

CAREGIVING FOR LOVED ONES WITH A BRAIN TUMOUR

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ABSTRACT

This study sought to examine the experiences of family caregivers of people with brain tumours. Fourteen family caregivers participated in an interview and filled out a questionnaire battery aimed at understanding their caregiving experiences, including areas such as demands, needs, burden, and use of resources. The interviews were transcribed and analyzed using a phenomenological perspective. Descriptive statistics of the questionnaire data were used to supplement the qualitative findings. The qualitative analysis resulted in a fundamental structure of caregiving for a loved one with a brain tumour that included the themes of making adjustments, being a health care paraprofessional, being a source of support, and having needs. Other themes that emerged from some but not all protocols included issues related to respite, questioning caregiver skills, and a desire to help other caregivers. The findings of this research have implications for support services aimed at helping these caregivers carry out their role and cope with their experiences.

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INTRODUCTION

Statistics indicate that over 136,000 new cases of cancer were expected to be diagnosed in Canada in the year 2002, and the comparable estimate for British Columbia was over 17,000 (National Cancer Institute of Canada, 2002). The diagnosis of cancer not only impacts patients but also the families of these patients. Family members must face the demands of the illness itself and are also the main source of emotional support for patients (Cassileth et al., 1985; Lewis, 1986). Family adjustment occurs in three stages as reviewed by Stetz (1987). The first stage revolves around personal concerns and symptoms at the time of initial diagnosis. The second stage involves the patient becoming more dependent on the family as the illness progresses. The third stage involves total dependency of the patient on the family at the terminal phase of the illness.

The effects of cancer on the family are especially evident as patients become increasingly cared for at home due to the chronic nature of cancer and the changing health care system's reliance on outpatient care (Given, Given, & Kozachik, 2001; Hileman, Lackey, & Hassanein, 1992; Houts, Nezu, Nezu, & Bucher, 1996; Laizner, Yost, Barg, & McCorkle, 1993; Schumacher, Dodd, & Paul, 1993). Those individuals in patients' social networks who take responsibility for helping patients with the physical aspects of care as well as providing support in coping with the disease are known as family caregivers (Blank, Clark, Longman, & Atwood, 1989; Hileman & Lackey, 1990; Houts et al., 1996; Laizner et al., 1993; Thomas, 1993). These caregivers are often immediate family members but may also be other relatives, friends, or volunteers (Houts

et al., 1996). Family caregivers have become important members of the health care team in managing cancer.

The acquisition of the caregiving role occurs when the cancer patient's ability to care for him/herself is reduced as a result of the illness and consequently help is needed from others (Schumacher, 1995). Loved ones of a person with cancer are affected by the difficulties experienced by that person. When a loved one starts giving care to the person with cancer, the caregiving is motivated by an emotional attachment and may involve a long-term commitment (Yates, 1999). Other factors influencing role acquisition include feelings of family obligation (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Collins, 1995), demographics, family structure, the nature of family relationships, situational factors such as competing roles and responsibilities, societal norms, and available resources within social and community networks (Aneshensel et al., 1995; Schumacher, 1995). Once acquired, the caregiving role is a dynamic one. As the health of the care recipient changes, so do the behaviours and attitudes of the caregiver (Schumacher, 1995).

Literature Review

The caregiving literature to date has focussed on three main areas. One area of study involves the tasks and demands of caregiving; in other words, these studies focus on what caregivers actually do. Second, the majority of research on family caregivers of cancer patients has focused on the impact of caregiving and on variables that moderate the degree of impact. Finally, a third area of research investigates caregivers' needs with respect to carrying out their role. A summary of these areas of research is presented below.

Caregiving Demands

What caregivers actually do and how well they do it contributes greatly to patient care and well-being (Brown & Stetz, 1999; Thomas, Morris, & Harman, 2002). The demands or tasks of caregiving have been classified in different ways by different researchers, but generally fall into three main areas: care work, emotion work, and other role demands. Past research involving interviews with caregivers of breast, colorectal, lung, and lymphoma patients (Thomas et al., 2002) and advanced cancer patients (Brown & Stetz, 1999; Rose, 1998; Stetz, 1987) identifies some of the specific tasks involved with each of these three areas. Care work involves those tasks directly associated with managing the illness. Family caregivers are expected to transform themselves into "health care paraprofessionals" (Ruppert, 1996, p. 41) and as such their role includes helping with activities of daily living such as washing, dressing, and toileting (Rose, 1998; Thomas et al., 2002), arranging and attending appointments, providing transport (Thomas et al., 2002), dealing with the health care system (Brown & Stetz, 1999), and managing treatment regimens (Stetz, 1987). Emotion work for caregivers includes managing feelings, both their own and those of the patients. This type of work might entail being strong (Thomas et al., 2002), trying to understand the situation both presently and in the future (Rose, 1998; Stetz, 1987), preparing for death (Brown & Stetz, 1999), standing by (Stetz, 1987), and making sure that patients do not feel alone (Thomas et al., 2002). Finally, caregivers must also deal with the demands of their other roles. For example, they may carry out household duties such as cooking, cleaning, and finances (Rose, 1998; Stetz, 1987; Thomas et al., 2002) as well as tasks related to work or childcare (Rose, 1998).

The time and energy spent carrying out these tasks varies. Studies of caregivers of radiotherapy patients (Oberst, Thomas, Gass, & Ward, 1989) and chemotherapy patients (Carey, Oberst, McCubbin, & Hughes, 1991) found that the greatest time expenditure was associated with providing transportation, giving emotional support, and doing extra housework. On the other hand, tasks such as helping with personal care, mobility, or treatments were less demanding. Not surprisingly, both studies also found that time demands were higher for caregivers when their loved ones were more dependent. When asked how difficult it was to carry out various tasks, providing emotional support was found to be the most difficult activity (Carey et al., 1991).

The Impact of Caregiving

The energy that caregivers expend in the process of caring for the ill patient may leave few resources to care for themselves and thus their own health may be compromised (Steele & Fitch, 1996; Wilson, 1987). This impact that caregivers experience is often referred to as caregiver strain or burden. It encompasses disruptions in the caregiver's life as well as attitudes or reactions to caregiving (Montgomery, Gonyea, & Hooyman, 1985; Siegel, Raveis, Mor, & Houts, 1991). Several studies (Ferrario, Zotti, Massara, & Nuvolone, 2003; Flaskerud, Carter, & Lee, 2000; Gilbar, 1994; Given et al., 1993; Hinds, 1992; Jensen & Given, 1993; Mor, Allen, & Malin, 1994; Oberst & James, 1985; Oberst et al., 1989; Payne, Smith, & Dean, 1999; Stetz, 1987; Weitzner, Meyers, Steinbruecker, Saleeba, & Sandifer, 1997) and two reviews of the literature (Kristjanson & Ashcroft, 1994; Lewis, 1986) have identified specific types of burden experienced by family caregivers of loved ones with cancer. The types of disruptions caregivers experience in their lives include family role changes and conflict,

restriction of roles and activities (e.g., in their work or social life), additional role responsibilities related to the patient (e.g., accompanying loved ones to appointments), and financial strain. The emotional and physical strains associated with caregiving include distress, depression, anxiety, fear, anger, uncertainty, fatigue, sleep disturbances, and diminished physical health.

A great deal of literature has investigated the relation between patient, caregiver, and illness characteristics and caregiver strain and burden. Results vary due to the wide range in predictor and outcome variables incorporated in different studies. For example, a study of caregivers of new and recurrent patients found that recurrent disease was associated with greater depression, but was not associated with impact on caregiver's health or daily schedule (Given, Given, Helms, Stommel, & DeVoss, 1997). Results for certain correlates have also been inconsistent. In studies of caregivers of patients with laryngeal cancer (Blood, Simpson, Dineen, Kauffman, & Raimondi, 1994), colorectal cancer (Nijboer et al., 2000), terminal cancer (McMillan & Mahon, 1994; Payne et al., 1999), and mixed tumour types (Hagedoorn, Buunk, Kuijjer, Wobbes, & Sanderman, 2000; Matthews, Baker, & Spillers, 2003; Morse & Fife, 1998) female caregivers reported more strain and burden than male caregivers. However, in studies of caregivers of colorectal patients (Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999) and patients of mixed tumour types (Ferrario et al., 2003; Schott-Baer, 1993) no gender differences were found for burden.

Several other variables have been associated with burden. Greater burden has been associated with younger patients (Kurtz, Given, Kurtz, & Given, 1994; Schumacher et al., 1993), increased patient symptomatology (Given et al., 1997; Given et al., 1993; Siegel, Raveis, Mor, et al., 1991), greater patient dependency (Carey et al., 1991; Given

et al., 1997; Given et al., 1993; Nijboer et al., 1999; Schumacher et al., 1993), and decreased patient mobility (Given et al., 1997; Given et al., 1993; Kurtz, Kurtz, Given, & Given, 1995; Siegel, Raveis, Mor, et al., 1991). Caregivers also report greater burden as the patient's stage of illness progressed (Kurtz et al., 1994), and with recurrent or metastatic disease (Morse & Fife, 1998). With respect to caregiver characteristics, those who are younger (Carey et al., 1991; Mor et al., 1994; Nijboer et al., 2000; Schott-Baer, 1993; Weitzner et al., 1997), less educated (Cameron, Franche, Cheung, & Stewart, 2002; Ferrario et al., 2003; Oberst et al., 1989), have a lower socio-economic status (Nijboer et al., 1999; Oberst et al., 1989), and are in poor health themselves (Carey et al., 1991; Oberst et al., 1989) report greater burden. Furthermore, caregivers report increased levels of burden with less time spent in the caregiving role (Blood et al., 1994; Nijboer et al., 2000). More research is needed to clarify the relationships between patient, illness, and caregiver characteristics and caregiver burden.

Caregiver Needs

Given the burden reported by caregivers, they may not have the resources necessary or available to deal with potential stressors or problems, and therefore may have unmet needs (Hinds, 1985). A need has been defined as "a condition that is important to the subject and that is not being satisfied in the subject's present environment" (Northouse, 1989; cited in Hileman et al., 1992, p. 772). Studies indicate that cancer patient family caregivers' greatest needs include issues related to patient care such as obtaining information regarding illness and treatment, finding ways to combat symptoms, and taking care of household responsibilities (Eriksson & Lauri, 2000; Googe & Varricchio, 1981; Grande, Todd, & Barclay, 1997; Grobe, Ahmann, &

Ilstrup, 1982; Harrington, Lackey, & Gates, 1996; Hileman & Lackey, 1990; Hileman et al., 1992; Hinds, 1985; Longman, Atwood, Sherman, Benedict, & Shang, 1992; Morris & Thomas, 2001; Rose, 1999; Silveira & Winstead-Fry, 1997; Soothill et al., 2001; Stetz & Hanson, 1992; Watt-Watson & Graydon, 1995; Wingate & Lackey, 1989; Wong et al., 2002; Wright & Dyck, 1984). Psychological needs such as ways of coping with the illness, stress, depression, and fear are also identified as important (Blank et al., 1989; Hileman & Lackey, 1990; Hileman et al., 1992; Hinds, 1985; Soothill et al., 2001; Steele & Fitch, 1996; Watt-Watson & Graydon, 1995; Wingate & Lackey, 1989; Wright & Dyck, 1984). Other caregiver needs include interacting with family and friends (Blank et al., 1989; Hileman & Lackey, 1990; Longman et al., 1992; Silveira & Winstead-Fry, 1997), and taking care of personal needs and responsibilities including respite (Blank et al., 1989; Grobe et al., 1982; Steele & Fitch, 1996).

As was the case with caregiver burden, caregiver needs have been shown to vary with various patient and caregiver characteristics: patient disease stage (Harrington et al., 1996; Soothill et al., 2001; Wright & Dyck, 1984), time since diagnosis, patient activity level, living arrangement, caregiver income, and caregiver age (Hileman et al., 1992), as well as spousal role (husband vs. wife) (Soothill et al., 2001; Stetz & Hanson, 1992).

The Current Study

Previous research of family caregiving in oncology has focussed on samples that include a variety of different tumour types or those with terminal or advanced stage cancers. Given the wide range in cancer diagnoses and prognoses that exist, intuitively one might expect that there would be variability in the experience of caregiving. For

example, does the caregiving experience differ for those who care for loved ones with colorectal cancer versus pancreatic cancer or for those with curable versus terminal illness? The focus of the current research is on caregiving for loved ones with brain tumours. Little research exists that focuses specifically on the experience of caregivers of brain tumour patients. One study indicated that relatives of brain tumour patients may experience poorer psychological status compared to relatives of patients with other tumour types, but these findings were based on a small sample (Cassileth et al., 1985).

Primary brain tumours account for 3% of all tumours (BC Cancer Agency, 1999d) and therefore constitute a small population compared to other tumour sites such as lung, breast, or prostate. The experience of those individuals caregiving for loved ones with brain tumours is of interest for several reasons. First, brain cancer has been classified as having a poor prognosis based on the fact that for every 100 new cases estimated to occur in a year, 66 deaths from brain cancer are estimated in that same year (National Cancer Institute of Canada, 2002). In fact, the average life expectancy for some patients is no more than five years (BC Cancer Agency, 1999b; BC Cancer Agency, 1999c); and for high grade malignancies half of patients survive one year after surgery and few patients survive beyond two years (BC Cancer Agency, 1999a). Thus, the journey for brain cancer patients and their families is a potentially rapid one where much may be experienced in a short period of time. Second, depending on the tumour's location in the brain, caregivers may need to deal with changes in their loved one's personality, physical or motor functioning, sensory functioning, and cognitive functioning (BC Cancer Agency, 1999d; Curren, 2001). Third, this population of family caregivers appears to be an understudied one, possibly due to their relatively small numbers. The support available to this small group of patients and their families may be limited and difficult to

access (Curren, 2001). In British Columbia in 2002 nearly 300 newly diagnosed individuals and their families (National Cancer Institute of Canada, 2002) as well as those already living with the illness may be in need of support. For all these reasons, the experience of caregivers of loved ones with brain tumours warrants better understanding.

Original Objectives

Originally, the aim of this study was to find ways to reduce caregiver burden for caregivers of loved ones with a brain tumour. Presumably, a major source of the strain and burden that caregivers experience is in failing to meet their needs, either those related to their personal needs or those directly related to patient care. In other words, they may be faced with a problem, not have the resources to meet the demands that their roles entail, and subsequently experience a negative impact. Caregivers who find ways to meet their needs should be affected less negatively, and this more positive state of being should have beneficial effects for their patients. Part of the strain may be lessened by providing services or intervention programs that address the perceived needs of caregivers (Harrington et al., 1996; Northouse & Peters-Golden, 1993; Wingate & Lackey, 1989). Thus, the first step in this direction would involve identifying the specific needs of caregivers (Grobe et al., 1982; Steele & Fitch, 1996).

As reported above, the impact of caregiving and caregiver needs have been investigated previously. However, the association between unmet needs and impact has not been established. If these unmet needs were found to have a negative impact on caregivers, then it would also be important to identify those patient and caregiver characteristics that might predict which caregivers have unmet needs so that these

people could be directed to appropriate intervention programs. Finally, in an effort to help structure intervention programs, the original study also aimed to better understand caregivers' specific resource needs. The study would determine what services were utilized and obtain perspectives on the types of education and support programs that caregivers would find most useful in addressing their unmet needs.

The purpose of the original research study was therefore to guide future interventions for caregivers by gaining a better understanding of caregivers' needs and the impact that unmet needs may have on caregivers and their patients. Based on the issues addressed above, the original objectives were to:

1. Identify the needs that caregivers considered important and their current level of satisfaction with how these needs were met. Specifically, unmet needs (i.e., those that were important but not satisfied) would be identified.
2. Determine the relationship between caregivers' unmet needs and caregiver outcome. It was hypothesized that those caregivers whose important needs were not being met would experience greater burden and decreased well-being.
3. Identify those disease and caregiver characteristics that predict unmet need.
4. Explore caregivers' perspectives regarding the type of help they would find useful to address their unmet needs.

Revised Plan and Objectives

The original methodology for this study included both a quantitative (based on questionnaire data) and a qualitative (based on interview data) component. The aims of the study were revised due to difficulties encountered during the data collection phase. Over the first six months only five interviews were completed. Specific recruitment

difficulties revolved around caregivers feeling they could not take the time to participate or feeling too overwhelmed to participate. As well, the health care professionals who were recruiting the caregivers sometimes were not able to introduce potential participants to the study due to the hectic schedule of the clinic. At other times the staff chose to protect individuals by making the decision not to approach them (e.g., in cases where patients and/or families were being notified of a recurrence during their appointment). After several months of data collection indicated that the required sample size would not be obtained, a decision was made to focus on the qualitative component of the study. In total, 17 individuals were interviewed over a period of 30 months. In the revised plan, the interviews became the focus and the use of questionnaires for predictive purposes was abandoned. Instead, the questionnaire data was used for descriptive purposes to supplement the qualitative results.

Focussing on the qualitative and more exploratory aspect of the study was justified since little research had been done on family caregivers of brain tumour patients. Thus, it is not known what their experiences are or whether their experiences differ from those caregivers who have been studied previously. The main objective of the revised study was to gain an understanding of what the experience of caregiving for a brain tumour patient is like. Many qualitative strategies exist for analyzing interview data. Grounded theory, for example, involves the formulation of a theory about people's experiences from concepts that emerge from the data (Ryan & Bernard, 2000). This approach was not appropriate for the current study because theory generation was not the aim. Ethnography, on the other hand, aims to describe a cultural or social group using data gathered from spending extensive time in the field with the group of interest

(Creswell, 1998); this was not applicable to the current study. The method of inquiry chosen for this research project was phenomenology.

Phenomenology is aimed at understanding the phenomenon of interest and to determine its essential or fundamental nature, not to look for correlations or causation (Dukes, 1984). The phenomenon is explored through the experiences of individuals and the meaning that they attribute to these experiences of their life events (Becker, 1992). The approach has been used in the social sciences, including psychology (Creswell, 1998). This particular qualitative method fits with the researcher's goal of exploring, through the caregiver's own words, the experience of caregiving for brain tumour patients. Three main areas of exploration were of interest:

1. What do family caregivers of brain tumour patients do in carrying out their roles?
2. What types of needs do caregivers have?
3. What resources have they used to help them and what resources do they need?

These research questions served as a guide for the study and, in particular, the interview questions.

METHOD

Participants

Participants consisted of 16 family caregivers of loved ones with primary brain tumour diagnoses. Two caregivers were deleted from the sample due to technical difficulties with the interview audiotape, leaving a final sample of 14 caregivers. A brief profile of each individual caregiver is presented in Table 1 and a summary of the sample is provided here. The sample consisted of 6 male and 8 female family caregivers. Caregivers had a mean age of 53 years ($SD = 11$). The majority of caregivers had a post-secondary education ($n = 8$) and worked full-time ($n = 7$). All caregivers were of European descent.

Table 1:

Profile of Participants

Caregiver Pseudonym	Relation to Patient	Caregiver Age	Length of Time Caregiving	Patient's Tumour Type
John	Spouse	50-59	> 5 years	Malignant
Linda	Spouse	40-49	< 1 year	Malignant
Robert	Spouse	40-49	< 1 year	Malignant
Barbara	Spouse	30-39	> 5 years	Benign
Charles	Spouse	60-69	1-5 years	Malignant
Susan	Spouse	40-49	> 5 years	Malignant
Mary	Spouse	50-59	1-5 years	Malignant
Kathy	Spouse	50-59	< 1 year	Malignant
Richard	Spouse	70-79	< 1 year	Malignant
Michael	Spouse	60-69	< 1 year	Malignant
Nancy	Relative	60-69	> 5 years	Malignant
Thomas	Spouse	30-39	1-5 years	Benign
Sandra	Relative	40-49	< 1 year	Malignant
Patricia	Spouse	50-59	< 1 year	Malignant

The majority of the caregivers were spouses/partners ($n = 12$) and were living with their loved ones with a brain tumour ($n = 12$). Caregivers had been carrying out their caregiver roles for a median length of 1.1 years (range = 1.5 months to 17.5 years). Twelve of the caregivers' loved ones had malignant tumours (specifically, gliomas, which are the most common type of primary tumour) and two of the loved ones had benign primary tumours.

Procedure

Ethics approval for the study was obtained from all organizations involved, namely Simon Fraser University (see Appendix A), the British Columbia Cancer Agency, and the Vancouver Hospital and Health Sciences Centre. A convenience sample of participants was recruited through the Cancer Agency brain tumour support groups and outpatient clinics in Vancouver and Victoria, as well as through the oncology practice of a neurosurgeon from Vancouver Hospital and Health Sciences Centre. Depending on the particular location, a nurse, social worker, or physician made the initial contact with potential participants. In cases where the researcher was present, she introduced the study to the caregivers. Otherwise the individuals were asked to contact the researcher by telephone or provide a phone number where the researcher could contact them.

After the purpose of the study was explained to caregivers, interested individuals were given the option of participating either in the questionnaire portion of the study only, or both the questionnaire and interview portions. For the questionnaire only group, questionnaires were distributed to individuals (either in person or by mail), completed at home, and mailed back to the researcher. Those individuals who were also willing to participate in the interview portion of the study were scheduled for interviews. Interviews

took place at a mutually convenient location. After signed informed consent was obtained, audiotaped interviews were conducted. At the completion of the interview, these participants were given a questionnaire package that they were asked to complete at home and then mail back to the researcher.

The exact response rate is difficult to determine due to the nature of the recruitment. That is, initial contact persons did not record which eligible individuals were or were not introduced to the study. Automatic introductions to all eligible caregivers may not have occurred for several reasons, the most common of which would have been inappropriate timing as judged by staff and busyness of the clinic. In total, the researcher had contact information for 42 individuals. Of these, 10 individuals declined (by virtue of not returning questionnaires or phone calls), 3 individuals agreed to participate but later declined because they felt overwhelmed by their situation, 12 individuals completed only the questionnaire portion of the study, 1 individual took part in an interview but then asked to be removed from the study, 1 individual took part in an interview but did not return the questionnaire, and 15 individuals completed both the interview and questionnaire portions of the study. Because the interview became the main focus of the current study, the sample consisted of those 15 individuals who completed questionnaires and interviews and the 1 individual who completed only the interview.

Measures

Interview

A semi-structured interview was conducted with caregivers to explore their caregiving experiences. The interview guide included the following questions.

1. Tell me as much as you can about the diagnosis and treatment.
2. Take me through a "typical" caregiving day: If I followed you around, what would I see you doing, what would you be feeling? Describe what you are experiencing, what it is like for you.
3. How has the experience of caregiving changed for you over time?
4. What are some of the most difficult challenges you have faced as a caregiver?
5. What would you say are the most important needs you have as a caregiver right now? In the past?
6. Which of these important needs are not being satisfied?
7. What resources do you know of for family caregivers?
8. What sorts of things have you done to help you carry out your role as a caregiver?
9. What kinds of help would you like to see available to you?
10. If I were a new family caregiver of a person with a brain tumour, what would be the most important piece of advice you could give me? What about your experience would you most want to share with me?

Participants were encouraged to speak freely about their experiences. Therefore, the researcher gauged the content of the interview as it proceeded and determined whether questions had to be specifically posed to the caregiver or not, based on whether the

topics of interest had been covered. The interview typically was 60 to 90 minutes in duration.

Questionnaires

The questionnaire package included measures designed to gather demographic and illness information and to assess caregiver's current levels of demand, need, burden, competence, and mood.

Demographic and Illness Information

A set of questions was developed to gather demographic information such as gender, age, ethnic/cultural background, marital status, education, employment status, and income. Information about the caregiving situation was also obtained: the caregiver's relationship to the family member with cancer (i.e., spouse, parent, child, etc.), living arrangements with respect to patient, and length of time in caregiver role. Finally, caregivers were asked to provide information about their loved one's illness: date of diagnosis, disease stage, and type of cancer.

Caregiving Demands

Caregivers were asked to directly assess the extent or demands of their caregiving using a modified version of the demand subscale of the Caregiving Burden Scale (Carey et al., 1991). This measure assesses the time spent in 14 caregiving activities including giving emotional support, managing illness-related finances, doing housework, and providing transportation. Each activity is rated on a five-point scale ranging from "little or no" time to "a great deal" of time spent in the activity. The caregiving activities have been validated and the scale has demonstrated internal consistency reliability ($\alpha = .83$).

Caregiver Needs

The Home Caregiver Need Survey (HCNS; Hileman et al., 1992) contains 90 items assessing six categories of need: psychological, informational, patient care, personal, spiritual, and household. Psychological needs include items such as ways to cope with feelings such as depression and anger, ways to maintain a normal family life, and ways to encourage the loved one with cancer. Informational needs include those related to the illness, treatment side-effects, symptoms, and medications. Sample patient care needs address issues such as patient independence, comfort, and nutrition. Personal needs include items such as rest, continuing social activities, and support from friends and family. The spiritual items address needs such as church support, faith, and hope. Finally, items related to the household include needs for help with housework and transportation as well as needs for a caregiver hotline and support group. Caregivers rate the importance of each need and their satisfaction with how each need is being met at the current time. Scoring specifically allows for the identification of those needs which are rated to be important but not satisfactorily met. The HCNS was developed for home caregivers of cancer patients, and is therefore well-suited for the current sample. Work with the HCNS (Hileman, 1989; cited in Hileman et al., 1992) has indicated internal consistency reliability (Cronbach's $\alpha = 0.93$ for the overall measure and $\alpha = 0.87$ to 0.97 for the various need dimensions). A panel of experts indicated that the measure was face and content valid, and principal factor analysis confirmed the multidimensional structure.

In addition to the HCNS, the researcher included an additional question about the relative importance caregivers placed on their needs versus those of their loved ones. They were asked to indicate whether they felt that fulfilling their loved one's needs was

“much more important, somewhat more important, just as important, somewhat less important, or much less important” than taking care of themselves and their own needs.

Caregiver Outcomes

Burden was assessed using two measures. The Burden Interview (Zarit, Reever, & Bach-Peterson, 1980) is a 22-item instrument that assesses the stressors and amount of perceived burden experienced by caregivers. For each of the items, respondents indicate how often they felt a certain way on the scale "never, rarely, sometimes, quite frequently, or nearly always". Internal consistency and test-retest reliability have been established, and validity was estimated by correlating the measure with a global rating of burden ($r = 0.71$). In addition, two scales from the Caregiver Reaction Assessment (Given et al., 1992) were used: Impact on Health and Impact on Schedule. These scales were initially developed for caregivers of patients with chronic physical and mental impairments and have been used with caregivers of cancer patients. Reliability estimates for the internal consistency of these two scales have been reported to be $\alpha = 0.82$ and 0.80 , respectively.

The Derogatis Affects Balance Scale (DABS; Derogatis, 1975) is a 40-item questionnaire that assesses both positive and negative aspects of mood. The positive dimensions include joy, contentment, vigor, and affection. The negative dimensions include anxiety, depression, guilt, and hostility. The DABS has demonstrated acceptable internal consistency ($\alpha = .79$ to $.94$) and test-retest ($r_{tt} = .78$ to $.84$) reliability. Principal components analysis confirmed the “majority of hypothesized constructs” and the DABS has also demonstrated good predictive validity.

The Caregiver Competence Scale is a 4-item measure developed by Pearlin and colleagues (1990). It asks caregivers to rate the adequacy of their performance by rating their level of competence, self-confidence, how much they have learned to deal with a difficult situation, and how much they feel that all in all they are a good caregiver. The scale has been found to be reliable ($\alpha = .74$) (Aneshensel et al., 1995).

Data Analysis

Interviews were transcribed verbatim except that nonessential phrases such as “um” were deleted as were repetitious words or stuttered starts to words that occur in the course of normal conversational speech (e.g., the the radiation, rad-radiation). Excerpts from participant protocols that are reproduced in this report for illustrative purposes have been modified to protect the confidentiality of participants. Thus, pseudonyms are used and unique identifying information is omitted.

Several phenomenological methodologies exist to analyze interview data. Polkinghorne (1989) reviewed three different methods and concluded that they employed a similar series of steps: (1) Protocols are divided into units; (2) Units are transformed by the researcher into meanings expressed in psychological and phenomenological concepts; and (3) Transformations are tied together to make a general description of the experience. The methodology employed to analyze the transcripts in the current study is based on one developed by Colaizzi (1978). This particular method was chosen over others for both practical and theoretical reasons. For example, in Colaizzi's methodology the researcher can perform the qualitative analysis of the data herself. van Kaam's methodology, on the other hand, uses multiple independent judges to analyze the data (Polkinghorne, 1989); this was not seen as a

feasible endeavor for the current study. The emphasis in Colaizzi's method is in seeking universal essences of an experience. This contrasts with one such as Giorgi's which is interested in seeking more context- or situation-specific descriptions (Polkinghorne, 1989). This was not appropriate in the current study given the small number of participants.

Colaizzi notes that researchers should feel free to modify his methodology in order to best suit the needs of the researcher, and, in fact, minor changes were made for the purposes of this study. The steps of the analytical protocol are outlined below and modifications are noted where applicable. These steps were used to formulate a description of the phenomenon of interest, namely the experience of caregiving for loved ones with a brain tumour.

1. All the participants' descriptions (protocols) were read to acquire familiarity with them.
2. For each protocol significant statements were extracted. These statements were phrases or sentences that directly pertained to the phenomenon. Although Colaizzi suggests that statements that contain the same or nearly the same content could be eliminated, all significant statements were retained.
3. Meanings were formulated for each significant statement. Here the purpose was to determine what participants mean by what they have said.
4. Clusters of themes emerging from formulated meanings that were common to all protocols were organized. It should be noted that these theme clusters represent structural similarities among all the protocols. However, the particular way in which these structures were manifested in participants' experiences may have

differed. For example, all caregivers may describe that they need to find ways to cope, but the particular coping strategies they adopt may differ.

- a. Clusters were referred back to the original protocols in order to validate them. Thus, a check was made to see if anything in the original protocols was not accounted for in the clusters and if the clusters proposed anything which was not implied in the original protocols.
 - b. Any discrepancies among clusters (such as those that contradict others or appear totally unrelated to others) were noted. The researcher accepts possible discrepancies as real and valid.
5. A description of the phenomenon was formulated that integrated the above results, with the aim of making a statement about the fundamental structure of the phenomenon.
 6. A final step, not part of Colaizzi's method, involved an analysis of themes that were not found in *all* protocols, yet reflect various aspects of the caregiving experience for a number of participants.

Colaizzi's methodology also includes a validation step that involves taking the findings back to the participants for their feedback. This member-checking was not performed in the current study. Instead the participants were asked to check the accuracy of the transcripts and to modify, add, or delete portions of the transcript that did not reflect their views or experiences. This checking of the transcripts was seen as important because the data analysis rested on using participants' own words (i.e., their voice) as representations of their experiences. The researcher then interpreted these words in order to generate a description of the phenomenon of caregiving.

Other strategies used with respect to validity or rigor of the research included internal coherence, presentation of evidence, and auditing (Smith, 1996). The internal consistency or coherence of the findings was addressed using steps 4(a) and (b) above. Presentation of evidence was achieved by including actual raw data (i.e., quotations from participants) in the description of the results. This allows readers to examine (and question) the interpretations made. Auditing involves a "paper trail" that would allow someone to make sense of the current paper by following the researcher's thinking and decision-making. In the current case, the chain of evidence included the researcher's notes about the development of the research questions, the interview schedule, the audiotapes and transcripts of the interviews, drafts of the codebook, and drafts of the analysis.

The qualitative software program AnSWR (Version 6.4.169) (Centers for Disease Control and Prevention, 2001) was used as an organizational tool in the analysis process. Specifically, the protocols were imported into the program, the researcher identified the significant statements, and coded the statements according to the meanings attributed to them. AnSWR was then used to generate reports which indicated those codes that occurred in all participant protocols and all codes that were present in each individual protocol.

Finally, analysis of the questionnaire data was performed and used for descriptive purposes. It should be noted that there was a difference in timelines between interview and questionnaire data. While the interview data was analyzed across the caregiving experience, the questionnaires focussed on caregivers' current level of functioning.

RESULTS

Qualitative Findings

After reading through the protocols, the analysis called for significant statements to be extracted. The initial readings of the protocols as well as the extraction of significant statements allowed the researcher to develop an initial set of meaning codes. Additional meaning codes were added to the list as the analysis of protocols progressed. After the list of codes was deemed to be complete, all significant statements were re-coded for meaning. The final version of the codebook is reproduced in Appendix B. Table 2 presents a sample excerpt from a research participant's protocol, the significant statements extracted from the protocol, and the formulated meanings for each of those statements.

Themes Common to All Participants

In order to determine those aspects of the caregiving experience that were shared by all participants, meaning codes that were common to all protocols were identified and organized into clusters of themes. The clusters that emerged from the data are presented in Table 3 and are discussed in greater detail below.

Table 2:**Sample Extraction of Significant Statements and Attributed Meanings**

Excerpt: When she was first diagnosed because she was so sick, I don't know, my needs just got absolutely put on hold. There's no other way to put it. There were no needs. While she was in hospital, I was busy getting my place ready, getting her place fixed up, paying her bills, paying her rent, making sure that family was all communicated with, that somebody was going to visit her every day. I was going to visit her every day. I would have to say again my needs were just not, they were just not there. When she came home from hospital there was more time to actually look at what my needs were as well as her needs. But especially for the first week when she was not able to be independent at all because her legs were so bad my needs were just simply for a lot more rest.

Significant statements:

1. When she was first diagnosed because she was so sick, I don't know, my needs just got absolutely put on hold. There's no other way to put it. There were no needs.
 2. While she was in hospital, I was busy getting my place ready, getting her place fixed up
 3. paying her bills, paying her rent
 4. making sure that family was all communicated with
 5. that somebody was going to visit her every day
 6. I was going to visit her every day.
 7. I would have to say again my needs were just not, they were just not there.
 8. When she came home from hospital there was more time to actually look at what my needs were as well as her needs.
 9. But especially for the first week when she was not able to be independent at all because her legs were so bad my needs were just simply for a lot more rest.
-

Meanings:

1. Loved one seen as the first priority; everything revolves around that person.
 2. Do loved one's household chores.
 3. Do loved one's household chores.
 4. Keep other family members up to date about loved one's condition.
 5. Coordinate/organize various aspects of loved one's care.
 6. Provide emotional support to loved one.
 7. Loved one seen as the first priority; everything revolves around that person.
 8. Make decisions regarding family situation.
 9. Becomes fatigued as a result of caregiving.
-

Table 3:**Clusters of Common Themes****Making adjustments**

1. Caregivers feel a sense of responsibility.
2. Caregivers view their loved ones as a top priority.
3. Caregivers deal with personality and/or behaviour changes.
4. Caregivers express feelings of uncertainty and fear or anxiety in relation to their situation.

Being a health care paraprofessional (Becoming part of the health care team)

1. Caregivers are aware of diagnosis and treatment.
2. Caregivers monitor, interpret, and make decisions.
3. Caregivers express views about dealing with the health care system.

Being a source of emotional and practical support

1. Caregivers provide emotional support.
2. Caregivers provide practical support.

Having needs

1. Caregivers need to find ways to manage the situation and their feelings.
2. Caregivers need information.
3. Caregivers find they need support for themselves.

Making Adjustments

In contrast to professional caregivers, family caregivers are unprepared for their caregiving roles. Becoming a family caregiver brings with it a multitude of changes. It is more than just the case that the caregiver is faced with the fact that a loved one has a brain tumour. This in itself involves an array of reactions, both emotional and physical. Caregiving, however, involves changes in the caregivers' lives as well as changes in their loved ones. Caregiving entails new responsibilities, re-establishing priorities, dealing with changes in their loved one's behaviour and personality, and experiencing feelings of fear, anxiety, and uncertainty.

Feeling a Sense of Responsibility

Becoming a caregiver means assuming the responsibility of caring for a loved one. Participants indicated that caregiving was something they felt they had to do. For some individuals adopting this role seemed to be automatic because it was seen as part of their spousal role. Charles stated his position this way:

She was always there to raise the kids and all that so I feel obligated to now look after her the rest of her life because she can't go anywhere now and I've got to be there to support her because she supported me all these years. You owe a debt to society, or a debt to your wife.

For others, such as Sandra, assuming the role was natural because they essentially viewed themselves as caregivers anyways.

I've always been somebody who is comfortable being responsible for other people. . . . you know even as a kid I looked after the younger kids on the block when I was a teenager. I helped look after my grandmother. When I was in school, I was a school monitor. . . . I'm here to serve. And so that's just part of it. It was natural for me to be involved in her life. It was natural for me to look after her.

Loved Ones Become the Top Priority

Caregivers find that accommodating the various needs of their loved ones means that their loved ones become the top priority in their lives. Sometimes this shift is one that is made voluntarily; at other times it seems to have been thrust upon the caregiver.

Michael likened his experience to having a newborn baby:

We changed our way of operating with each other. When we were first together, when [my wife] first got out, I used an analogy I guess talking with [the social worker] that [my wife] had changed in the way that a young couple when they're first married or with each other together, but then a baby comes along and the baby takes over. I felt that way about [her] tumour. Because, you know, suddenly [her] whole life was dealing with her tumour and our life was really dealing with the tumour.

One way in which all caregivers demonstrated this shift in priorities was in making adjustments in their regular routines or schedules. For example, missing work or

changing work schedules to accommodate the needs of their loved ones was cited often.

Richard described how his days are "chopped up":

Doctor's appointments. Sometimes they're in the morning. Sometimes they're in the afternoon. So it's hard to accomplish anything. You try and arrange it so if there's grocery shopping you can do it while you're out and errands like that. The bank. It doesn't always work out because sometimes I have to be ready to pick her up. Sometimes I have to do the errands in the morning and take her to the doctor in the afternoon. They usually seem to be late, 3:00 or something. So it interferes with getting dinner ready.

Other adjustments indicative of placing their loved ones needs above their own involved making personal sacrifices in order to carry out caregiving. They may have had to change their personal ambitions (e.g., regarding work), take time away from other roles (e.g., parenting), or give up certain leisure activities.

Charles: It's your mindset that you have to realize that you can't do the things you did before. You can't keep going out with the boys. You can't go to certain functions. Your career path is suddenly cut off.

Susan: At the time that I stopped going to choir I remember just thinking "Oh, I just can't do this. I mean the church just can't expect me to be there" sort of thing and you know I'd forgotten how much I used to just enjoy it. So and anyway so I mean that's just there's just a lot of things I gave up when [my husband] was ill, when the kids were young that some of it I didn't even realize I was giving up. I thought it was just a matter of course. And that I would rather be home with my kids than be I felt I had a choice, you know, so but I didn't really.

Dealing with Personality and/or Behaviour Changes

One of the many adjustments family caregivers of brain tumour patients find themselves having to make involves dealing with or getting used to personality and/or behaviour changes in their loved ones. For example, some caregivers note how their loved ones exhibit repetitious behaviour such as asking the same questions or washing the same dish again and again.

Charles: Once I get home, she'll just keep talking. And really I've heard it all over and over and over again so it's kind of strange sometimes because this person who hasn't spoken to anyone all day, you suddenly come home at night, you're tired, and she wants to talk and talk and talk and talk. The trouble is the questions are the same over and over and over, the repetitiveness. . . . But you've got to be able to block out certain things. You can't listen to everything. That's the caregiver's problem.

Other changes seen in loved ones include aggressive behaviour, confusion, and memory loss.

Mary: I get mad, but just for that moment that he'll - like he'll swear quite verbally at you, you know, in the middle of the room, with four other patients and I guess it bothers me how other people perceive it, you know, when he does that. . . . but sometimes it's hard to just walk away from it, so then you - and then he calms down the next minute and he'll say a few good things and then all of a sudden, he gets quite verbal again and I find that really difficult, you know. Probably a little more easier to handle if other people aren't around.

Experiencing Uncertainty and Anxiety

Given all the adjustments caregivers make with respect to their new role and the demands of the role itself, it is not surprising that they speak of feeling stressed.

Nancy: Sometimes that's very very difficult, to drive all the way downtown, especially in hot weather, with a person who is dreading their treatment, and then coming back and literally, you know, so sick. That's very hard. Well, you know, it feels bad because it's your own family but just with anybody doing it, it's very hard. I think that's a big wearing thing on families, taking patients to treatment, but I don't know if there's any way around that except to have more help in the driving.

Thomas: [The social worker] would when we were coming in, she'd ask how we were doing, how I'm doing, and I'd be like I'm ready to cry here, and it's like, you know, "Oh, I'm doing fine." And I could just feel my whole just not feeling very good and it's like getting twitching and stuff. I think that has to do with a bit of the stress. . . . So it was one of my friends that actually said, "You look stressed." And I said, "Well, you know . . .", it's like every time somebody asks me how [my wife's] doing, "She's fine." Because if I go into deeper detail, the tears and the choking in the throat.

Two aspects of caregiving that contribute greatly to this stress are uncertainty and anxiety or fear surrounding the illness. These two emotions are linked closely to

each other: often it is those aspects of the illness and the caregiving itself that make people feel uncertain that also make them anxious or afraid. There may be uncertainty around the diagnosis. There may be uncertainty around the prognosis; for example, will there be a possible recurrence and if so, when? Will the diagnosis of brain tumour result in death of the loved one? There may also exist uncertainty regarding how the loved one will be affected. Will symptoms worsen or will they improve? Will neurological deficits occur? Did we choose the right course of treatment? What will the next MRI results be? Is it okay to leave my loved one alone? What happens if my loved one has a seizure? Am I doing everything I can? What happens if I miss something?

Patricia: We'll be talking about a particular trip or whatever and then I sort of suddenly - we both stop and think, "Holy Christ. This might never happen." So we both are all in the back of our minds we're always very conscious that it's a terminal disease. And for me personally we've been really close so his death would be really really rocky for me for sure afterwards so I certainly have, you know, pre-MRI get really uptight over that just thinking because then it becomes a reality that he may not be around in six months. . . . Well, it was unbelievable strain emotionally. So I mean it was the fear of it. It was him appearing as though he would not even get back and even if he didn't have the tumour, it looked like major brain damage; but he's really come back a lot. The fear of death of loved one obviously is going to cause incredible strain.

Michael: And I came back and they hadn't quite got her into the ward yet and the intern was on the phone and he eventually he said, "Well, I wanted to talk to you" and I waited. And he told me that she had a really serious brain tumour and that she had six weeks to live. Aaaaggh. You know, just knocked it right out of me. . . . I didn't know quite what to do. I couldn't stay in there for very long actually because I was, you know, they dropped this on me. So stayed there with her for a short while and then went for a big long drive just to sort myself out.

Being a Health Care Paraprofessional (Becoming Part of the Health Care Team)

Family caregivers, in taking on their roles, assume some responsibility for the health care of their loved ones. This means that a basic level of knowledge becomes necessary about the illness, treatment, and the health care system. Specifically,

caregivers learn to know many details about their loved one's diagnosis and treatment. As well, their problem-solving abilities are put to test as they monitor their loved one's symptoms and behaviour, interpret what they see, and make decisions about courses of action to take. In helping to care for their loved ones they also become very familiar with their health care providers and the health care system and develop attitudes about the care they have received.

Knowing the Details of Diagnosis and Treatment

Family caregivers of people with brain tumours are intimately engaged in the health care of their loved ones. They are often present when their loved ones hear their diagnosis and prognosis and accompany them through treatment (e.g., surgery, radiation, chemotherapy) and any side effects. Regardless of whether they are actually present at all these times, caregivers are knowledgeable about their loved one's illness and treatment. Their ability to recount details perhaps reflects the tremendous impact the diagnosis of cancer has had on their lives. For example, Linda described the circumstances leading up to her husband's diagnosis:

And the GP down there was able to say that he saw a growth - that they couldn't tell us too much of what it was. There was a mass - they couldn't tell if it was a growth, if it had been a bleed, like due to a stroke or what. So, then, the whole day was spent for a neurosurgeon to get involved and he read the CAT scan and said that there was indeed a growth there. They felt it was a tumour and he ordered an MRI the next day. And the MRI showed more exact what size, what type they thought it was, etc., etc. So, it is a glioma and a fairly large one in his speech area - left temporal. . . . And so, a week after they had the MRI, which is a day after he got in the hospital, they did a biopsy on it and found - going in, they warned us that it would probably be - there are four stages of cancer. Going in, they told us without a doubt they felt it was a Grade IV cancer. So, we had a lot to deal with in a very short amount of time. Our whole world was blowing apart. And, so upon getting the results they were very excited when they realized that the pathology report was a Grade II. And

even at that, it was a low grade of Grade II, which is a very good, very very good sign.

Monitoring, Interpreting, and Decision-Making

Outpatient care is a major responsibility for caregivers. They described monitoring their loved ones to see how they are doing, being watchful of any changes in symptoms, personality, and/or behaviour. They then try to interpret and make sense of their observations: What is happening? Should they seek medical attention? Finally, caregivers make decisions regarding the best course of action to pursue. John described how he dealt with his wife's first seizure episode:

Then one night she had a seizure in the middle of the night and I could hear her having the seizure, but I didn't know what was happening. And I woke up, I was still half asleep, and I turned the light on, and she seemed to be out of it. Her tongue was sticking out and I knew something was wrong. I mean I didn't know what was wrong, but I thought, well, my first aid survival, survival first aid told me to clear the airways. I knew she wasn't breathing. Immediately, I didn't know she was breathing and I cleared her air passage. I tried to give her mouth-to-mouth and she told me. She said "I'm breathing, I'm fine," or something to that effect. But, she was doing that subconsciously and she was still having this grand-mal seizure, just at the tail end of it. And so, I said "Well, there's something wrong." And, finally, in the next few minutes, she woke up and acting normal and said "No, there's nothing wrong." In the meantime, I was phoning the doctor and telling them that we were coming in.

Being part of the health care team also involves attending medical appointments with loved ones. These include appointments with neurosurgeons, oncologists, and family physicians, as well as appointments for radiation and chemotherapy. Caregivers' attendance provides them with the opportunity to hear what the doctor says, help to explain what their loved one is experiencing, and ask questions.

Attitudes Towards the Health Care System

Caregivers expressed their feelings, both positive and negative, about the health care system. In negotiating their way through the myriad of doctors and diagnostic examinations, at one time or another many caregivers felt frustrated. Some caregivers' frustration stemmed from delays in the system, lack of coordination within the system, physicians and medical staff who were seen as unavailable, or delays in getting diagnoses.

Robert: Now on Friday - we stayed in town Thursday night - on Friday it was 6:00 in the morning admissions, operation suppose to go at 7:45, didn't get started till 8:30 because somebody forgot to write down that she's suppose to have an MRI that morning just prior to the operation. So she's sitting in one area, the doctor's sitting in another area so somebody finally twigged to this fact because the doctor came down and said, "I'm waiting. Where are you?"

Others were disappointed that their physicians were not willing or able to provide a concrete prognosis for their loved one's situation.

Charles: But he wouldn't come out and answer how long [my wife] has to go. She said, "Do I have a year? Do I have six months? What do we got?" He said, "I really don't know."

In cases when a prognosis was delivered, some caregivers complained that the physician delivering the news provided little hope for the patient or the family.

Linda: That was a pretty bad day. Because the chemo doctor - he was not giving us - he was not presenting the news very well. He was quite flip, quite blunt, and when he was talking about survivorship, he was talking about really low numbers. And you know we were always given a high number, like years down the road. So, this in itself, it shook [my husband] and it shook me and I think I cried for 24 hours.

On the other hand, some caregivers spoke very positively of the care they received.

Richard: The system here covers things pretty well. . . . I thought they were great. Probably as good as you could find anywhere.

Kathy had the following to say even though she had also talked about some of her frustrations with the system.

But [our doctor] is a terrific guy, too. I'm really glad we had him because he's just - everything went bang bang bang. They can say what they like about the way things go but when it has - you know, delays and everything - but when it has to work, it works. It sure did for us anyway.

Being a Source of Support

One of the main caregiving demands or tasks that caregivers perform is providing support to their loved ones with a brain tumour. Although these individuals may have been a major source of support before their loved one's diagnosis, the support provided as a family caregiver entails additional facets that are specific to caring for and caring about a loved one with a brain tumour. The types of support that caregivers described fall into the two general categories of emotional and practical support.

Providing Emotional Support

Caregivers provide emotional support in a variety of ways. In general terms, they report "being there" for their loved ones. Their reason for attending medical appointments is often just to be there as a support. Caregivers try to comfort their loved ones and are available to talk with them and listen to them. Caregivers also talk about providing encouragement to their loved ones, often with the aim of trying to keep their loved ones involved in activities or to make them feel useful. Barbara described helping her husband in this way:

I also feel you can do too much help. I feel one needs to be encouraged. "Do you want to get yourself a glass of water?" Just encourage them to slowly start to do things in the home just so they get their confidence back and re-orient themselves.

Mary described how she tried to encourage her husband to stay positive.

And when he's had these confusing times, it's hard for him to - like you'll reinforce that "Oh, [the doctor] said that he's pretty sure he got it all and they can't find the primary. Now, that's a good thing. It's been a year." And you just keep trying to tell him you know . . . all the positives about the treatments and the prognoses and stuff like that so. As long as you can still have you know a good prognosis then you can keep reassuring.

Providing Practical Support

Caregivers also provide a great deal of practical support to their loved ones. Due to the nature of brain tumours and most often the possibility of seizure activity, all family caregivers noted how they needed to take over the responsibility of driving or arranging transportation for their loved ones. These driving responsibilities not only included transport to and from appointments but also running errands such as grocery shopping or more leisurely pursuits. This responsibility was easier for some caregivers to carry out than for others.

Robert: The thing that she doesn't like the most is the fact that she can't drive right now so then she has to sort of come and "Can we do this? Can we go do that?" "No problem." So I'm able to drop stuff and able to then go and go shopping if that's what she wants.

Michael: There's a lot of places like I drive [her] to places that I - if she could drive, I'd say, "You drive yourself." So going places that normally I wouldn't - like we do a lot of shopping. I don't like shopping.

All caregivers also described ways in which they had become coordinators or organizers in their loved one's lives. This coordinator role may apply to scheduling appointments, ensuring others could assume responsibilities when the caregiver could not, obtaining medical aids such as wheelchairs or bath boards, applying for financial aid, or planning meals.

In the three cases where minor children were involved, child care was a part of caregiving duties. Various other forms of practical support were also mentioned by at least half of the caregivers. Direct care included activities such as helping with

medication administration or helping with bathing or toileting. Indirect forms of support included doing household chores such as grocery-shopping, cleaning, and laundry; and making sure that loved ones ate nutritious meals and got plenty of rest. Some of the types of support mentioned by only a few of the caregivers included reminders, keeping the loved one active socially, exercise, and financial help.

Having Needs

In addition to fulfilling the needs of their loved ones, caregivers also have to determine what their own needs are. The needs found to be common to all caregivers in the sample revolve around ways to better carry out their roles and ways to cope with their situation.

Managing the Situation and their Feelings

In order to deal with the emotional stresses of caregiving, caregivers adopt various strategies to deal with their feelings about their situation. For example, they try to make their lives as normal as possible, take one day at a time, or just get on with their lives.

Patricia: And the amazing thing is if you think of a family, you know, other families that I've known that have had cancer in the family or a terminal disease I sort of thought it would have been the worst thing in the world and that your whole life would be taken up with that horrible panicky feeling but it's amazing how your system kicks in and it doesn't take over your life. It only it becomes a once-in-a-while crisis and most of the time it's not that you forget. You just go on living normally.

Mary: It for me it's just been very emotional, you know, and it's just one thing after another and then you just sort of wait and then the next thing happens and you just deal with it when it comes, you know.

Thomas: When you can cope with that you're never - you won't be the same person that you were before the surgery, before the tumour, then you can start getting on with the recovery. Because if you keep on going and try and do things that you were doing before everything, you're not

coming to grips with what you're going to be like now because it's going to change your life, you know, in some way.

Caregivers may also cope by protecting themselves emotionally (e.g., minimizing the situation), thinking optimistically, or engaging in a form of social comparison whereby they feel fortunate because they believe their situation could be worse than it is. Other caregivers note that they just needed to accept the cancer as part of the path their life had taken.

John: Well, it's kind of funny because I try to put it out of my mind that there's a big problem here. That's the only way you can deal with it because I go to work and people would look - when I first started going back to work, the whole staff at the office was frozen. They'd look at me the first day, and they'd say "Hi [John]. How are you?" sort of thing. And I'd say "I'm fine. How are you?" Because that's the only way to get through. "What are you up to today?" and that sort of thing and it shocked them at first because that's the way - they weren't used to that sort of reaction, but that's how I dealt with it. I put it out of my mind that it wasn't bad.

Patricia: It would have been very very different if he had had a personality change and was difficult to get along with which he wasn't because he's always unbelievably appreciative. Or if he didn't get back his sense of humour and being able to talk to - so it would have been a completely different issue if I was talking with a vegetable or with somebody cranky. It would have been completely different issue so I was lucky that way.

Caregivers also find themselves in the course of caregiving addressing others about the patient's situation. This usually involved keeping people up-to-date but sometimes also involved dealing with people's reactions towards the patient and addressing the reactions and coping of the patient's children.

Needing Information

To help them carry out their roles as part of the health care team, family caregivers speak about needing information to help them understand their loved one's illness.

Linda: I think that's a natural thing with people, to want to know everything about that thing when you're given a diagnosis. You want to find out everything about it, the good and the bad, and then because the more informed you are, that's a good thing. Ask tons of questions. Always go prepared when you talk to doctors.

Most often, they want information that will help them know what to expect and to know what to be vigilant of.

Susan: If somebody had just tapped me on the shoulder and said, "You know what, he's got this frontal lobe injury here and you know what, here's a list of the things that it could affect. Maybe it's not affecting all of it. These are the things it could affect. You know, does it do they look kind of familiar?" And I would have gone, "God, yes." . . . I understand now that there are, you know, there are specific areas of the brain that control things like judgement and reasoning and that was the very area that seemed to be where his tumour was. And that information would have been really valuable to me so. . . . But I think the stuff that would have been most helpful was just the actual things, the scientific research of the area of the brain injury and what it tends to affect.

Many caregivers wish that they had a list of resources so they would know whom they could contact when they needed help.

Nancy: In the first few months you need information and access to it. You need people to give you a sheet of stuff in your hands and say, "Keep this at home. If you need it, it's there for you." Not, "There's the library. Go look up a book." Or "There's the video center. Go try and find a video." You need people putting it your hand and telling you or "Here's a person to phone and liaison with if you have any questions, please phone." You know, like in a way, a counsellor. People that you can access information from without - you don't always get it from the Cancer Center as such - you know, you'll get a little slot of time.

Needing Support

As a result of the new responsibilities caregivers take on, they come to rely on support from others, either because they have asked for it or because it has been offered to them. The support caregivers receive from others helps address the needs mentioned above regarding managing feelings and needing information, as well as needing respite, which is discussed later. All caregivers mention receiving some kind of

support. The most often cited sources of support were family, friends, and formal organizations (e.g., hospital, library, etc.). Caregivers also spoke of getting support from their professional caregivers (e.g., doctors, nurses, other medical staff), going to a support group or an individual counsellor, using written materials (e.g., books, pamphlets), the Internet, and church/faith. Many caregivers said they needed support in the way of being able to talk to others, usually those who were in the same situation (e.g., other caregivers) or knowledgeable about the situation (e.g., counsellor). Others just needed someone to talk to (e.g., family member). Although all caregivers found support in others, many also indicated that they tend to cope on their own as well.

The majority of caregivers indicated that they were aware of various resources but did not use them or had no need for them. In most cases caregivers were required to take the initiative in finding outside resources (i.e., those outside their own personal support networks) or were not aware of any resources for caregivers until they found them themselves. Many caregivers indicated that they felt some of the support available was inadequate in some way and a few caregivers indicated that their personal support systems were inadequate.

Mary: Not living in Vancouver like meetings for for caregivers, for families dealing with brain tumours, there's - I think there's support groups and things. I see those kinds of things but don't live in town and have never been here when there's been a meeting for that and I feel for myself personally I think it's great to to talk to people but I I've got like I say good family support groups so anytime I want to talk, I can.

Charles: Professionally, I haven't found very much. From the time of the operation to the time I took her home, there was nothing, absolutely nothing. I took her home from the hospital and nobody contacted me from any organization. I found that unusual. . . . There's probably a lot of support there for people, but they don't tell you. There's no communication. . . . You see, you only see a doctor, get worked up by him. You see a nurse and get worked up by her. You see a receptionist, and then you see all the clinical people in all the places like radiation and

clinical workers. That's the only contact you have. And nobody else. Unless you go searching for them. You have to go searching for them. . . . It took me over two years to even figure out there was a support group and I found it through the Internet through the BC Cancer Agency. . . . But there was no book on cancer patients. "Your wife has a brain tumour. You can expect this. You can expect this. This may happen. This may not happen. Here's where you can call for such and such." A handbook. Small handbook. I know there is a handbook put out by the library. But I think a little resource pamphlet would be handy. And these pamphlets are no good unless they're put in the hands of the patient or the caregiver. They've got to be put in as soon as the person leaves the hospital.

Linda: So the resources are out there if you know what to look for and you know what you need. And sometimes you don't know what you need. It's hard to know what to ask for because you don't know. You've never been in that situation before.

Fundamental Structure of Caregiving for a Loved One with a Brain Tumour

Based on the theme clusters that were formulated above, a description of the fundamental structure of caregiving for a loved one with a brain tumour was formulated:

Being a family caregiver of a person with a brain tumour means caring for and caring about a loved one, adjusting to a new life situation, and finding ways of best carrying out the role and coping with it. Caregivers assume the responsibility of caregiving for their loved one and view their loved one as the top priority in their lives. Feeling anxious and uncertain about their loved one's illness situation is common, and they find themselves learning to live with a person who exhibits different personality and behavioural attributes than they are used to. As caregivers, their roles include paramedical, emotional, and practical forms of support. They need information while caregiving as well as coping strategies and personal support systems for themselves.

Other Themes

A number of themes emerged in a subset of participants' protocols. These aspects of caregiving that are experienced by some but not all caregivers are seen as important and relevant because they are still part of some people's experiences. These themes are described below.

Needing Respite

Caregiving is emotionally stressful. To help alleviate this stress, caregivers find that they need some kind of respite. (Indeed, only one caregiver did not allude to any respite needs but instead felt she did not want to spend any time away from her loved one.) They need to take occasional breaks from their caregiving duties. These breaks usually involve taking time out for themselves and needing to take care of themselves.

Barbara: Just to have somebody that you can phone and say "Let's go for coffee." Just have a bit of space. I think everybody needs a bit of space, you know. . . . I think also going to work, that's helped as well cause you get out of there and get your mind off it.

Sandra: Oh, I would like to say that I'm calm, cool, collected, and philosophical, but it's not true. I am aware of stuff that I do for stress relief anyway because of the type of job that I work at. . . . It was harder for me when I was with her 24 hours a day because it was harder for me to do some of the stuff that I normally do for stress relief. Like go for a walk. It's a pretty small apartment to walk in. Some of the other stuff that I do for stress relief is very easy for me now. To do my yoga, to go do my gardening, to just go for a walk, to sit and read a book and not think about anything else. For some of the time actually coming to work was a stress relief but that was mostly when there was a lot of family issues involved. Just send me to work. I know what I'm doing there. It's simple. . . . I just kind of jump and skip and click my heels whenever I have the house to myself. (laughs) And it's not that she's intrusive. It's just that feeling of not - I'm used to having more time on my own and it's something that I've given up to support her. But every once in a while now I'll be at home, she'll be off with her friends or out with her dad or something and I actually have time. There's nobody else there. I can put on my music on the stereo (laughs) and do whatever I darn well please and I'm just me again, which is wonderful.

For 9 of the 14 caregivers, respite needs were also indicated by the need for help from others or the importance they placed on accepting help or asking for help. Six caregivers felt they needed respite but did not want to bother or burden others to help. Four of the participants felt that there was no one that could fulfill the role of relieving the caregiver.

Questioning Caregiving Skills

Ten participants spoke about how they have had feelings of inadequacy as a caregiver. They felt they could not manage or felt ill-equipped to carry out their role.

John: The doctors also expect me, I feel, that they expect me to be constantly there to counsel her. And they'll talk to me as if I'm her counsellor almost, at times. And so here I'm feeling like I'm not an educated person in any medical field except I have survival first-aid training. But I'm expected to be her medical coordinator, her counsellor, that type of thing so I guess at times feeling very inadequate but feeling very responsible.

Many (9 of the 14) caregivers also spoke about the need for reassurance: to know that what they were doing was okay or how they were feeling was normal.

Kathy: But you just hate to sit [in the doctor's office] and say, "Well, what should I be watching out for" with [my husband] sitting there. I find that difficult. Cause I don't want to cause him any more pressure or stress than he has already. I guess I don't know if that's right or not but that's how I feel about that. Other than just actually knowing that you're doing the right thing. Cause you know you don't want to think you're doing something wrong and then it's gonna make him worse or whatever. They've given us a lot of brochures and a booklet on brain tumours. I've read all of that but it's very general and of course, I mean even two people with the same thing aren't going to react the same so I know that they can't - they can't give me what I want - what is going to happen to him.

Dealing with Aspects of the Illness

Caregivers find themselves dealing with various aspects of the illness and treatment, some of which are specific to brain tumours and others that are not. One

brain-tumour specific symptom that eleven of the caregivers spoke about is that of seizure activity. Some caregivers recalled the rather traumatic experience of witnessing their loved ones having a seizure. Another aspect of seizures that caregivers spoke about was the fear they had about the next seizure occurring or about the possibility of one occurring if it had not already.

Nine caregivers also spoke of the rapidity with which events occurred with respect to diagnosis and initial treatment.

Thomas: Saw her, did some stuff with her eyes, and resistance tests. And showed concern for me because he was looking at or into one of her eyes for quite a long time. And then this went on and then he said we could go home and then on Thursday, the next morning, he wanted us to come in for a CAT scan, and that's when, you know, thinking we were just going in to get a CAT scan and come home and carry on. But they admitted her right away and that's when they told us that she had a tumour and admitted her right away. They actually wanted to do surgery that weekend, but she had to wait another week. The Friday after, that's when she had the surgery. . . . it is a big thing, getting your head cut open, especially in a short period, within a week. You have a tumour and surgery.

Charles: So they had her in for an x-ray, then an MRI, and a CT scan. And boom, within nine days, they operated. They had to get it out right away. It's that aggressive.

Another issue that eight caregivers discussed is recurrence or the possibility of recurrence of the tumour. Five caregivers talked about needing to make plans for the future, for example, in case their loved one's situation worsened or resulted in death.

Mary: The ups and downs when the diagnosis of a new tumour . . . what if it comes back, and the closer it would get to the scans, that's too, when he would escape a little bit and get a little foggier and more confused the closer we would get to the hospital, the more confused he would get. So that part just trying to get him through each test and trying to remain positive. . . . [The surgeon] said, "Well, the tumour is back." . . . Anyway he went in for a second operation . . . and again he felt that you know it looked good you know from what he could see, he took as much area as he felt was safe to take. . . . But he was very surprised that it had grown, I think, that quickly, so maybe they had done one scan in-between, I can't

remember, but that it had changed that quickly so then he started doing the scans every four weeks.

Kathy: You just worry. That's a big thing for me to worry about those symptoms coming back and when this is all going to happen, of course. Nobody can tell you because it may never come back but that I think is being really optimistic.

Nine caregivers also talked about issues related to their loved one's independence. They often spoke of recognizing that their loved one's independence was threatened and the difficulty involved in their loved one losing that independence or having to take that independence away. Robert spoke about his sensitivity to this issue and how he tried to encourage his loved one's independence:

I also recognize that she needs to have her independence and therefore be able to do things so I try not to correct the words. I try not to overcompensate by doing things for her. Dishes. We usually do them together, but she now wants to do them alone. And she says that on the basis of "I need something to do." And I say, "Well, if you need some help, give me a call." . . . So just be sensitive to that, that the person is still trying to express herself in an independent way and keep that independence where you possibly can. It didn't take us too long to figure that one out. . . . Maybe recognize that the law states that a person can't drive and therefore a great deal of independence has been taken away and therefore rationalize it or understand that a person's values and worth can be greatly shaken by that so you should find ways in which to bolster them up and just encourage them in as many different ways as possible because they have had a major system, life support system taken away from them, their independence.

The demands of caregiving varied greatly across the sample of participants. Eight caregivers talked about caregiving changing, sometimes being a very heavy to sometimes being a very light load. Not surprisingly, ten caregivers talked about their loved one going through ups and downs during the illness. Six of the caregivers said that at times they were doing everything or indicated that caregiving was constant.

Additional Emotional and Physical Consequences of Caregiving

Besides the uncertainty, fear, and stress that all caregivers experienced, other feelings were talked about. Ten caregivers expressed feeling shocked or surprised at some point, usually at finding out the diagnosis or prognosis.

Linda: I still have a hard time believing this all happened so I just go around shaking my head and I just cannot believe it because it seems like yesterday that it happened. And because there was no warning, this came out of left field. He didn't have headaches or nothing.

Nine caregivers talked about feelings of resentment or guilt or regrets connected to caregiving. Thomas talked about how he felt it was important to avoid becoming resentful as a caregiver:

I think the caregiver also, you know, needs to change with the changes for with their spouse, because if they don't - if they're not willing to change - this is all coming up a bit now - if they're not willing to change, you know, I think that's where the conflicts start coming in. The resentment. Like at no one point did I ever ever resent have feeling of resentment, I think. But I think if somebody was to start feeling that way, that they're getting all the attention or it's too much, I think that's where you need to figure out as a caregiver what you're willing to do and how far you're willing to do it, before you start feeling the resentment.

Eight caregivers spoke about frustration experienced during the course of their caregiving. Four caregivers expressed having to be patient and tolerant.

The emotions that caregivers experience in the course of caregiving are not always negative. A third of caregivers talked about positive aspects of caregiving. For example, they found the experience rewarding, felt they had become stronger people as a result, or had developed a closer relationship with their loved one.

Being a caregiver of a loved one with a brain tumour may take its toll physically. More than half of caregivers talked about fatigue resulting from caregiving.

Barbara: In the beginning I was exhausted especially in hospital I found that really hard because you've got to work and then it's off to the hospital

and then if you have anybody else at home to organize them. . . . And I found that my days would be really long. By the time I got home, I was whacked, you know.

Four participants talked about developing health problems. For example one caregiver spoke about experiencing hearing problems that he felt were brought on by stress while other caregivers spoke about high blood pressure and weight loss.

Desire to Help Other Caregivers

The experience of caregiving for their loved ones left half of the caregivers feeling they would like to help other caregivers in the future. This desire seemed to stem from the realization that they had something to offer others in the way of knowledge and experience as well as an appreciation for the difficulties that caregiving might entail.

Nancy: I'd give them my phone number. Say, "Phone me anytime, day or night." You know, "Phone me if you can't do anything and you just want to cry. Phone me if you want to ask a question. I can help answer it." That's the first thing I would be: available for anyone because I'd just say, "I have the ability to know what you're going through."

Linda: There is no brain tumour support groups out our way which is surprising, I guess. So I wouldn't mind starting it. I don't even know how to go about it except that if you want to meet at my house and I do have a lot of educational information, I could share, but I do think that would be a good thing.

Thinking about the Family Situation

Nine caregivers talked about having to make decisions regarding their family situation. For example, some caregivers talked about having to take over all household and family decision-making and others considered whether they would continue to work or have to quit in order to carry out their caregiving. Ten caregivers talked about either experiencing financial difficulty or stress or at least thinking or re-thinking their financial situation.

Barbara: It does affect one financially as well. Before we knew that he was going to have the operation, we went and we found out that we could get a little bit of assistance because of his medical condition. Well, they said because of what I earn and it's not a fortune, that we couldn't get it because I earned too much. I don't know how people cope. Not that you want to be paid a fortune but just to have a bit of assistance I think is important. It's a big financial burden as well when you've got the one income. So that's another worry for both of us, the financial side.

Quantitative Findings

Quantitative measures focussed on recent functioning, usually how caregivers were feeling "now", that is, at the time of filling out the questionnaires, or during the one or two weeks prior to filling out the questionnaire.

Caregiving Demands

As seen in Table 4, results from the Caregiving Burden Scale indicated that the most demanding activity with respect to time was giving emotional support. Caring for other people in their lives and managing mood and behaviours was also time-intensive. These findings are consistent with the qualitative themes common across participants of providing emotional support and dealing with personality and behaviour changes. The least demanding activities for family caregivers were providing medical and nursing treatments, assisting with mobility, and providing personal care to the patient.

Table 4:***Perceived Demand for 14 Caregiving Activities as Measured by the Caregiving Burden Scale***

Questionnaire Item	<i>M</i>	<i>SD</i>
Giving emotional support	4.0	1.2
Managing illness-related finances	2.2	0.8
Doing extra housework	2.9	1.5
Providing transportation	2.9	1.6
Managing mood/behaviours	3.2	1.3
Monitoring/reporting symptoms/progress	2.6	1.5
Running extra errands	2.7	1.3
Structuring and planning activities	2.3	1.3
Coordinating and scheduling	2.5	1.1
Providing medical/nursing treatments	1.8	1.1
Assisting with communication	2.3	1.0
Assisting with mobility	1.9	1.1
Providing personal care to patient	2.0	1.3
Caring for other people in life	3.3	1.6

Note: Response scale ranged from 1 “little or no” to 5 “a great deal” of time spent in activity.

Caregiving Needs

Findings from The Home Caregiver Needs Survey indicated that the categories of greatest need (i.e., those that were rated as important but not satisfied) were personal, psychological, and informational (see Table 5). Caregivers identified relatively fewer needs related to the household. An analysis of the top ten unmet needs identified by caregivers indicated that they are consistent with themes identified in the qualitative analysis of the interviews (see Table 6).

Table 5:**Areas of Greatest Need as Measured by the Home Caregiver Needs Survey**

Questionnaire Subscale	<i>M</i>	<i>SD</i>
Informational	11.6	5.1
Household	5.6	3.0
Patient care	7.3	4.4
Personal	13.0	4.1
Spiritual	7.0	4.4
Psychological	12.1	5.1

Note: Possible range for need score is 1 to 49, based on weighting dissatisfaction score (ranging from 1 to 7) according to importance score (ranging from 1 to 7).

Table 6:**Congruence Between Needs Identified in the Home Caregiver Needs Survey and Qualitative Themes**

HCNS Unmet Needs	Qualitative Theme
Finding ways to deal with the unpredictability of the future, information about what to expect in the future, and having hope for the future	Experiencing uncertainty
Information about what symptoms to expect and information about patient's psychological needs	Needing information
Finding ways to maintain a normal family life	Managing the situation and feelings
Maintaining one's own health, getting time to rest, and having adequate sleep	Physical consequences of caregiving; needing respite
Finding ways to be more patient and tolerant	Dealing with aspects of the illness

When asked to assess the relative importance of their own needs and those of their loved ones, 15% of caregivers indicated their loved one's needs were much more important, 46% somewhat more important, 31% just as important, and 8% somewhat

less important than their own needs. This finding supports the qualitative theme that loved ones become the top priority in caregivers' lives, sometimes at the expense of their own needs.

Caregiving Outcomes

Scores on the Burden Interview were relatively low (see Table 7), indicating that issues of burden were, on average, experienced rarely to sometimes. A mean score of 35 would indicate mild to moderate burden according to the test developers. A range in scores of 17 to 48 indicates some caregivers experienced little or no burden while others experienced moderate to severe burden. The items that were associated with the most burden were being afraid of what the future holds (again, congruent with qualitative findings) and feeling the patient was dependent on them. Caregivers almost never felt uncomfortable about having friends over, which was the least burdensome issue for caregivers.

Subscale scores from the Caregiver Reaction Assessment indicated that caregiving for loved ones had little impact on caregivers' schedules and health (see Table 7). This conclusion is based on the fact that mean scores of 15 and 12 on the Impact on Schedule and Impact on Health subscales, respectively, would indicate neutral ratings. An analysis of individual questions did, in fact, indicate mean neutral ratings by caregivers. However, caregivers agreed that their activities were centred around caring for their relatives and that they had eliminated activities from their schedules. On the other hand, they also indicated that they felt they were healthy enough to care for their relatives.

Results from The Affects Balance Scale (see Table 7) indicated that caregivers' mean scores on the positive affect dimensions (joy, contentment, vigor, and affection) were higher than the mean scores on the negative affect dimensions (anxiety, depression, guilt, and hostility). Although caregivers' mean scores were within the normal range, the scores indicated less positive affectivity and greater negative affectivity than the community (nonpatient) norm. Specifically, the scores on the positive affect scores fell within .75 to 1 standard deviation below the mean. Scores on the negative affects fell within .25 to 1.15 standard deviations above the mean, with depression being the most elevated.

Mean scores on items from the Caregiving Competence Scale (see Table 7) indicated that caregivers felt fairly competent in their caregiving, scoring an average of 3 out of 4. Thus, they felt competent and self-confident, felt they learned to deal with a difficult situation, and felt that they were good caregivers all in all. These findings would suggest that the qualitative finding regarding feelings of inadequacy as a caregiver may have been more a periodic feeling than an ever-present one.

Finally, an exploratory analysis of the relationship between unmet needs and caregiver outcomes was performed (see Table 8). Some of the correlations were in the expected direction (i.e., that having greater unmet needs would be associated with poorer outcomes), while others were not. For example, having unmet patient care needs was associated with greater impact on schedules and greater negative affect. On the other hand, having unmet personal or psychological needs did not seem to be related to impact on schedules. However, these correlations should be interpreted with caution given the small sample size.

Table 7:**Descriptive Statistics for Caregiver Outcomes**

Questionnaire Subscale/Item	<i>M</i>	<i>SD</i>	Possible Range in Scores
<i>Burden Interview</i>	35.1	10.9	0 - 88
<i>Caregiver Reaction Assessment</i>			
Impact on Schedule	16.8	3.2	5 - 25
Impact on Health	10.2	2.0	4 - 20
<i>Affect Balance Scale</i>			
Joy	10.2	3.3	0 - 20
Contentment	10.7	3.2	0 - 20
Vigor	10.1	2.8	0 - 20
Affection	12.8	4.4	0 - 20
Anxiety	8.0	2.6	0 - 20
Depression	7.5	4.2	0 - 20
Guilt	5.8	3.2	0 - 20
Hostility	7.2	4.0	0 - 20
Overall level of positive affectivity (PTOT)	43.8	10.5	0 - 80
Overall level of negative affectivity (NTOT)	28.4	10.4	0 - 80
Affects balance (ABI)	0.8	0.9	0 - 40
Overall level of emotional responsiveness (AEI)	72.2	11.2	0 - 160
Proportion of total affectivity associated with positive affects (PAR)	0.6	0.1	0 - 1
<i>Caregiving Competence Scale</i>			
Feel competent	2.9	0.6	1 - 4
Feel self-confident	2.9	0.6	1 - 4
Believe learnt to deal with a difficult situation	3.4	0.8	1 - 4
All in all, a good caregiver	3.4	0.7	1 - 4

Table 8:
Correlations Among Unmet Needs and Caregiver Outcomes

Outcome	Type of Unmet Need					
	Information	Household	Patient Care	Personal	Spiritual	Psychological
Burden	.13	.50	.21	.26	.13	-.09
Impact on Schedule	.40	.38	.51	.06	.41	-.08
Impact on Health	-.47	.37	-.07	.21	-.26	-.29
Positive Affect	.28	-.38	.34	.16	.50	.33
Negative Affect	.49	.57*	.42	.27	.34	.19
All in all, a good caregiver	.07	-.46	.32	.15	.34	.18

* $p < .05$.

DISCUSSION

The Findings

Family caregivers of brain tumour patients play crucial roles in the lives of their loved ones. This study used a primarily qualitative approach to ascertain the nature of this caregiving experience. From participants' own words, stories emerged of change, adjustment, and adaptation. A number of similarities in caregiving experiences were apparent among participants. The fact that common themes were found from caregivers' descriptions of their own experiences (as opposed to similarities that may have been found in questionnaire prompts) is compelling because it suggests that these issues were salient aspects of all caregivers' experiences. These common themes indicated clearly that caregivers were greatly impacted by their loved one's diagnosis of a brain tumour. The data indicated that significant changes in the relationship between caregivers and their loved ones occur. From the caregivers' perspective, they must deal with taking care of, not just caring about, their loved one. This entails acquiring some medical knowledge as well as providing some paraprofessional health care. The role also involves observing and adapting to physical, behavioural, and personality changes that occur in their loved ones. Caregivers need to learn to adapt to these changes if they are to carry out their roles successfully. Indeed, caregivers noted how they adopted various coping strategies such as trying to keep their lives as normal as possible, seeking out information, and getting support (e.g., from family and friends).

Not only are the relationships with their loved ones affected but their lives as individuals are affected as well. Indeed, caregiving becomes the top priority for these individuals. For many they become so involved in their caregiving that they do not take

much needed time away from their caregiving situations to care for themselves. These caregivers may fail to take care of their own needs such as socializing or participating in leisure activities. Adopting a caregiving role may also bring about feelings of self-doubt. Because they have embarked on rather unfamiliar territory, they come to question whether they are doing their caregiving well. On the other hand, their role also affords them an appreciation for what they learned as caregivers and many express an interest in helping other caregivers in the future.

Findings from this study regarding caregivers of loved ones with a brain tumour were consistent with previous research on caregivers of patients with various cancer types. Generally, the caregiving demands identified in the current study fell into the categories of emotion work and care work as described by Thomas, Morris, and Harman (2002). More specifically, caregivers in the current study had experiences consistent with previous research, including social, family, and employment-related changes (Siegel, Raveis, Mor, et al., 1991), increased anxiety, and thoughts about death and dying (Gilbar, 1994). In addition, caregivers managed the physical care of their loved ones, coped with alterations in the physical and/or emotional state of their loved ones, coped with additional role responsibilities and economic demands, maintained a schedule or routine, located or obtained assistance, and observed the illness (Stetz, 1987).

Few studies have been done specifically with caregivers of brain tumour patients. Similarities between the current findings and those done previously with this population are apparent. For example, Strang and Strang (2001) also found that their sample of spousal caregivers of patients with malignant brain tumours needed information about the illness and the future, and that gaining this type of information served as a coping strategy to increase caregivers' comprehensibility and sense of manageability of their

situation. Furthermore, these caregivers reported personality changes in their loved ones, losses in their social lives, and fears about recurrence (Adelbratt & Strang, 2000). The findings from the current study therefore provide support for shared experiences among both caregivers of loved ones with brain tumours as well as among caregivers of loved ones with other types of tumours.

The themes that emerged from this investigation are consistent with a stress and coping framework. Aneshensel and her colleagues (Aneshensel et al., 1995) put forth a theory of caregiving for people with late-life dementias that focussed on the stress process, and which is applicable to the current study. Like dementia patients people with brain tumours often experience cognitive and behavioural changes and thus there are similarities between the two populations. According to the theory caregivers face two types of stressors. Primary stressors consist of the actual demands of caregiving such as helping with activities of daily living or dealing with behavioural problems. Secondary stressors such as role strain or conflict result from having to carry out the role of caregiver as well as having to fulfill their roles in other social institutions such as family or work. In reaction to both these types of stressors, caregivers must find ways to cope. How well they cope depends, in part, on their access to and use of psychosocial resources (Aneshensel et al., 1995). If they are not able to cope effectively, their stress levels and feelings of burden may increase, which may ultimately affect the level and quality of caregiving they are able to provide to their loved ones.

Clinical Implications

This exploration of family caregivers' experiences provides a sense of how much these individuals are doing and how much they are contributing to the care and well-being of their loved ones – a load which has been transferred from the formal health care system to the home. Because the stress of caregiving may result in a decline in caregiver well-being and compromise patient care (Cull, 1991; Hardwick & Lawson, 1995; Longman et al., 1992), it has the potential of dissolving the home care arrangement (McMillan & Mahon, 1994; Siegel, Raveis, Houts, & Mor, 1991). If this were to occur, both the patient and the caregiver are at risk for placing heavy demands on an already taxed health care system. Finding ways to help family caregivers carry out their role and cope with their situations is key to maintaining the informal caregiving network.

Before discussing specific areas of support that should be addressed, support providers must recognize that caregivers have been found to underutilize available community resources (Laizner et al., 1993). They may be reluctant to seek help or support because, as was the case in the current study, many of them place the needs of their loved one above their own (Harrington et al., 1996; Jones, Hansford, & Fiske, 1993; Morris & Thomas, 2002). Perhaps the first step is to ask caregivers how they are doing. Subsequently, efforts should be made to legitimize caregivers' needs and assure them of the importance of their contribution (Thomas et al., 2002). Caregivers need to recognize the importance of taking care of themselves in order for them to be able to take good care of their loved ones.

Interventions

The findings from the current study can be used to guide future development and restructuring of education and support programs designed to increase family caregiver effectiveness and caregiver well-being. Specifically, these programs should include the following elements.

1. Information provision. Although caregivers often see their needs as less important than those of their loved ones, information needs are seen as valid (Morris & Thomas, 2002). Indeed, results indicated that caregivers want information. Specifically, they want to know what to expect: what to expect about their loved one's illness, their loved one's behaviour, how their own lives will be changed, and the future. Having information would help caregivers deal with the uncertainty and anxiety that they experience throughout their caregiving. Mishel (1989) suggests that uncertainty and the inability to predict outcomes may result in pessimism about the future. Besides specific information about caregiving, a number of caregivers also indicated that they would appreciate having a resource list, that is, a list of health care professionals or organizations that they could call when they needed help. Compiling such a list seems to be a fairly straightforward task and could be given to caregivers early in the disease process.

Caregivers may also need to know what kinds of information to obtain from which health care professionals. Some caregivers in the study noted how they were frustrated that they did not obtain the information they wanted. However, they must be made aware of the fact that the type of information they seek can be provided by some health professionals and not others. In other words, caregivers need to learn which domains of

information belong to which health professionals. As well, the need for patient confidentiality must be addressed as does the patient's wishes for others having certain kinds of information. Where information-giving is divisive (i.e., where patient or carer are told more than the other), there is the potential for creating greater stress in an already stressful situation; in this case a decision must be made about whether information should be shared (Rose, 1999).

Being informed is a way in which caregivers may increase their sense of control. The construct of control is particularly relevant to family caregivers because they may often feel a loss of control in their own lives while concentrating on taking care of their loved ones (Davidhizar, 1994). However, one might argue that feeling a sense of control is particularly important for caregivers because they are, in many respects, in charge. Research with caregivers of patients with chronic physical and mental illnesses (Wallhagen, 1992-93) and spinal-cord injuries (Schulz, Tompkins, Wood, & Decker, 1987) indicated that caregivers who perceived greater degrees of control experienced greater life satisfaction, less depression, and better psychological well-being. Caregivers of dementia patients who felt in control not only experienced less depression but also less strain (Morris, Morris, & Britton, 1989). For caregivers, being in control provides a sense of manageability of the situation (Wallhagen & Kagan, 1993).

Research about control and information-seeking, however, does indicate that people have varying levels of desire for control and information (Burger, 1992; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Miller, Brody, & Summerton, 1988). An individual's literacy level and cultural beliefs about communication will influence this information style (Harris, 1998). Therefore, caregivers and support providers will need to gauge caregivers' level of comfort with the amount of information that they want. For example,

some caregivers want to have information about their loved one's prognosis, while other caregivers would not. But they also want hope.

2. Coping skills training. Another way in which caregivers may increase their sense of control is through skills acquisition. When faced with the responsibility of caring for a loved one, results indicated that family members undergo significant adjustments in their lives. Not only do they become health care providers, but they also deal with personality and behaviour changes in their loved ones, and are faced with major decision-making responsibilities. Although caregivers noted using a variety of coping strategies such as becoming informed, trying to live a normal life, and being patient; formal education or training that would increase caregivers' repertoire of coping strategies would no doubt be beneficial. Problem-solving skills training would also aid caregivers in dealing with all the new and unfamiliar types of events that they encounter, and may help them to make sound, informed decisions. In essence, caregivers need to find ways to cope.

3. Support network for caregivers. A support network for caregivers of brain tumour patients should be established. Although the brain tumour support groups in Vancouver and Victoria provide a great source of support for some caregivers, people who live outside these areas indicated that it is difficult for them to attend. Given that half of the sample indicated a willingness to provide peer support to other caregivers, a telephone or email support network might be helpful. In this way caregivers could provide and obtain support more conveniently. It would give those individuals who feel they need to talk to someone in the same situation or need affirmation about what they are doing a means of getting the support they need.

Another type of support caregivers need is respite services. Although most caregivers recognized the need for respite, not all had the resources or gave themselves permission to take respite. Thus, they would probably benefit from strategies that would help them to actually take breaks. For example, caregivers need to be encouraged to accept help from others. As well, they need to recognize that putting their own physical and psychological health at risk by not taking adequate respite could negatively affect the adjustment of their loved ones. By not taking the time for leisure and social activities, caregivers might experience increased stress as their normal coping strategies and social supports may be reduced (Cull, 1991). Providing respite to caregivers may help them to lessen the extent of interference on their lifestyle (Cameron et al., 2002). Reducing caregiver burden may also decrease the likelihood of patients having unmet needs (Siegel, Raveis, Houts, et al., 1991).

Systemic Changes

Some of the difficulties caregivers experienced have implications for the way the health care system and health care professionals function. One of the complaints about the system revolved around lack of coordination. This complaint is not new and certainly is not specific to brain tumour patients and their families. The system of cancer care in Canada is a complex one. From the time they are first diagnosed, patients and their families are set on a journey that involves a multitude of tests, procedures, and doctor's appointments that often includes seeing a number of different service providers in different settings. Unfortunately this journey is not always a smooth one. Patients and their families often encounter their share of "bumps in the road" including wait lists, duplication of tests, delays in document transfer, and miscommunication or non-

communication among service providers. Such a fragmented system of care is a strain on both consumers and service providers and is not cost-efficient. In order to address consumers' dissatisfaction with fragmented care and policy makers' issues with health care costs, it is imperative that the system of cancer care become more integrated. Improving coordination and continuity within the system of cancer care has been identified as a priority in Canada (Haggerty, Reid, McGrail, & McKendry, 2001). Although models of integrated cancer care exist, little research evidence is available to advocate the use of any particular model (O'Connell, Kristjanson, & Orb, 2000). A more coordinated system would be able to better address the social and psychological impact and long-term commitments of the family and could better target interventions towards families (Yates, 1999).

While many caregivers were satisfied with the care they received from their health care professionals, some caregivers were disappointed with the bedside manner of some of their physicians. One of the common complaints was a lack of providing hope to patients and their families. Perhaps efforts could be made here on the part of professionals to recognize the importance to caregivers of having hope for the future and provide a balance in communication between providing a false sense of hope and conveying realities of the situation.

Limitations and Implications for Future Research

Sampling Issues

Recruitment within the institutional setting of the British Columbia Cancer Agency and Vancouver Hospital and Health Sciences Centre proved to be a difficult task for the researcher. Part of the difficulty may have been due to the slightly haphazard method in

which potential participants were introduced to the study. The staff (nurses, social workers, physicians) who were involved used their discretion in choosing whom they would introduce the study to, which was understandable given that there are circumstances when participation in research is not a priority or may be inappropriate (e.g., after hearing of a recurrence). However, that meant that not all eligible individuals were approached. In other cases, the frenetic activity in the clinic may have prevented staff from approaching individuals about the study. In other situations, caregivers did not accompany patients. In these cases, patients were asked to pass along a flyer to their caregivers, but this places the onus on the patient to do this. Perhaps the biggest obstacle in recruiting participants, however, was that the researcher herself could not approach eligible individuals. The researcher believes that she may have been more successful if she could have made face-to-face contact with each eligible individual. This would provide potential participants with the opportunity to connect a face with the project and ask any questions they might have.

Future recruitment endeavours could formalize the recruitment process in order to improve the chances for success. For example, the computer database of patients at participating institutions could be used to obtain a list of patients with primary brain tumour diagnoses. With the permission of the institutions these patients could be sent a letter about the study and the need to recruit their primary caregivers as participants. They could be asked to give an introductory letter to their caregiver with contact information for the researcher and the researcher could follow up with a phone call to the patient and/or caregiver. The researcher could then introduce the study to the caregiver directly. Alternatively, introductory letters to the patients could inform them about the study and request that they bring along their caregivers to their next appointment. The

researcher could then make arrangements to introduce eligible individuals to the study at that appointment.

Limitations also exist with the sample that was recruited for this study. The individuals who took part may have been coping particularly well. Some were already attending support groups and others were receiving individual counselling. Given that a number of the individuals who were contacted and who declined participation did so because they felt overwhelmed at the time, were too busy, or could not take the time to participate because their loved ones were not doing well, caregivers who may have been having particularly difficult times may have chosen not to participate. Thus, it could be that the brain tumour patients in this sample were also relatively higher functioning. It is not known what their functional status or quality of life was. Perhaps greater efforts could be made to recruit this group of individuals. Alternatively, assessments of caregiver well-being or coping could be performed so that the caregiving experiences of individuals who are coping more or less well could be compared.

Another shortcoming of the sample is that all participants were of European descent. It is conceivable that family caregivers from different cultures and backgrounds may cope differently. Future efforts should be made to recruit individuals from a wide variety of ethnic backgrounds. For the Lower Mainland area, in particular, individuals of Chinese and Indo-Canadian backgrounds would be of interest. In order to improve the probability of success in recruiting such individuals, it may be necessary to have bilingual or multilingual researchers or interviewers who could administer interviews and questionnaires in different languages such as Cantonese, Mandarin, or Punjabi. Such a multicultural approach would aid in more effectively targeting the content of support programs to meet the needs of different cultural groups.

Due to the small number of participants the current study was not able to assess the effects of various illness (e.g., severity of disease, recurrence, treatment phase), patient (e.g., functional status, age), and caregiver characteristics (e.g., gender, socio-economic status) that have been found in previous literature to play a role in the caregiving experience. In future studies, specific sub-populations could be studied independently or a sufficient number of caregivers in each sub-population could be recruited in the same study in order to address these variables.

Design Issues

Having caregivers recall their experiences without specific regard for the length of time in their caregiving role may have produced different descriptions than if they had been asked about their experiences at different points during their journeys. A longitudinal design where caregivers participate at different points in the caregiving trajectory may be fruitful. For example, caregivers could complete interviews and questionnaires following diagnosis, after treatment, and at 3 months, 6 months, and 12 months post-treatment. Multiple assessment points would provide a better understanding of caregiving experiences at specific phases of their loved one's illness.

A number of themes that were not common to all participants were identified. It is not known whether these themes are truly not aspects of all caregivers' experiences. It could be that they are, but that not all participants spoke about these aspects of their caregiving during the interview. Although interview transcripts were sent back to caregivers for validation purposes and they were invited to change, delete, or add comments, the research findings themselves were not validated directly by participants. An additional validation step could have been added that had participants review the

findings and confirm whether themes were indicative of their personal experiences. In this way, participants could be given the opportunity to indicate whether or not non-common themes were aspects of their own experiences.

Improvements in methodology related to sampling and design would enhance the current findings. The results of the study are valid because they do describe the experiences of the caregivers of brain tumour patients who participated. However, expanding the methodology in the ways described above would help to determine whether the findings would also apply to a population with differing illness, patient, and caregiver characteristics.

Conclusion

Family caregivers have become important members of the health care team in managing cancer. Thrust into their roles, usually with no preparation or warning, they become responsible not only for the physical care of their loved ones but also act as their loved one's main line of emotional support. Caregivers of brain tumour patients face the additional tasks of having to deal with personality and behaviour changes in their loved ones and, in many cases, poor prognoses. It is not surprising that these caregivers experience a great deal of strain in relation to all the caregiving demands and life changes that they face. By delineating the nature of the experience of caregiving for a loved one with a brain tumour this study sheds light on ways in which this strain can be reduced. Specifically the findings can be used to develop support programs for caregivers that target their particular concerns, needs, and experiences.

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APPENDIX A

SIMON FRASER UNIVERSITY

OFFICE OF RESEARCH ETHICS



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October 2, 2003

Ms. Colleen Poon
Graduate Student
Department of Psychology
Simon Fraser University

Dear Ms. Poon:

Re: Caregiving for loved ones with a brain tumour
B.C. Health Research Foundation

The above-titled ethics application has been granted approval by the Simon Fraser Research Ethics Board, in accordance with Policy R 20.01, "Ethics Review of Research Involving Human Subjects".

Sincerely,

Dr. Hal Weinberg, Director
Office of Research Ethics

APPENDIX B

CODEBOOK FOR QUALITATIVE ANALYSIS

- A01** Provides emotional support to patient, including being there, talking, listening, comforting
- A02** Attends appointments with patient, often to know what's happening and to hear for self what doctor says, to be second set of ears (note taker), to help explain things
- A03** Does household chores such as laundry, cleaning, running errands, grocery shopping
- A04** Helps patient with medications by way of administration or reminders
- A05** Encourages patient to be involved, feel useful, to stay positive
- A06** Coordinates/organizes/plans for medical appointments, home, supervision
- A07** Does driving or arranges for transport for transfer to medical appointments, running errands
- A08** Does everything
- A09** Makes sure patient is eating well
- A10** Gets patient to exercise
- A11** Helps patient with bathing, dressing, eating, toileting
- A12** Not needing to do much caregiving (usually with reference to physical care)
- A13** Does social things with patient
- A14** Makes sure patient gets rest
- A15** Mix of down times and busy times: Amount of caregiving varies from doing alot to doing less
- A16** Takes care of children
- A17** Provides financial help to patient
- A18** Reminds patient about things

- C1** Takes time off work/adjusts schedule: Had to make adjustments in routine or schedule (e.g., work) to do caregiving
- C4** Experiences financial difficulty/stress or noted thinking about financial situation

- C5** Deals with or getting used to personality and behaviour changes in patient (e.g., aggressiveness, perseverance, memory loss, paranoia, confusion)
- C6** Life not normal anymore: Has had to sacrifice personal ambitions or activities that would normally do; has needed to adjust various roles
- C7** Put on [cancer] path, accept it
- C8** Caregiving is a constant job
- C9** Everything revolves around patient: Patient is first priority

- CON1** Physically fatigued or tired
- CON2** Developed health problems/conditions
- CON3** Some aspects of caregiving were positive (e.g., rewarding, became closer)

- COPE1** Trying to live life as normally as possible
- COPE2** Taking one day at a time
- COPE3** Keep going on with life, carry on
- COPE4** Protect self emotionally (e.g., try not to get upset, minimize, humour, denial)
- COPE5** Feel fortunate in own situation; other people are worse off
- COPE6** Think positively, optimistically
- COPE7** Have to be patient (e.g., to deal with patient's behaviour)

- D1** Making decisions to address symptoms; making decisions about illness/treatment (problem-solving); calling for medical help or getting patient to go to doctor
- D4** Making decisions regarding family situation

- DR1** Frustration with doctors/medical care/health care system (e.g., lack of coordination within medical system)
- DR4** Doctors had poor bed side manner (e.g., in delivering prognosis, provided little hope)
- DR6** Difficulty getting prognosis information from doctors
- DR7** Health care professionals (e.g., doctors, nurses) and health care system are doing a good job, feel getting good care

- E01** Feels sense of responsibility towards patient; it's where caregiver has to be
- E02** Feelings of uncertainty (regarding diagnosis, prognosis, death, possible recurrence, effects of illness)
- E03** Feelings of fear and anxiety surrounding illness
- E04** Emotionally stressed/exhausted
- E05** Has regrets
- E06** Feelings of frustration
- E08** Feel inadequate as caregiver (i.e., could not manage, was ill-equipped)
- E09** Feelings of resentment or wanting to ward off resentment
- E10** Feeling guilty about taking time for self
- E12** Having to deal with issues of patient independence (it being taken away or trying to maintain)
- E15** Feelings of shock/surprise regarding diagnosis/prognosis

F1 Address reactions and coping of children

F4 Addressing others about patient's situation (dealing with reactions, keeping people up to date)

INTERPRET Making sense of what is observed with respect to symptoms, changes, diagnosis, etc.

M1 Notices changes in behaviour and/or personality

M3 Monitors how patient is doing, keeping an eye on things

N1 Need information about illness, about what to expect

N2 Need a list of available resources that they could access to help them with caregiving

N3 Need for reassurance that what they were doing was okay or how they were feeling was okay

N4 Need to make plans for the future (e.g., in case patient's situation worsened or resulted in death)

- R1** Need a break from caregiving situation
- R2** Need help from others, or notes importance of accepting help or asking for help
- R3** Need to do things for self and to take care of self
- R4** In speaking about need for respite, noted that there was a sense that no one could fulfill role of relieving caregiver
- R5** Need for respite but did not want to bother or burden others to help

- S01** Church or faith is source of support
- S02** Family members are source of support
- S03** Friends are source of support
- S04** Counsellors (e.g., social workers) are source of support
- S05** Organization (e.g., home care, blue cross, library) is source of support
- S06** Support group is source of support
- S07** Internet is source of support, usually in form of source of information, but also in the way of discussion groups
- S08** Was required to take initiative in finding resources or was not aware of any resources available for caregivers until found them by self
- S10** Expresses desire to help other caregivers in some capacity
- S11** Finds or needs support in the way of being able to talk to others, usually those who are in the same situation (i.e., other caregivers), or just someone to talk to (e.g., a family member or friend), or those knowledgeable about the situation (e.g., counsellors)
- S12** Found that personal support system was not adequate
- S13** Felt resources available to caregivers were inadequate and did not address needs
- S14** Finds support not in talking to others, but tends to cope on own
- S15** Written material (e.g., books, pamphlets) is source of support
- S16** Health care professional (e.g., doctor, nurse, medical staff) is source of support
- S17** Notes that there were resources that were available that they themselves did not use or have a need for

- T1** Hearing diagnosis or prognosis and being able to recall in very specific detail (e.g., date, day of week, etc.)
- T2** Goes through diagnostic tests (CAT, MRI, etc.) and treatment with patient, being able to recall specific details
- T3** Speaks of recurrence being diagnosed or thinking about possibility of recurrence happening in future
- T4** Notes rapidity with which sequence of events happened with respect to diagnosis and initial treatment
- T5** Course of dealing with illness includes side effects of treatment and medications
- T6** Unexpected occurrences with respect to diagnosis or prognosis, for example, changes or differences between doctors
- T7** Course of illness involves ups and downs for patient
- T8** Illness involves seizures in some way, usually witnessing them in the patient, often fearing or anticipating that one will occur