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Identifying the needs of brain tumor patients and their caregivers

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Abstract The purpose of this study is to identify the needs of brain tumor patients and their caregivers to provide improved health services to these populations. Two different questionnaires were designed for patients and caregivers. Both questionnaires contained questions pertaining to three realms: disease symptoms/treatment, health care provider, daily living/finances. The caregivers' questionnaires contained an additional domain on emotional needs. Each question was evaluated for the degree of importance and satisfaction. Exploratory analyses determined whether baseline characteristics affect responder importance or satisfaction. Also, areas of high agreement/disagreement in satisfaction between the participating patient-caregiver pairs were identified. Questions for which >50% of the patients and caregivers thought were "very important" but >30% were dissatisfied include: understanding the cause of brain tumors, dealing with patients' lower energy, identifying healthful foods and activities for patients, telephone access to health care providers, information on medical insurance coverage, and support from their employer. In the emotional realm, caregivers identified 9 out of 10 items as important but need further improvement. Areas of high disagreement in satisfaction between participating patient-caregiver pairs include: getting help with household chores

(P value = 0.006) and finding time for personal needs (P value < 0.001). This study provides insights into areas to improve services for brain tumor patients and their caregivers. The caregivers' highest amount of burden is placed on their emotional needs, emphasizing the importance of providing appropriate medical and psychosocial support for caregivers to cope with emotional difficulties they face during the patients' treatment process.

Keywords Brain tumor patient needs · Caregiver burden · Quality of life

Introduction

The focus of Neuro-Oncology at UCSF has traditionally been on improving therapeutic strategies to treat brain tumor patients. In addition to discovering and improving treatment, we recognize the importance to address the needs that affect the quality of life (QOL) in patients and their caregivers across the span of the illness. This study was undertaken to assess which needs were perceived by patients and caregivers as important and how well the needs were met to identify resources that could improve this aspect of care.

The incidence of primary brain tumors in the United States (US) is about 17,000 per year, with a case fatality of about 10,000 per year. Gliomas make up 80% of primary brain tumors and account for significant mortality. Gliomas can be classified as either low-grade (LGG) or high-grade (HGG). Despite medical management with surgery and irradiation the median 10-year survival rates for LGG range from 17 to 49%. HGG are extremely aggressive tumors and even with rigorous treatment, the median survival ranges from 1 to 3 years after initial diagnosis [1].

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Due to the shorter life expectancy in these populations, understanding and improving the QOL is important to patients and their caregivers. Moreover, several studies have shown that improved QOL is associated with prolonged survival in patients with head and neck cancer [2, 3]. Therefore, QOL is an imperative area that should not be overlooked in the disease management of cancer.

Many investigations have been undertaken to explore the multi-dimensional QOL of brain tumor patients. The instruments most commonly adopted by investigators are the FACT-BR (Functional Assessment of Cancer Therapy-Brain) [4] and the QLQ-BN20 [5]. The FACT-BR is a validated instrument and provides a comprehensive assessment of the emotional, social, psychological, and cognitive aspects of a brain tumor patient's life. The QLQ-BN20 addresses symptoms that are specific to brain cancer or its treatment. However, the FACT-BR and QLQ-BN20 do not examine the many other issues patients and caregivers are struggling with such as their disease management, healthcare and daily living needs.

Caregivers of brain tumor patients face unique challenges among caregivers of cancer patients [6]. In addition to cancer-related issues, they are routinely confronted with neuro-cognitive and neuropsychological issues prevalent among brain tumor patients such as alterations in functional status, cognitive status, and behavioral changes [7]. To date, little research has explored the specific needs of the caregivers of brain tumor patients, as most research is focused on improving patient outcomes (e.g., symptom management and QOL). Sherwood et al. [7] developed a conceptual model for providing care to a person with a primary malignant brain tumor. Their model described factors that may affect the caregiver's stress in response to this unique care situation. A cross sectional study performed by Sherwood et al. [6] identified that a patient's neuropsychiatric status consistently affected caregivers' depressive symptoms and burden. Schubart et al. [8] interviewed caregivers of brain tumor patients about their challenges and provided recommendations for improving the delivery of information about the patient's diagnosis and treatment, enhancing communication among patients, families, and health care providers, and providing psychosocial support for family caregivers. Northouse et al. [9] showed the following interventions: psychoeducational, skills training, and therapeutic counseling with caregivers of cancer patients significantly reduced caregiver burden, improved caregivers' ability to cope, increased self-efficacy and QOL.

A study performed in Australia used the Supportive Care Needs Survey (SCNS-34) to identify the unmet supportive care needs of brain tumor patient and caregivers. This study found that patients frequently reported that they required support to overcome fatigue, uncertainty about the future

and not being able to do the things they used to do [10]. Caregivers wanted help dealing with the following issues: their fear about the patient's mental or physical deterioration, the impact that caregiving had on their own lives, and the ability to reduce stress in the patient's life [10]. Leavitt et al. [11] described the experiences and needs of brain tumor patients who participated in support group meetings. They reported that support groups provided a specific therapeutic forum for patients with brain tumors and their families, especially regarding the difficulties of survival and maintaining quality of life after initial treatment.

This study was undertaken at UCSF with the aim to survey important issues of QOL thought to impact the lives of brain tumor patients and their caregivers. The targeted population consists of brain tumor patients of mixed types as well as their caregivers. In addition to members of the health care team, caregivers play an integral role in the treatment process of the patients. It is our hope that the knowledge gained from this study will help UCSF Neuro-Oncology and other clinics prioritize health services to focus on the important QOL aspects of brain tumor patients and their caregivers.

Patients and method

Subjects

This study was conducted at the University of California, San Francisco (UCSF) Neuro-Oncology clinic. The study was designed to enroll a heterogeneous population of primary brain tumor patients and their caregivers in different stages of the treatment process. Patients with any histological tumor types were eligible. The study was designed to enroll approximately 85 patients and 85 caregivers. This accrual goal was thought to be feasible over a period of 1 year based on the normal patient volume at our clinic. Patients must have had a histologically confirmed diagnosis of a primary brain tumor. Eligible caregivers were the primary caregiver of a patient with a brain tumor. No more than one caregiver for the same patient was included in the analysis. Professional caregivers who received financial reimbursement for caregiving services were excluded from the study. Other inclusion criteria for the patients and caregivers included: (1) over the age of 18, (2) English-Speaking, and (3) willing and able to complete questionnaires. Institutional Review Board approval was obtained prior to beginning the study. During patient clinic visits, potential participants were screened and identified by UCSF Neuro-Oncologists. Patients and caregivers who were interested and willing to complete the questionnaires were consented. Patients and caregivers were not required to participate as a pair.

Assessment

Eligible brain tumor patients and caregivers who agreed to participate in the study were each asked to complete a questionnaire. The two questionnaires, one for patients and one for caregivers, are structured similarly. Refer to the UCSF neurosurgery website for copies of the questionnaires [12, 13]. The questionnaires were modified versions of the Canadian Cancer Society patient and caregiver needs survey [14]. The Canadian Cancer Society [15] created the data collection instruments by reviewing literature and having key informant interview with cancer survivors, advocates, volunteers, and health professional. A factor analysis was applied to determine the relevant need domains. UCSF Neuro-Oncologists, nurses, and clinical researchers reviewed these questionnaires and felt the issues were also relevant to the UCSF brain tumor patient and caregiver population. Slight modifications were made to the wording of the questions to cater the items to a brain tumor patient and caregiver experience. Since no validated questionnaire exists to date that survey both brain tumor patients' and their caregivers' needs, we thought this was an ideal starting point to understand areas where health services can improve QOL in these populations. The patient needs questionnaire contains 28 questions divided into three major realms: disease symptoms and treatment (DST), health care provider (HCP), and daily living and finances (DLF). The Caregiver needs questionnaire consists of 41 questions with four domains, three of which mirror those in the patient questionnaire with an additional realm on emotional needs (EN). All questions in the patient questionnaire are included in the caregiver questionnaire with minor modification in wording to address the appropriate respondent. Questions are based on a Likert scale 1–5, with (1) being described as “not at all”, (2) as “a little bit”, (3) as “somewhat”, (4) as “quite a bit”, and (5) as “very much”. Every question is presented in pairs with the first item intended to evaluate the level of importance the respondent deems the issue and the second to assess the respondent's degree of satisfaction on the current status of the issue. Table 1 summarizes internal consistency for responses regarding the level of satisfaction in each questionnaire by domain. Internal consistency was very high, with Cronbach alpha above 0.82 for all the domains. Each domain provides a free-text field for the respondents to write additional comments about their needs, even though these comments are not included in the statistical analysis.

Statistical analysis

Data were analyzed using the statistical software R, version 2.7.1. Summary statistics and frequency distributions were generated for demographic and disease characteristic

Table 1 Internal consistency: Cronbach alpha

	Overall	DST	HCP	DLF	EN
Patient questionnaire	0.93	0.90	0.82	0.84	N/A
Caregiver questionnaire	0.96	0.92	0.85	0.88	0.92

Internal consistency are calculated based on the response for level of satisfaction in each questionnaire

variables. The frequency distributions of responses to each question were tabulated separately for patients and caregivers. The needs which subjects frequently identified as important but unsatisfied with were tabulated. The Wilcoxon Rank-Sum test was used to determine if subject's response to particular questions may differ by certain baseline characteristics. The association between two ordinal variables was assessed using Kendall's tau correlation coefficient when appropriate. It was also of interest to measure the level of agreement and disagreement between the participating pairs of patient and caregiver with regard to the common questions surveyed. The proportion of the patient–caregiver pairs whose difference in their responses was within one unit in the Likert scale was summarized; items for which the proportion exceeds 80% were identified as being highly agreed upon and those with less than 50% as disagreed upon. In addition, the Wilcoxon Signed Rank test was used to determine if the responses from the paired patients and caregivers tended to differ significantly. Due to the exploratory nature of this study, adjustment for multiple comparisons was not made and P values of ≤ 0.02 was used to indicate statistical significance.

Results

General

Overall 116 patients and 124 caregivers were approached to participate in the study but only 83 patients and 83 caregivers returned the questionnaires and were analyzed. Despite request, it is unknown as to why participants did not return the questionnaire as no follow up was performed. One patient was excluded due to not having a primary brain tumor. Sixty-three patients and 60 caregivers completed the questionnaires in clinic and 20 patients and 23 caregivers completed the questionnaires outside of the clinic. Patients who did not complete the questionnaire in clinic were given the option to complete the questionnaire at home and return it by mail.

Baseline demographics and disease characteristics are summarized in Table 2. The disease characteristics presented in the caregivers' column pertain to those of the patients they care for. Tumor grade was determined based

Table 2 Baseline and disease characteristics

Characteristics	Patients (<i>n</i> = 83) No. (%)	Caregivers (<i>n</i> = 83) No. (%)
Age (years)		
Median	49	50
Range	23–80	23–78
Sex		
Male	52 (63)	22 (27)
Female	31 (37)	60 (73)
Race		
White	68 (82)	–
Asian	4 (5)	–
Other or N/A	11 (13)	–
Education		
High school or less	19 (23)	19 (23)
Associate or bachelor's degree	34 (41)	38 (46)
Graduate/professional	30 (36)	23 (28)
Household income		
Under \$75,000	30 (36)	18 (22)
\$75,001–\$125,000	21 (25)	25 (30)
\$125,001–\$200,000	19 (23)	19 (23)
Over \$200,000	11 (13)	13 (16)
KPS		
Median	90	90
Range	60–100	60–100
Tumor grade (most recent surgery)		
II	22 (26)	18 (22)
III	25 (30)	24 (29)
IV	33 (40)	41 (49)
Unknown or N/A	3 (4)	–
Prognosis status*		
Stable disease (SD)	75 (90)	72 (87)
Progressive disease (PD)	8 (10)	11 (13)
Receiving chemotherapy at time of form completion		
Yes	32 (39)	37 (45)
No	51 (61)	46 (55)
Time from initial diagnosis (years)		
Median	1.6	0.8
Range	0.02–28	0.02–14.8

– data not collected

* Based on most recent clinic visit

on most recent surgery: among participating patients, 33 (40%) had grade IV tumors, 25 (30%) grade III, 22 (26%) grade II, and 3 (4%) with tumor grade undetermined or unavailable. The distribution of tumor grade is similar among patients whose caregivers participated in this study. The median KPS at time of questionnaire completion was 90 (range 60–100). Note only 2 patients had a KPS of 60 and 4 patients had a KPS of 70. About 80% of caregivers were either a spouse or partner of the patients. 87% of caregivers lived with the patient. The median time of caring for the patients was 9 months (range 1–180 months).

In general, the questions in the DST and EN domains had the highest completion rates i.e., the non-completion rate ranged from 0 to 12%. Non-completion was more prevalent in questions that surveyed respondent's satisfaction level in the DLF domain with non-completion range (11–49%). Since 'not applicable' was not a possible response option in the questionnaire, respondents were instructed to leave questions blank if they felt that the question was not relevant. For the most part, patients and caregivers indicated the level of importance for all the issues with high completion rates.

Table 3 Questions identified by both patients and caregivers as important and requiring improvement

Domain	Question	Patient		Caregiver	
		Very important (%)	Not satisfied (%)	Very important (%)	Not satisfied (%)
DST	Getting information about what causes brain tumors	60	52	49	61
	Dealing with the patients lower energy	53	42	65	46
	Knowing what foods and activities are good for the patient	55	37	76	44
HCP	Having telephone access to health care provider who knows me	68	29	82	30
DLF	Getting support and understanding from my boss or employer about my illness	48	29	53	33
	Understanding what is covered by benefits/extended medical insurance	67	47	77	55

Approximately $\geq 50\%$ of both patients and caregivers identified as “very important” and approximately $\geq 30\%$ of patients and caregivers felt “unsatisfied”

Satisfaction of needs among patients and caregivers

Table 3 summarizes the questions by domain for which greater than 50% of both patients and caregivers thought were “very important” and greater than 30% were relatively dissatisfied (“not satisfied”, “a little satisfied”, or “somewhat satisfied”) with their knowledge or support on the issue; thus indicating the areas where improvement is required at UCSF. Among these questions, the items that were identified by both patients and caregivers as important but require improvement over the current status quo include: understanding the cause of brain tumors, dealing with the patients lower energy, knowing what foods and activities are good for patients, telephone access to health care providers, medical insurance coverage, and support from their employer about their situation. Of note, in the HCP realm, the single item that was identified by the highest percentage of both caregivers and patients as very important is their need to feel respected by their health care provider (73% of patients and 77% of caregivers, respectively). Almost all respondents felt that this need is well met (97% patients and 97% caregivers).

Caregivers needs

Table 4 lists the areas identified by only the caregivers as important and requiring improvement. Caregivers tended to have higher dissatisfaction rates than patients in understanding how to manage symptoms and side effects regarding different treatments. In the emotional realm (surveyed only among caregivers), 9 out of 10 items were identified as very important but warrant further improvement. Among these needs, the items identified with the highest percentage of dissatisfaction include having the opportunity to talk to someone who has been through a similar experience (70%) and obtaining support to deal with their anxiety or stress (63%).

Factors that may affect importance or satisfaction of needs

Exploratory analyses were performed to determine if the respondents’ level of importance or satisfaction for a specific question differed by a certain baseline or disease characteristics. The demographic variables of interest included age, gender, education, and household income while disease variables included tumor grade and time from initial brain tumor diagnosis. Age and time from diagnosis was dichotomized at respective median values of the distributions. These analyses were conducted separately for patients and caregivers when appropriate. Older patients (≥ 49 years in age) tended to feel that information about home nursing care from community agencies is important (P value = 0.02). Patients who reported lower household income felt less satisfied with the level of support they received on coping with financial issues (P values = 0.002). In the emotional realm we compared the needs of male and female caregivers and found that females placed higher importance on obtaining support to deal with their anxiety and stress ($P = 0.0006$). Caregivers of patients diagnosed ≤ 1.6 years felt information about transporting to and from the healthcare facility and maneuvering around the health care facility is important ($P = 0.003$). There was no relationship found between the level of importance for any question and the tumor grade of the patient (all P values > 0.03), this may be due to small numbers of each grade and further evaluation is needed.

Patient and caregiver pairs

Sixty-one patients out of 83 participated with their caregiver as a pair. Among the participating pairs, we sought to determine their level of agreement and disagreement in satisfaction with respect to all issues surveyed. This subgroup analysis is restricted to the set of 28 questions that are included in both questionnaires. The baseline

Table 4 Areas caregivers identified as important and require improvements

Domain	Question	Caregiver	
		Very important (%)	Not satisfied (%)
DST	Knowing what symptoms I might experience and knowing what to do about them	89	44
	Knowing enough about the drugs I am taking (side effects, timing, and amount)	82	35
	Knowing enough about the side-effects of the treatments (e.g., radiation, chemotherapy)	86	33
	Knowing how to help the person I am caring for manage pain	69	32
HCP	Knowing which member of my patient's health care team to call regarding a particular problem	80	31
DLF	Getting information about the support services available to me	58	61
	Understanding the Family Medical Leave Act and how it applies to my situation	49	61
	Getting help with financial issues	55	52
EN	Having the opportunity to talk to someone who has been through a similar experience	52	70
	Finding ways to help the person I am caring for maintain the independence he or she wants	72	50
	Finding the best way to comfort and reassure the person I am caring for	81	49
	Being able to speak openly about the cancer with the person I am caring for	76	29
	Coping with the physical or emotional changes in the person I am caring for	81	58
	Coping with the changes in my social, work, and family life	62	60
	Dealing with the reaction to the illness of my family and friends	58	46
	Accepting the cancer diagnosis in the person I am caring for and the uncertainty about the future	84	58
	Support dealing with my anxiety or stress	64	63

Approximately $\geq 50\%$ of caregivers identified as “very important” and $\geq 30\%$ of caregivers felt “unsatisfied”

demographic and disease characteristics of these 61 pairs of participants were similar to those presented in Table 2 and hence are omitted here. For the purpose of summarizing the results, we defined “agreement” as the occurrence that a patient's response to a question is within one unit in the Likert scale of their caregiver. The questions where greater than 90% of the participating pairs agreed in satisfaction include understanding how doctors uses medical examinations (91%), understanding how to make appointments (91%), and feeling respected by the health care provider (95%). Areas that had high disagreement in satisfaction include: getting help with cooking, cleaning, and shopping (P value = 0.006), and finding time for personal needs (P value < 0.001). In both of these items caregivers tended to feel less satisfied compared to the patients.

Additional concerns noted by respondents

Our version of the questionnaire included a comment section at the end of each domain for additional concerns. In review of this section, patients and caregivers indicated information needs on the following topics: physical therapy, occupational therapy, holistic treatment options, mechanism of current treatments and recent publications, understanding the entire treatment timeline with various specialists and dealing with different medical opinions, applying to social security, and lodging near the hospital.

Discussion

Overall the questionnaires were able to explore the needs in the general population of brain tumor patients and their caregivers. In addition, within this heterogeneous population, the needs based on demographic factors and disease characteristics were explored. The analysis of the participating pairs showed the areas where patients and their caregivers agreed and disagreed. These findings highlight that healthcare services should focus on the specific needs based on the individual patient and caregiver.

The questions generated by this study can be used by other Neuro-Oncology clinics to understand the areas in which healthcare services are lacking. Patients and caregivers at UCSF identified understanding decisions about treatment options as their most important need. Patients were not satisfied with their knowledge in understanding the cause of brain tumors—suggesting that patients are interested in participating in more epidemiological studies to help researchers understand the causes of brain tumors. Caregivers identified having the opportunity to talk to someone who has been through a similar experience as not adequately addressed. According to Schubart et al. [8] effective strategies in providing specific information include providing clear communication of information and presenting the same information numerous times in different formats (e.g. spoken, written, on the web). Thus several of the brain tumor patients' and caregivers' needs

can be addressed through effective communication and providing information on available resources to them such as a nutritionist, social worker, and support groups.

This study demonstrated that the caregivers of brain tumor patients at UCSF need additional resources and information on coping with the emotional burden of the disease. These findings indicate that the information obtained during clinic visits is inadequate to satisfy these needs. Treating the caregivers' emotional needs can improve their quality of life and in turn improve the overall care of the patient. Since it is not feasible for most Neuro-Oncology providers to spend extensive time discussing the emotional impact of the disease with the patient and their caregivers, a social worker or psychologist, if not further psychiatric evaluation and counseling, may prove beneficial in helping families cope with a diagnosis of a brain tumor. The unifying theme in all the questions in the emotional domain is the caregivers' need to share the experience with someone else; thus, distributing information on support groups and educational sessions at clinic visits may be effective methods to satisfy this need. In addition providing information about foundations such as the American Brain Tumor Association (ABTA) or the National Brain Tumor Society (NBTS) are beneficial as they provide support based on the unique challenges brain tumor patients and their families face. Creating a treatment plan that encompasses medical, psychological, and social resources may improve healthcare services to these populations.

In this study we also observed the needs of brain tumor patients and their caregivers based on the different stresses and factors that can affect ones' quality of life. It is important to realize the difference in needs among the subgroups within this heterogeneous population and deliver healthcare services on an individual basis. There is also a disagreement in concerns between patients and their caregivers. For example, caregivers would like more information about assistance with daily chores (cooking, cleaning, shopping, etc.) because they are burdened with these responsibilities. In review of the comment section of the questionnaires, patients and caregivers indicated information needs on various topics ranging from support services as well as more information about the mechanism of treatment as well as recent publications in the medical literature. Designing a future study that incorporates these issues may create a stronger questionnaire catered to brain tumor patients and their caregivers.

Some limitations existed in the questionnaire design. The questionnaires were tailored for our patient population and were not validated. The questionnaires may not have included issues that patients and caregivers identify as important and unsatisfied. The questionnaires were also not designed to rank which needs were more important.

The responses of the patients and caregivers are a reflection of their experience at the UCSF Neuro-Oncology clinic and may not be generalizable to other settings. Several of the questions in the health care provider and disease, symptoms, and treatment domains are site specific; thus the results may not be extended to all brain tumor patients and caregivers. For example our study supported Schubart et al. [8] findings that families need information to make treatment decisions, but approximately 75% of the participants in this study were quite satisfied with this need at UCSF. Another limitation was that our study only explored the needs of English-speaking patients and caregivers; thus religious, cultural and ethnic differences in patient and caregiver needs were not explored. Also, the results of this study reflect patients and caregivers of patients with good performance status and it is likely that patients with lower performance status and their caregivers may report different needs.

Recommendations for future studies

In this study, patients and caregivers were enrolled regardless of the grade of the patient's tumor or time point along the treatment process. Future work should look at the needs of brain tumor patients and/or their caregivers of a specific population at a standard time point. It would also be interesting to compare the needs from different population of patients and caregivers. The staff involved in enrolling patients and caregivers noticed that those patients and caregivers of patients with poor performance status or were distressed at a particular clinic visit were enrolled in much lower numbers, thus those who are expected to be most burdened were not included. It may also be beneficial to explore how satisfied brain tumor patients are in coping with the diagnosis of such a devastating disease and compare the results with their caregivers. We are currently surveying the social priorities and the psychological impact of the possible loss of reproductive function in female patients undergoing therapy for primary brain tumors. After identifying the brain tumor patient's and caregiver's issues, a study can implement changes in their healthcare services that target those specific needs and measure the change in satisfaction rate to evaluate the effectiveness of the method.

Conclusion

The results of this study provide valuable insight into the improvement of services for brain tumor patients and their caregivers. Caregivers experience their highest amount of burden in the realm of emotional needs, elucidating the importance of providing support for brain tumor caregivers

to cope with the emotional difficulties they face during the patients' treatment process. In addition, it is important to recognize that health care services in these populations need to be delivered based on individual circumstances.

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