregivers that they are important health care providers, and that their issues and concerns warrant attention. This also formally recognizes them as essential members of the treatment team. Screening and assessment also provides important information regarding relationships, dynamics between family members, personality traits and preexisting variables associated with depression, self esteem and anxiety. These precursors and indicators can help clinicians focus on individual coping strengths and target interventions appropriately (Hudson, 2003; Stajduhar, Martin et al., 2008).

Even though there are a few standardized and empirically validated caregiver screening tools in the literature (Dumont, Fillion et al., 2008) respondents indicated that none were used with caregivers. This seems to be consistent with the current health care approach and reflects the lack of practice guidelines in this area. The maintenance of this approach is difficult to reconcile as proactive assessment of risk, at different points, is recognized to mitigate problems and a way to avert crisis, depression and complicated grief reactions. The lack of screening and routine assessment of caregivers is in sharp contrast to one clinician's passionate approach in role modeling to team members how little needs to be done in order to ensure that the caregiver is included and feels like part of the focus. This respondent spoke about the importance of simply acknowledging the caregiver, as being a major intervention; *recognition of the caregiver is a small act but with potential for significant consequences* (P#3). On-going assessment of the patient is regarded as the basis for timely interventions that can be provided at critical key points in the illness trajectory. However, proactive screening and assessment of caregivers was not the norm despite the compelling evidence in the literature that recognizes that caregiver needs are different from the patients' and that there is good reason to ensure that caregivers have opportunities to get their needs assessed and addressed (Berg & Woods, 2009; Schumacher et al., 2008; Glajchen et al., 2005; Soothill et al., 2003; Chambers et al., 2001; Sharpe et al., 2005; Hudson et al., 2004; Walsh et al., 2007).

Instrumental interventions. Instrumental interventions included the provision of information and training, financial advice and referrals to community resources. Caregivers' need for different types of information is well documented in the literature (Schubart et al., 2008; Braun et al., 2007; Dumont et al., 2006). However, timely information and training for caregivers in the acute phase seems limited. This includes information about the illness, its trajectory and available resources and this leaves caregivers on their own to confront patient confusion, altered behaviour and other symptoms (Catt et al., 2008; Sze et al., 2008; DuBenske et al., 2008). To further confound this situation in the early stage of the illness trajectory is the urgent requirement for informed decision making pertaining to treatment options. There is evidence that access to information allows patients and caregivers to exercise autonomy and influences their ability to make informed decisions (Dumont et al., 2005). Respondents recognized that information and education is the way to empower caregivers but the lack of routine involvement with caregivers suggests that the need to empower caregivers was not a clear priority of respondents and/or was not facilitated by the service system. The dynamic communication process supported by the literature does not come easily to health care providers (Burns et al., 2007). This is evidenced by poor communication among practitioners and the system's refusal to regularly include caregivers or utilize an interdisciplinary approach to information provision. Caregivers require information that is proactively provided. Without this proactive intervention, caregivers' sense of control, capability and self-competence can be undermined (Scott et al., 2001; Bee et al., 2008).

Having the ability to master the role with competence is associated with the likelihood of using problem-focused coping strategies to meet care demands and is linked to good preventative health behaviors by caregivers, which can decrease their stress response and increase personal satisfaction with the caregiver role (Sherwood et al., 2004; Kim & Given, 2008; Folkman, 1997; Osse et al., 2006; Waldrop 2006, 2007; Stajduhar, Martin et al., 2008).

A perceived contradiction arises when it is suggested that caregivers can be trained to acquire skills that took professionals years to attain through their training (Armstrong & Armstrong, 2004). The admission that families have worthwhile knowledge that can contribute to overall patient care requires time to unfurl. This can only happen through assessment and inclusion. The limited expertise that programs currently have, as reflected in the generic approach to care, inhibits health care professions from providing information for fear of not knowing or agreeing on what kinds of information needs to be shared, fear of saying too much too soon, or doing more harm than good (Hudson et al., 2004; Dumont et al., 2005). Care providers struggle with what information to give and are further confounded by caregivers' ability to absorb, filter and retain information, which can be compromised by memory loss, depression, fear, anxiety, and sleep deprivation. There is evidence in the literature that anxiety may be minimized if the caregiver is well informed, postulating a relationship between level of information and level of anxiety as caregivers are able to make educated decisions about managing the physical, emotional, and social aspects of their experience. The BTFC Executive Director iterates the importance of having precise information, given separately from the patient, so that the caregiver can meet their role responsibilities in the most prepared way. Concerning is that only half of the respondents, most of whom were specialized clinicians, referred to information as a need, and none spoke about the deliberate and specific time that ought to be allotted to caregivers to meet this need. This may illustrate the time constraints associated with front-line work. However, this neglect is even more pronounced in the rural setting where services are vastly more limited than in the urban centres and adds one additional risk for rural caregivers.

An instrumental intervention that is frequently utilized with caregivers is the provision of assistance with financial problems. The literature shows that psychological distress for caregivers is affected by financial burden which is associated with career sacrifices due to disrupted employment, monetary losses and increased out of pocket expenses. This includes workplace discrimination and inadequate income replacement benefits (Dumont et al., 2006; Stajduhar, Martin et al., 2008; Schubart et al., 2008). The vast majority of respondents, inclusive of generic and specialized clinicians, spoke of the inadequacy of the Federal Employment Insurance Compassionate Care Benefit (CCB) of 6 weeks as well as the 15 weeks of Employment Insurance (EI) Disability Benefit. All agreed that the EI benefits do not adequately reflect or compensate for the longevity of brain tumour illness. Williams et al. (2011) speak to the inadequacy of the CCB and the importance of having compassionate care benefits as an independent program apart from EI. The benefit would be provided to those who provide care, thus truly being a compassionate benefit (Flagler & Dong, 2010).

It is notable that the clinicians did not refer to the meaning of being employed as it pertains to social role and caregiver coping. There is in fact some literature that shows that employment may “buffer” or protect caregivers against stress (Gaugler et al., 2008;

Swanberg, 2006). Supporting caregivers to continue their work outside the home and assisting them with the complex work inside the home would have costly implications for community resources that would have to be substantially increased. Respondents were unanimous in recognizing the commitment required by caregivers especially when patients had to relocate for radiation treatments. The expectation that a caregiver be available is universally assumed. It follows then, that infrastructure should be available to support mandated medical treatment. For example, this would mean that radiation patients would have a place to stay for the treatment duration, free of charge or with a significant and easily accessible subsidy. The burden of costs associated with relocation was addressed routinely by social workers, yet the underlying implications associated with dislocation and employment disruption, were not identified as issues warranting intervention. The Manitoba government began addressing the economic value of caregiving in 2009 through the Primary Caregiver Tax Credit program. The criteria for eligibility include the needs of the care recipient and caregiver involvement in physical and emotional assistance. This does not appear to be a well-known program and accessibility seems to be substantially reliant on clinician knowledge similarly to the CCB. However, it is a systemic demonstration of caregiver recognition and compensation, albeit limited and inadequate for the care provided. It is a start.

Bridging the somewhat artificial division between instrumental interventions and those that involve some form of social work counseling are caregiver support groups. Although supportive education groups are promoted and justified in the literature as an integral part of cancer care (Leavitt et al., 1996), there is no consensus or empirical evidence that supports the utility or effectiveness of group work in this tumour site. Nor were groups offered or facilitated by study respondents. Respondents did refer clients to existing generic support groups in the community, but they acknowledged that these were not well attended, speculating that they were not meeting caregiver needs. Notably, generic clinicians referred to the heavy caseloads that interfered with planning and running groups. Specialized practitioners pointed to the fact that patient and caregiver needs differ and therefore mixed groups were regarded as being less useful and often ineffective for caregivers. Some clinicians recognized that it was useful for caregivers to speak with others similarly situated, and support groups are documented in the literature as useful and legitimate interventions (Hudson, 2004; Kim, Baker et al., 2006). There are qualitative and quantitative studies that demonstrate that the sharing of information in a group format assists caregivers in developing realistic expectations consequently increasing positive perceptions of the caregiver role. This finding is important as positive perceptions may well act as a buffer against negative psychological factors influencing caregivers' experience (Hudson et al., 2008). The group format has also been shown to result in the need for fewer resources (Sze et al., 2006). However, developing opportunities to run groups must be supported by organizational infrastructure dovetailing with specialized clinician knowledge pertaining to these caregivers. Only one psycho-educational program for caregivers of malignant brain tumour patients was found in the literature (Cashman et al., 2007) and this group required patient consent for caregiver participation. The typical psychosocial staff member is likely to experience difficulty incorporating such a useful educational tool within the complexity, time and resource constraints in the current health care environment.

The respondents representing the BTFC, which sponsors volunteer peer facilitated support groups, referenced membership, recruitment and retention issues. The organization's representatives also spoke about the difficulty in meeting caregiver needs, noting this was only possible when there were enough members in attendance in concert with the availability of more than one facilitator. An annual Information Day was referred to as the only protected time where workshops focusing on the caregiver were specifically scheduled; BTFC Information Days were only available in five cities across the country.

The provision of instrumental interventions is complicated due to limited resources within treatment centres and in the community at large. The role of social work is to advocate for, link with, and manage scarce resources. The use of, and referral to community resources is pervasive throughout psychosocial intervention across the country. Unfortunately, the level of respondent knowledge pertaining to available services seems to impact what is offered to clients. Services in the community were described as being very limited and requiring manipulation by practitioners in order for families to be able to access service; the ability to manipulate resources was dependent on practitioner knowledge, interest and experience. Respondents were vocal about the importance of additional community services with liberal eligibility criteria. Easier access would reduce stigma and incorporate the social importance of the service as a universal adjunct to the caregiving role.

Affective counseling and other interventions. In addition to instrumental interventions, caregivers were sometimes provided with specific counseling pertaining to their role, grief counseling and formal social support to alleviate burnout. Respondents who were specialized in their involvement in the brain tumour area seemed more likely to identify grief and loss as pervasive in their work with patients and caregivers. The rationale for most other clinicians' omission with regards to grief and loss seems to be associated with their acknowledged short term involvement, lack of routine assessment, and the normative nature of interventions typically associated with instrumental matters related to the medical treatment. It is difficult to reconcile this omission as it is well documented in the literature that "grief is experienced throughout the context of life-threatening illness" (Doka, 2006, p. 205). The literature also recommends targeted assessment of, and interventions with caregivers prior to the loss of a loved one as this may help to protect bereaved individuals from future mental and physical morbidity (Kim, Loscalzo et al., 2006; Dumont, Dumont et al., 2008; Doka, 2006). Recognizing and acknowledging grief is a prime example of why specialized psychosocial care is relevant in this tumour site. Without the proactive attention to this matter, families can be further isolated and left to deal with frightening sadness without any support and without the understanding that what they are experiencing is in fact grief. Understanding the factors that influence caregivers' abilities to cope is an important intervention for front line health care providers. Anticipating problems that may arise is essential in the process of ameliorating burden and minimizing risk for complicated grief (Tomarken et al., 2008; Stajduhar, Martin et al., 2008; Hudson, 2006).

The issue of social support for caregivers is closely associated with anxiety, ability to cope and burnout (Lopez et al., 2007; Ergh et al., 2003; Hudson, 2003; Aoun et al., 2005; Dumont et al., 2006; Sharpe et al., 2005). The combination of caregivers not taking the time, not having the time and not knowing what resources are available to them is dire for meeting support needs and increases their risk for burnout. In order for caregivers to have the confidence that they are not wasting professional time, they need proactive psychosocial service targeted to them. The perception that professional time is limited is systemically perpetuated through minimal services and the lack of mandated targeted programs aimed at caregivers. This coexists with the professional assumption that caregivers would request help when they need it. This is confounding evidence in a setting where it is known that caregiving burden and anxiety are associated with the ability to provide appropriate care. Service providers can only provide targeted intervention if they have a better understanding of caregiver needs and the ability to have a better awareness is strongly associated with screening and assessments; if caregivers are not asked about their social resources, intervention cannot be targeted. If clinicians do not have the capacity to hone particular skills associated with this tumour site, they are less likely to be able to provide targeted intervention.

Hudson's (2003) Supportive Intervention model which is based on Lazarus & Folkman's (1984) and Folkman's (1997) stress and coping theory speaks eloquently to the importance of intervention with caregivers and is fitting in the stressful brain tumour setting. Knowledge and information are critical variables required to impact coping. To acquire this information it is essential to assess the caregiver's cognitive appraisal of their experience as well as their ability to identify what, if anything could be done to overcome the situation, or increase the likelihood of benefit. Assessing caregiver needs and coping skills resulting in more successful adaptation to stress, would inform the clinician's choice of psychosocial intervention. Coping, as a dimension related to caregiver needs is associated with feeling competent and in control. This helps to protect against exhaustion and psychological distress (Dumont et al., 2006).

There is abundant research that demonstrates that caregiving comes at a personal cost that can expose those who care to health risks, manifesting as depression and anxiety, reduced self esteem, feelings of isolation, mental and physical fatigue, guilt, resentment, anticipatory grief, anxiety and sleep deprivation. The evidence in the literature suggests caregivers report high levels of distress when compared with the general population and they have a high level of supportive care needs (Lopez et al., 2007; Ergh et al., 2003; Dumont et al., 2006; Hudson, 2003; Aoun et al., 2005; Sharpe et al., 2005; Janda et al., 2006; Doka, 2006; Sherwood et al., 2004; Salander & Spets, 2002; Wyness et al., 2002; Salander et al., 2000; Horowitz et al., 1996; Leavitt et al., 1996; Khalili, 2007). The compounding issue that is associated with the accompanying losses experienced by caregivers is also well documented and there is evidence that caregivers of PMBT experience more distress when compared to other caregiver populations (Janda et al., 2006; Ploeg et al., 2001; Ergh et al., 2003). Psychosocial clinicians, primarily social workers in community based oncology settings, can use these findings to justify making regular supportive and therapeutic contact with caregivers during the course of illness. Inadequate social support resulting in social isolation may translate to limited assistance with the caregiving burden; accessible counseling, validation and formal support may help ameliorate the burden. Uniformly all psychosocial clinicians commented on the importance of support and therapeutic contact with caregivers even though many were not in a position to provide this intervention.

An omission in the study's findings is any discussion of the rewarding aspects of caregiving. There is evidence in the literature, albeit less perceptible than the literature addressing needs, that the rewards and burden of caregiving can coexist (Waldrop, 2006, 2007). Additionally, attention to needs and advance preparation along with having a sense of purpose or meaning associated with the caregiving experience can impact coping during the illness phase (Stajduhar, Martin et al., 2008; Hudson, 2004). This can manifest in caregivers' improved sense of self-worth and increased satisfaction and less likelihood of feeling overburdened (Kim & Given, 2008; Rainer & McMurry, 2002; Hudson, 2006; Hudson, 2003). The evidence also shows an association between satisfaction and the acceptance of professional support (Aoun et al., 2005).

Recommendations and Conclusions

This study has demonstrated that the majority of cancer care clinics across the Canadian landscape provide some level of psychosocial services to brain tumour patients. The underlying expectation of the health care system is that caregivers assume the responsibility for the provision of essential services for these patients that supplement what the system has to offer. This approach is in direct contradiction to gold standard collaborative, family centered models that are identified in the literature by Hudson (2003), Sherwood et al., (2004) and Rolland (2005). In spite of assigning this burden of care to caregivers, no mandated programs targeting caregivers specifically were identified. All ambulatory facilities represented by the respondents in my study, regardless of whether brain tumour patients were followed in generic clinics or specialized ones, provided patient centered care. These services, which are supported by policies and procedures directed specifically at patients, need to be modified. Specifically, it is recommended that:

1. Practice guidelines be established to ensure consistent standards and proactive inclusion of, and service to, caregivers of brain tumour patients. Practice guidelines

should be directed at two levels:

a. Systemic / programmatic: a specialized brain tumour team, inclusive of psychosocial representation, should develop these practice guidelines. Since WHO staging guidelines are used for purposes of medical diagnosis of brain tumours, the use of the WHO definition of comprehensive care is justified. This definition recognizes the family as the unit of care and not solely the individual patient. The focus of brain tumour program guidelines would be to ensure that all care automatically includes caregivers. This would dovetail with a psychosocial assessment that establishes the identity of the caregiver and that includes standardized protocols that alert practitioners to the range of caregiver needs. The guidelines would also include direction regarding the core involvement of psychosocial expertise from the disclosure of the diagnosis onward and would serve to reduce the stigma of psychosocial care, as well as promote a specialized multi-disciplinary team approach to comprehensive care. The endorsement of a specialized treatment approach for brain tumour patients and their caregivers requires organizational commitment and direction.

b. Professional/ discipline specific guidelines highlighting and illustrating family system expertise: these guidelines should be developed by frontline psychosocial practitioners in order to ensure attention is given to psychosocial indicators at key points throughout the illness trajectory. One-to-one individual intervention is recommended using various approaches including specific attention to gender and diversity.

2. Educational programs in professional schools of social work as well as medical school and all allied health disciplines include compulsory courses and training that

incorporates caregivers in interventions. Communication skill development must be targeted along side the technical aspects of health care professional training.

3. Communication between rural and urban based professionals be proactively initiated, thereby reducing isolation and misunderstanding. Effective communication would ensure that a larger number of clinicians hone their professional skills and knowledge regarding caregiver needs thus ensuring a more orchestrated mobilization of their collective clout. The strength of a larger number of voices as a unified group is more apt to be heard when advocating for client services and rights.

4. Continuity and coordination of care be enhanced through better communication among all segments of the health care system, specifically among the hospital, ambulatory care and community services. Better communication would increase awareness and knowledge throughout the healthcare system regarding the brain tumour disease and its consequences. Raising the profile of caregivers through consistent proactive health care initiatives would contribute to ensuring that caregivers are recognized as valuable participants. A specialized social worker would be instrumental in facilitating this continuity of care throughout the illness trajectory. I have had the experience of being in the broadened ‘contact person’ role as described above, which has allowed me to provide seamless availability to patients, and caregivers from diagnosis in hospital throughout medical follow up in ambulatory care or in the emergency room of a hospital. With my professional experience along with the evidence reflected in the literature, I believe that case management as delineated above, would enhance program structure and comprehensive delivery of care.

5. That the BTFC strengthen its national presence, raising more awareness of brain tumour illness through written material and public relations strategies. It is also recommended that the BTFC take a more proactive approach to actively including existing programs and initiatives that promote interventions for brain tumour patients and their families. The current approach seems to promote only programs that are volunteer run under the auspices of the BTFC.

6. That lobbying with government and ‘champions’ of oncology issues recognize the uniqueness of the brain tumour illness. Putting monetary value on caregivers in this tumour site should be reflected by targeting existing social programs that are currently in place such as the Employment Insurance Compassionate Benefit and Employment Insurance Disability, for a longer benefit period. Separating the Compassionate Care Benefit from the EI program would broaden the base for qualification. As a national organization, the BTFC could be influential in lobbying and promotion in this effort.

This study has added to literature that primarily informs the medical treatment aspect of care to brain tumour patients and has contributed new information that speaks to the uniqueness of the caregivers of brain tumour patients. Further study could examine the changes that occur over time in the systems’ response to PMBT patients and their caregivers. Further research could also serve as a mechanism to bridge jurisdictions and begin to close the collegial gap.

While there are various strategies and efforts to improve medical outcomes for brain tumour patients, there is an urgent need to target their caregivers in terms of reducing their burden and enhancing their quality of life. The health care system cannot continue to assume that caregivers will provide the extensive care expected of them while continuing to marginalize these same caregivers by limiting their access to health care services at best and excluding them from health care services at worst. Caregivers' current contribution serves to stabilize the current system but continued inattention to their needs places the entire system at risk. It is apparent through the study findings, the literature and my own professional experience that the only viable option to ensuring the well being of our universal health care system is the universal inclusion of all stakeholders in program planning and service provision. As my research has illustrated an essential stakeholder is the caregiver.

Appendix A

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

Printed on University of Manitoba institutional letterhead for distribution to study participants

Title of Study: **Who cares for the caregivers? How are the needs of caregivers of primary malignant brain tumour patients met through structured ambulatory neuro-oncology programs in Canadian Centres?**

Researcher: Orit Reuter
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Advisor: Professor Lyn Ferguson
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This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I have been invited to participate in a research study that will contribute knowledge that will help people understand the nature of the problems associated with the needs of caregivers of primary malignant brain tumour patients. The attention to this unique subset of caregivers will also have an impact on the provision of service to this group. I understand that I have been asked to share my experience with patients and families in a neuro-oncology program as it relates to interventions used, program structure, and professional composition. The study focus is on my experience in working with clients in a centralized outpatient cancer program (as opposed to in-patient/hospital). The researcher wants to know what people who have been involved in front line service related to caregivers of brain tumour patients within the past year think about:

- the needs of caregivers
- the delivery of care to caregivers through a structured program
- useful types of therapeutic interventions in the care of caregivers

I understand that the researcher, Orit Reuter, is a graduate student in the Faculty of Social Work and is conducting this study as thesis research that is a requirement for completion of her Master of Social Work degree.

I understand that Orit Reuter will be interviewing me once for approximately one to one and a half hours. This interview will take place by phone and will be audiotaped. I understand that I have the freedom not to answer any of the questions that I am asked.

I understand that I will be asked questions about how caregivers of brain tumour patients are provided service. Orit Reuter will take notes to ensure that all of my ideas are included. The notes and any information identifying me that was collected for the purposes of this study will be kept in a locked box and will be destroyed after 7 years.

I understand that the information from the interview and the results of the study will be used for research purposes only, including a research report and publication. I further understand that all reports, publications and presentations in public forums will not directly identify individual participants and all information will be presented in a non-identifying manner. Despite efforts to keep my personal information confidential, absolute confidentiality cannot be guaranteed. My personal information may be disclosed if required by law. All records will be kept in a locked secure area and only Orit, the thesis advisory committee and the transcriber will have access to these records. I will be assigned a study code that will be used on my records, instead of my name, to help protect my identity.

I understand that there are minimal risks to participating in this study and that I can contact Orit Reuter if I require any additional information. If I have questions concerning the ethical aspects of this study I can communicate with Lyn Ferguson who is the faculty advisor of this research study. I understand that I can receive a copy of the draft report, by contacting the researcher by email.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and / or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Principal researcher: Orit Reuter
204.787.2189

Supervisor: Prof. Lyn Ferguson

204.474.8273

This research has been approved by the University of Manitoba Fort Garry Campus Research Ethics Board, Psychology/Sociology REB. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 204.474.7122 or e-mail Margaret_bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

____
Participant's Signature   Date

My mailing address is:
____
My phone number is:
____
The best time to reach me is:
____

____
Researcher Signature   Date

I am interested in receiving a summary of findings. My mailing address is: as above, or

____

Appendix B

Letter of Recruitment to Potential Study Participants

Dear Colleague:

I am a social worker in the neuro-oncology program at Health Sciences Centre and CancerCare Manitoba. I am also a graduate student in the Faculty of Social Work currently initiating a research study exploring the experiences of neuro-oncology social workers across Canada. This research study is being conducted as a requirement for the completion of my Masters of Social Work degree.

The purpose of this research is to contribute knowledge that will help people understand the nature of the problems associated with the needs of this unique subset of caregivers and also to have an impact on the provision of service to this group. In this study I am interested in understanding more about how neuro-oncology programs provide care for patients and their families. I want to hear from social workers if they are team members in the program. If there are no social workers on the team then I would like to interview a nurse who would be familiar with services to patients and families. I am interested in how your program is structured, who is involved, and what interventions are used. I am interested in your experience in working with clients in a centralized outpatient cancer program (as opposed to in-patient/hospital). I want to know what people who have been involved in front line service related to caregivers of brain tumour patients within the past year think about:

- the needs of caregivers
- the delivery of care to caregivers through a structured program
- useful types of therapeutic interventions in the care of caregivers

It is my intention to arrange for a confidential telephone conversation with social workers (or nurses) who wish to participate. I anticipate that the interviews will last approximately 1to 1 1/2 hours. The interview would be arranged at a time most convenient for you. If possible, interviews will be scheduled between September and December 2009.

If you are interested in participating or obtaining additional information, please contact me by phone at 204.787.2189 or by email at orit.reuter@cancercare.mb.ca.

Thank you for your time and consideration of participating in this study.

Sincerely,

Orit Reuter, B.S.W.

Appendix C

Follow-Up Phone Call Script

Hello ________,

This is Orit Reuter calling. How are you? Is this a good time for us to talk?

I am the Master of Social Work student and I sent you a letter a couple of weeks ago telling you about my study interest in brain tumour patients and their family. This letter was inviting you to participate. Did you receive it?

Did you have a chance to read it?

Do you have any questions about the project?

Would you be interested in participating in the study?

If the “participant” is **not** interested: Thank you for taking the time to consider this project. Have a good day.

If the “participant” **is** interested: (I will answer his / her questions). When will be a convenient time for us to set a telephone interview?

(Once this time is determined) I will send the consent form to you to look at and I will phone you to further ensure everything is clear. Then we will proceed with the interview. Does this sound reasonable?

Thank you very much for taking the time to consider my request. I appreciate your interest very much. I will be in touch…….

Appendix D

Follow-Up Phone Call Script with Executive Director of Brain Tumour Foundation of Canada

Hello [name],

This is Orit Reuter calling. How are you? Is this a good time for us to talk?

As you know, I am in the Master of Social Work program at University of Manitoba and I sent you an email some time ago and a letter a couple of weeks ago telling you about my study interest in brain tumour patients and their family. This letter was inviting you to participate. Did you receive it?

Did you have a chance to read it?

Do you have any questions about the project?

Would you be interested in participating in the study?

If the "participant" is **not** interested: Thank you for taking the time to consider this project. Have a good day.

If the "participant" **is** interested: (I will answer his / her questions). When will be a convenient time for us to set a telephone interview?

(Once this time is determined) I will send the consent form to you to look at and I will phone you to further ensure everything is clear. Then we will proceed with the interview. Does this sound reasonable?

Thank you very much for taking the time to consider my request. I appreciate your interest very much. I will be in touch…….

Appendix E

Interview Guide

Note: The narrative will guide the interview/conversation. The main questions will be asked and will only be followed by prompts in order to elicit more information and detail. The prompts are depicted by *

1. Please tell me about your experience in your role in the neuro-oncology program and what it has meant in your life.

   *years in practice?
   *length of time working in neuro-oncology?
   *professional discipline?

2. Please tell me about the **nature of the service** that is provided in the case of brain tumour patients and families?

   *please **describe the process** whereby a patient is able to **access your clinic/program/service**

   *How are the pathological results conveyed to patients, caregivers and members of the health care team?

   *How are patients treated medically?

   *Are services provided, in your program, by a **health care team?**

   *Please describe the **composition of the team** – their **professional affiliation?**

   *Please describe their **roles** and if and how they relate to caregivers?

3. Please describe the **services provided** to caregivers in the neuro oncology program?

   *What specific **interventions** do you use for caregivers
   *what do they receive in the way of information and concrete training?

   *Please describe to me the **needs** of the caregivers?

   *Can you tell me about:

   - social support
   - financial issues
   - emotional needs
   - prevention of complicated grief

- continuity of care

*Are there any differences in the way the team responds to caregivers who are:

- young/ old,
- female/male
- with multiple roles
- with health issues
- culturally diverse
- non English speaking/ English as additional language?
- multi generational legacies of illness

4. In your view, do caregiver needs **change over time**? If so, can you tell me how?

*how are changing needs addressed / met?

*how important are caregivers' subjective understanding of events?

*how are caregivers' subjective assessment accommodated by your program?

5. Are there any kinds of **services** in your program that are **mandated to caregivers**?

*do you use screening tools? If so, what kinds of screening tools do you use?

*does your program run caregiver support groups? educational groups?

*does your program provide individualized training and / or counseling sessions

6. How do you think the service to caregivers can be improved?

*are there **specific processes** that you recommend?

*best practice guidelines

*accreditation

*increased resources

7. Could you please speak to me about the challenges you experience in doing this job in relation to caregivers?

8. Are there any other comments you would like to add?

Appendix F

Interview Guide for Executive Director of Brain Tumour Foundation of Canada

Note: The narrative will guide the interview/conversation. The main questions will be asked and will only be followed by prompts in order to elicit more information and detail. The prompts are depicted by *

1. Please tell me about your experience with the Brain Tumour Foundation of Canada in relation to caregivers.

   *mission statement of the organization

2. Please tell me about services for caregivers of brain tumour patients across the country?

   *what are the identified needs?

3. Please tell me about any programs across the country that are particularly active in providing services to caregivers?

4. What are the emerging trends across the country in relation to providing services to caregivers and families of brain tumour patients?

5. What suggestions do you have for formal neuro-oncology programs?

6. Is there anyone else across the country with whom you recommend I speak on this topic?

7. Is there anything else that you wish to tell me about that we have not covered?

Appendix G

Table of Concept of Operationalization

Concept	Dimension	Category
1. PMBT grade	Low grade	Pathological result -disease entity High
2. Caregiver needs	2.i COC	2.i.1 confidence /needs change over time (responsiveness of changes by the system)
	2.ii info/concrete training	2.ii.1 self-efficacy (ability to participate in decision mkg from knowledge base-informed decision) **Meaning**
		2.ii.2 demonstrates assessment skills
		2.ii.3 cg attendance at appt & involvement with > engagement vocation, multiple roles
		2.ii.4 understanding implication of dx
	2.iii social support	2.iii.1 resource awareness
		2.iii.2 accessibility to resources /willingness to access
		2.iii.3 social stigma/ isolation
		2.iii.4 self-care
	2.iv Financial	2.iv.1 employment absenteeism/interruption
		2.iv.2 financial drain (relocation for tx) -income replacement benefits
	2.v Emotional	2.v.1 Coping (being able to mge the process as it unfolds) Dimensions of coping: **Negative**: Depression, anxiety, burden/ multiple role **Positive** impact of caregiving
	2.vi Prevention of complicated grief	2.vi.1 normal bereavement (ability to carry on)
	2.vii Mediating factors	2.vii.1 Age, gender, multiple roles, health
3. Program Structure	3.i Composition	3.i.1 Staff members, #, type
		3.i.2 Roles-what do they do (lit rev-sw as case magr)
	3.ii Adm. Referral process to neuro/onc program	3.ii.1 Referral process to various disciplines out pt, in pt, ambulatory ccmb/auto
	3.iii Inclusion of cg	3.iii.1 Process-what are the mechanisms that involve cgs) how do they participate
	3.iv Team function (medical focus on pt / cg	3.iv.1 Rds, referral, family mtgs., reviews -what do the rds address -are cg needs/issues addressed -is the referral process inclusive of cg -who does the team focus on

		-how well does the team function
4. Prog. Intervention aimed at cg	4.i Screening	4.i.1 -tools -process: frequency
	4.ii Assessment	4.ii.1 –Process / is this done -tools
	4.iii Individual	4.iii.1 –Resource availability -how often/frequency, focus/modality (crisis intervention, brief solution, cbt, relaxation, location (OPD, ER, In-pt)
	4.iv Groups	4.iv.1 –support feature: ed, peer, psycho-ed
	4.v Telephone	4.v.1 –nature and level of support (crisis or on-going, education, urban/rural) is this a routine service, how soon are phone calls returned

Appendix H

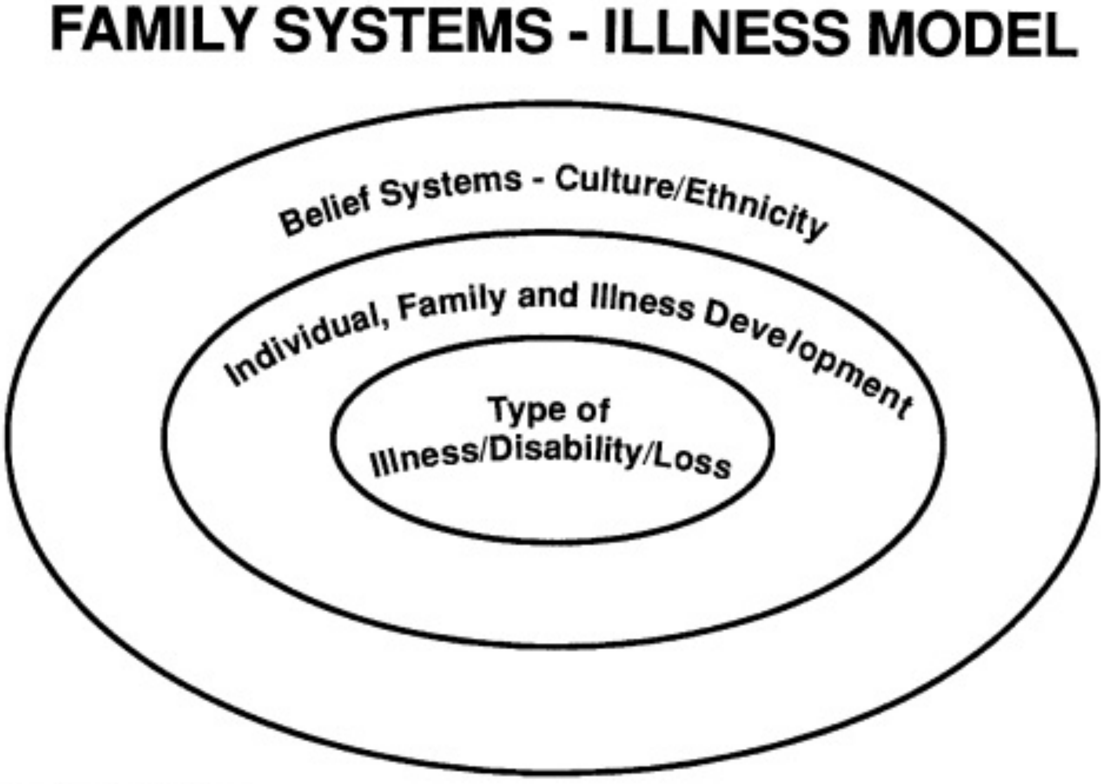
Recruitment Contact List

I will be contacting every provincial health ministry in order to locate ambulatory neuro-oncology programs. I have also contacted the Brain Tumour Foundation of Canada for their assistance in locating the desired programs.

The following are the provincial websites I will contact:
Alberta: www.albertacancerboard.ab.ca
BC: www.bccancer.bc.ca
NB: www.gnb.ca/0051/cancer/index-e.asp
NS: www.cancercare.ns.ca
NFLD: www.easternhealth.ca.nctrf/about
Nunavut: www.gov.nu.ca/health
ON: www.cancercare.on.ca
www.pencerbraintrust.com/index.htm
www.uhn.ca
QUE: www.mni.McGill.ca
www.infoneuro.McGill.ca
Sask: www.saskcancer.ca
Yukon: www.ykhealthguide.org

Appendix I

Rollands' (2005)



American Cancer Society

Figure 1. The Family Systems Illness model. Adapted from Rolland JS. Families, illness, and disability: an integrative treatment model. New York: Basic Books, 1994.[18]

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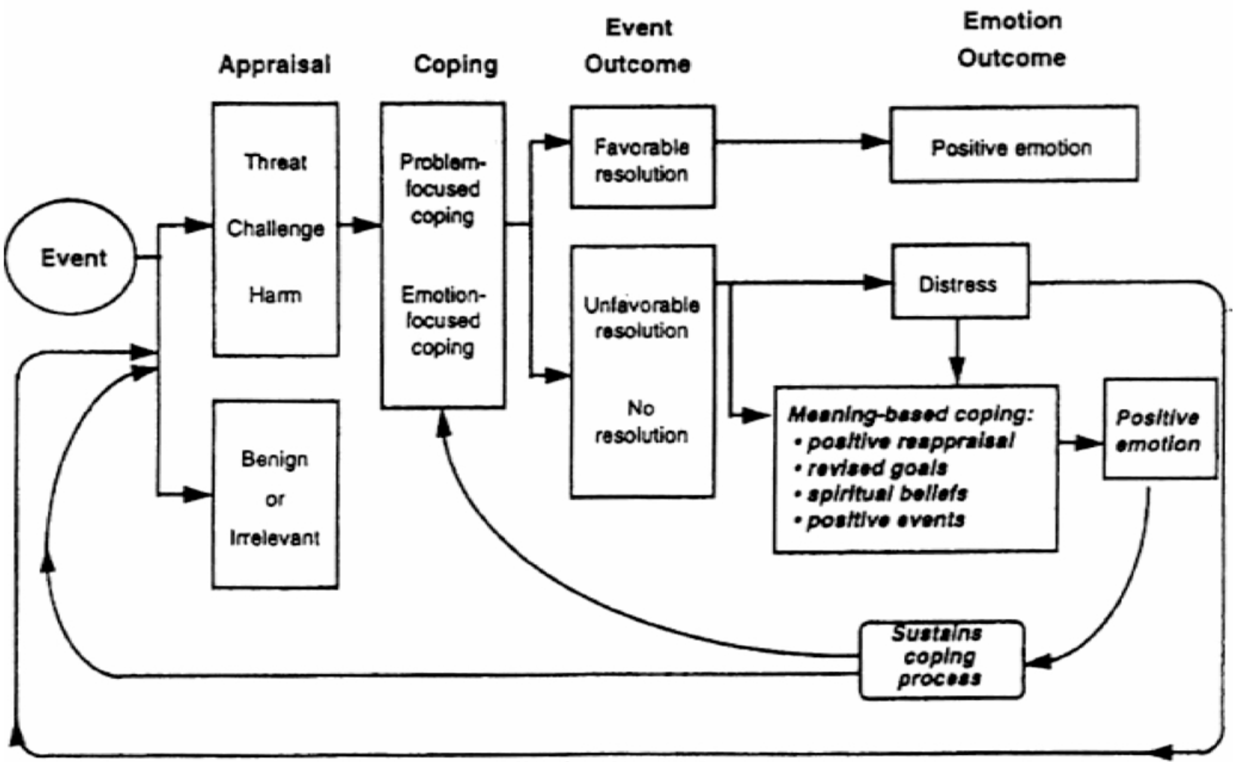
Appendix J

Hudson’s (2003) Supportive Intervention model



Revised model

Refinement of Lazarus and Folkman's (1984) original stress and coping model. Reprinted from Folkman (1997) with permission of Elsevier Science.

Used with permission from Cambridge University Press. Permission obtained Januray 29, 2011.

Appendix K

Sherwood et al., (2004) Family Care model

P Sherwood et al.

30

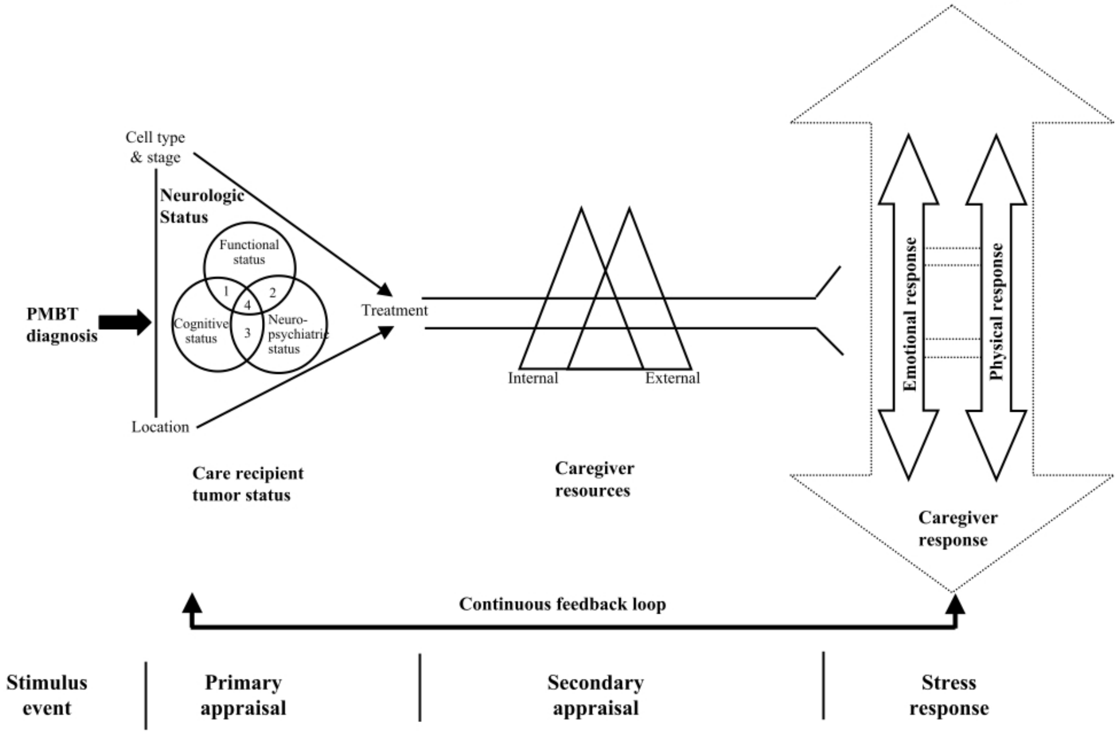


Figure 1 Family care of persons with a brain tumor.

Used with permission from John Wiley and Sons. Permission obtained January 29, 2011.

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Footnotes

[1] Cumulative Index to Nursing & Allied Health Literature (CINAHL), PubMed, PsycINFO, Social Services Abstracts, Social Work Abstracts and Social Sciences Citation Index (Web of Science), MeSH. A combination of key words and subject headings used included tumour or tumour, glioma, cancer, brain, caregiver, family caregiver, terminal, acute, needs and death, dying, end of life, interventions, social work or social workers, team, multidisciplinary, interdisciplinary, program, programme, and patient care team. I also attempted to look at the Disease Site Group policy at CancerCare Manitoba, as another source to add to program information.