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Primary brain tumor patients' supportive care needs and multidisciplinary rehabilitation, community and psychosocial support services: awareness, referral and utilization

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Abstract

Primary brain tumors are associated with significant physical, cognitive and psychosocial changes. Although treatment guidelines recommend offering multidisciplinary rehabilitation and support services to address patients' residual deficits, the extent to which patients access such services is unclear. This study aimed to assess patients' supportive care needs early after diagnosis, and quantify service awareness, referral and utilization. A population-based sample of 40 adults recently diagnosed with primary brain tumors was recruited through the Queensland Cancer Registry, representing 18.9% of the eligible population of 203 patients. Patients or carer proxies completed surveys of supportive care needs at baseline (approximately three months after diagnosis) and three months later. Descriptive statistics summarized needs and service utilization, and linear regression identified predictors of service use. Unmet supportive care needs were highest at baseline for all domains, and highest for the physical and psychological needs domains at each time point. At follow-up, participants reported awareness of, referral to, and use of 32 informational, support, health professional or practical services. All or almost all participants were aware of at least one informational (100%), health professional (100%), support (97%) or practical service (94%). Participants were most commonly aware of speech therapists (97%), physiotherapists (94%) and diagnostic information from the internet (88%). Clinician referrals were most commonly made to physiotherapists (53%), speech therapists (50%) and diagnostic information booklets (44%), and accordingly, participants most commonly used physiotherapists (56%), diagnostic information booklets (47%), diagnostic information from the internet (47%), and speech therapists (43%). Comparatively low referral to and use of psychosocial services may limit patients' abilities to cope with their condition and the changes they experience.

Keywords: brain tumors, supportive care needs, community services, neuro-oncology, quality of life, service delivery

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Introduction

Primary brain tumors are rare, accounting for 1.4% of all cancers by incidence, but have high rates of morbidity and mortality [1]. People diagnosed with primary brain tumors experience high levels of physical, neurological, cognitive and psychological morbidity, and subsequent changes in family, occupational and social roles [2,3]. A number of studies have documented impairments to patients' functional outcomes and high rates of unmet supportive care needs [4-6]. Treatment guidelines for adults diagnosed with gliomas (the most common primary brain tumors) recommend that patients be offered multidisciplinary rehabilitation to address residual deficits during and following treatment [7,8]. Referral to information, support and counseling services, and sources of practical assistance, are also recommended to address patients' concerns and needs [9,10]. Despite these recommendations, the extent to which adults diagnosed with primary brain tumors utilize resources or services to address their psychosocial, informational, or practical needs is uncertain.

Research with other cancer populations suggests that unmet needs vary across the cancer journey and depend on whether health services respond to their needs [11]. In neuro-oncology, research is limited regarding both how needs vary across the disease trajectory, and which resources and services are utilized by patients to meet their needs. Most research examining quality of life, function or supportive care needs has been cross-sectional and thus not able to assess changing needs. This research has also primarily been conducted among highly heterogeneous samples, such as patients at any stage of the disease trajectory [2,12], or highly selected samples, such as patients undergoing specific treatments [13,14] or receiving palliative care [15,16]. Research regarding service utilization is equally limited. In the state of Victoria, Australia, doctors reported that 70 of 828 glioma patients treated in the study timeframe were referred for rehabilitation, and two were referred to a psychologist or psychiatrist [17]. A similar US study reported that 65 of 565 patients were discharged to rehabilitation following surgery [18]. In the UK, over 80% of responding clinicians caring for glioma patients reported that they had referral access to a neurologist, physiotherapy, speech therapy and clinical trials; 60-70% had access to an epilepsy nurse, rehabilitation, occupational therapy, social work, counselor, complementary therapies, a neuro-psychologist, and support group; and 50% had access to clinical psychology [19]. However, the proportion of patients referred to these services varied considerably: approximately 1 in 5 clinicians reported that they referred up to half their patients to physiotherapy, and half to occupational therapy. In contrast, 32% of clinicians referred no patients to a neuropsychologist by, and 45% referred no patients to a social worker. Two retrospective case reviews from the UK also reported disparities between patient problems and allied health service use among glioma patients receiving palliative care [20,21].

Understanding primary brain tumor patients' use of health and support services, together with their physical and psychosocial experiences, is essential to develop service delivery models and interventions to meet their needs. Patients' needs and service utilization across the initial treatment and post-treatment period in particular have been understudied. This period is particularly important as patients adjust to changes in physical and cognitive functioning, communication, and work and social roles, and establish relationships and interaction patterns with health professionals and services [22,4]. This study aimed to ascertain the unmet supportive care needs of adults diagnosed with primary brain tumors in the first six months after diagnosis, and the services used by patients to address their needs. Further, the study aimed to understand the nature of the relationship between patients' health and psychosocial outcomes, and their service use.

Methods

Approval for this study was obtained from Queensland University of Technology Human Research Ethics Committee and the Queensland Cancer Registry (QCR). A longitudinal interviewer-administered survey study was conducted, with data collected from the QCR, and from participants at two time points: baseline (at approximately three months after diagnosis) and follow-up (six months after diagnosis).

Participants and procedures

To obtain a representative population-based sample, patients were selected from the QCR, which records all diagnoses of primary brain tumors occurring in the state. Eligible patients were newly diagnosed (≤ 3 months previously) with any type of primary brain tumor, and at least 18 years old in 2013. Due to the concurrent conduct of another study through the QCR targeting young adults with cancer, and to prevent potential distress caused through repeated requests for study participation, only persons aged 25 years and older were approached for this study. Patients' treating clinicians were initially approached to obtain permission to contact patients and to screen for further eligibility criteria, which required that, in the clinician's opinion, each patient: 1) had a life expectancy of at least three months; 2) was aware of their diagnosis; 3) was competent to give informed consent; and 4) had sufficient English language comprehension and hearing to comprehend study materials and complete telephone interviews.

After obtaining permission from treating doctors, patients were sent a letter signed by their doctor, participant information sheet, consent form and pre-paid return envelope. Non-respondents were sent one reminder letter after two weeks. After written consent was obtained, patients were telephoned to complete standardized questionnaires. These were administered immediately after recruitment, and approximately three months later. Data was collected by telephone to allow the participation of patients with visual, speech or motor impairments; we have successfully used this approach in our previous research [23]. As it was expected that some patients might experience physical, cognitive or neuropsychiatric symptoms which could impair their capacity to participate and/or to understand their right to withdraw from the study (which is an element of informed consent), patients were invited to nominate a family member or friend to participate. The interviewer also informally assessed patient competence at the beginning of each interview. In the event of these changes, and with the prior consent of the patient and carer, (proxy) data was sought from the carer on the patient's behalf. Carer proxy reports have been shown to be congruent with brain tumor patient report of symptoms [24] and quality of life [25], providing a feasible approach to collect this information when patients are unable to participate.

Measures

Demographic (age, gender, postcode) and tumor characteristics (date of diagnosis, tumor type, grade, lobe, laterality and grade) were collected from the QCR. Data collected from participants included patients' demographic (age, gender, education, household income and work status) and medical characteristics (date of diagnosis, tumor type, side, malignancy, treatments received). Participants also reported patients' functional outcome at baseline and follow-up using the Katz Index of Independence in Activities of Daily Living and, to assess function relating to more complex activities which may be affected by more mild neurological or cognitive impairments, the Lawnton-

Brody Instrumental Activities of Daily Living. In the event that a carer provided proxy data for a patient, carer demographic characteristics and relationship to the patient were collected.

Supportive care needs

Supportive care needs were assessed using the Supportive Care Needs Survey short form (SCNS-SF) [26] and brain tumor-specific supportive needs items developed by Janda et al. [2]. Participants reported the magnitude of each need over the past month on a 5-point scale (ranging from no/met need to high unmet need). Items were combined to yield scores on five general domains: physical/daily living, psychological, patient care and support, sexuality, and health system and information needs, and the brain tumor-specific domain. Average supportive care needs scores, standardized to 0-100 with higher scores indicating higher levels of need, were calculated for each domain as recommended by McElduff et al. [27]. The proportion of patients reporting moderate or high levels of unmet need were also calculated.

Service Utilization Survey

Awareness of, referral to and use of supportive services was collected at follow-up only using a questionnaire developed by Beesley et al. [28], modified for brain tumor care through literature review and consultation with consumers and health professionals. The final questionnaire listed 32 individual services, resources or sources of support, divided into four categories: information sources and services; health professionals; support services; and practical assistance and was judged by consumers and health professionals to have face and content validity. A full list of services or sources of support is provided in Appendix 1. For each item, participants were asked if they were 'aware of' the service, had even been 'referred to' the service by a health professional (whether or not as part of a formal referral process), and if they had ever utilized the service (yes or no). Participants who were not aware of a service were asked if they 'would have used' the service, had they been aware of it.

Secondary outcomes collected from participants included distress (Distress Thermometer [29]), quality of life (Functional Assessment of Cancer Therapy-Brain [30,31]) and functional outcome (Katz Index of Independence in Activities of Daily Living [32] and Lawnton-Brody Instrumental Activities of Daily Living [33]). With the exception of service utilization, all quantitative measures were collected at each time point. Following completion of follow-up quantitative data collection, short qualitative interviews were also conducted to explore barriers and facilitators to service use. The results of the qualitative analysis will be reported separately.

Statistical methods

Descriptive analyses characterized the sample and summarized outcomes at each time point. T-tests or Mann Whitney U tests were used to compare scores over time, depending on variable normality. Linear regression was used to identify independent predictors of categories of service use (based upon the number of services in a category used by participants). As multiple comparisons may result in an incorrect rejection of the null hypothesis (false positive), specific hypotheses were developed to examine relationships between patient need and service utilization:

- Are health system and information needs (at either time point) associated with use of information services or sources?

- Are distress levels or psychological needs (at either time point) associated with use of support services?
- Are physical needs (at either time point) associated with use of health professionals?
- Are patient care and support needs (at either time point) associated with use of practical assistance?
- Are brain tumor specific needs (at either time point) associated with use of any categories of services?

Results

Participants

Two hundred and twelve persons were identified as meeting eligibility criteria through the QCR over the five month recruitment period. Ninety-seven patients were invited to participate after consent was obtained from clinicians, resulting in a sample of 40 patients (18.9% of all potentially eligible patients). Data was available for 40 patients (collected directly from 29 patients and from 11 via proxies) at baseline, and for 32 patients (collected from 23 patients and nine via proxies) at follow-up. Comparison of the demographic (age, gender, area of residence) and tumor (histology, grade, location and side) characteristics of the 40 participants and 182 non-participants showed no significant differences between groups. Participants who did not complete the study (due to death, n=4, or loss to follow-up, n=4) had lower levels of education than participants who completed the study (p=0.01) but these groups did not differ on any other demographic, disease or treatment characteristics.

Patients were predominantly male (58%), married (83%) and living in a major city (55%). Approximately one third of patients were educated to year 10 or less, and lived in a household with a gross income of less than \$40,000 per year. Patients were most commonly retired (43%) or permanently ill, disabled or unable to work (30%). In sixty percent of cases, the patient reported having a malignant tumor (Table 1), most commonly a glioblastoma (40%). The majority of patients received surgical debulking (88%), radiotherapy (58%) and chemotherapy (60%). Three quarters of participants self-reported full function for activities of daily living at baseline and 68% reported full function at follow-up. Mean scores for instrumental function were (out of a possible score of 8, representing full function) 5.2 (standard deviation 2.24) at baseline and 5.81 (standard deviation 2.28) at follow-up.

Patient data were reported by a family member or friend at baseline in 11 cases. The median age of proxy participants was 55 (range 42-65) years. Proxy participants were most commonly female (73%), married (55%), educated to a junior high school level or less (36%), and earned less than \$40,000 per year (73%). Proxy participants were most commonly the spouse or partner of the patient (64%).

Patient supportive care needs

The highest mean supportive care needs score at each time point was for physical needs, closely followed by psychological needs (Table 2). Over time, mean scores in all domains except for sexuality significantly declined. This decline was greatest for the patient care and support needs domain (mean 15.9 point decrease). Interestingly, when scores were compared between patients with

malignant and benign tumors, we found that although there were significant differences in scores by malignancy for at least one time point for four domains (health system & information needs, physical needs, psychological needs, sexuality needs), needs scores still declined (albeit not necessarily significantly) in each domain for patients with malignant tumors and those with benign tumors (Figure 1).

The ten items for which the highest proportion of patients reported moderate or high levels of unmet needs at each time point are shown in Table 3. At each time point, not being able to do the things you used to do, lack of energy or tiredness, uncertainty about the future, and feeling like you are not the same person as you were before the brain tumor were reported as moderate or high unmet needs by more than 40% of participants.

Service utilization

Patients' awareness of, referral to and use of support and rehabilitation services since diagnosis are shown in Table 4. All patients reported being aware of at least one information source, and one health professional, and a high proportion reported awareness of at least one support service (97%) and practical assistance service (94%). Around half of participants were referred to at least one support service (47%) or practical assistance (56%), with higher proportions referred to at least one information source or service (66%) or health professional (81%). Similarly, half of participants reported using at least one support service, and practical assistance. The majority of participants used at least one information source or service (78%) and accessed at least one health professional (88%). The mean number of services used by patients was highest for health professionals and lowest for support or counseling services.

At the individual level, awareness was highest for speech therapists (97%) and lowest for the Brain Tumour Alliance Australia (BTAA, a consumer organization, 0%). Referrals and service utilization were both highest for physiotherapists (77% of those aware were referred, and 60% used this service). In contrast, no participants reported being referred to BTAA, exercise physiologists, psychiatrists, financial counselors or advisors, or a wig and turban service, and usage rates followed these trends. Participants who were not aware of services were provided with information about these services, and asked if they would have used them if they had been aware. Services most desired by those not aware were the Cancer Council Queensland Brain Tumour Support Service (100% of those not aware), information booklets on their diagnosis (82%), care coordinator (80%), counseling service (80%), peer support group (78%) and social/welfare worker (75%).

Relationship between needs and service use

Results of hypothesis testing to identify predictors of use of different categories of service utilization are shown in Table 5. Distress thermometer score at baseline ($b=0.40$, $t(30)=2.40$, $p=0.023$), supportive care needs psychological domain scores at baseline ($b=0.49$, $t(30)=3.05$, $p=0.005$) and follow-up ($b=0.55$, $t(30)=3.60$, $p=0.001$), and brain tumor-specific need scores at both baseline ($b=0.56$, $t(30)=3.70$, $p=0.001$) and follow-up ($b=0.43$, $t(30)=2.61$, $p=0.14$) were significantly associated with greater use of support services. For example, for every one point increase in distress thermometer score at baseline, participants used 0.18 more support services. Greater use of a variety of health professionals was predicted by physical needs ($b=0.51$, $t(30)=3.27$, $p=0.003$) and

brain tumor-specific needs, both at baseline ($b=0.38$, $t(30)=2.24$, $p=0.32$). Brain tumor-specific needs at follow-up also predicted use of information sources or services ($b=0.38$, $t(30)=2.23$, $p=0.033$).

Discussion

Our data suggest that the unmet needs of patients with brain tumors early in the disease trajectory are highest for physical and psychological needs, consistent with that found for heterogeneous samples of cancer patients [34,35]. Our results also agree with previous longitudinal studies with cancer populations [36,37,11] which show a decline over time in the prevalence of unmet needs. This held true for both patients with malignant tumors and those with benign tumors, although the needs were lower overall for those with benign tumors (likely due to the resolution of their disease). This decline over time, particularly in patient care and support needs, may reflect the completion of initial treatments and post-operative recovery from surgery. Conversely, given that malignant brain tumor patients in particular are known to experience significant declines in physical and cognitive function over time [38], the decline seen may have resulted from an increase in the degree to which patients' needs were met by the healthcare system or other sources of support. This decline cannot be taken as evidence, however, that the needs of this population are not significant; the high rates of unmet need suggest much further support is required.

In fact, the results of our study suggest that recently diagnosed primary brain tumor patients may have higher levels of unmet needs than previous studies report. Using the same questionnaire, Janda et al. found that 36-44% of 75 primary brain tumor patients in Queensland, Australia had a moderate to high need for help with the top five most prevalent need items [2], which is somewhat lower than the 50-69% found in this study at baseline. In the US, using an original survey, Parvataneni et al. [39] reported that six of the 28 needs – which at least half of both patients and caregivers identified as “very important” – were not met for 29-52% of 83 patient participants. The greater prevalence of unmet needs in the present study likely reflects the differences between studies in time since diagnosis, as only 46% of the Janda et al. sample had been diagnosed in the past five years, and the median time since diagnosis for the Parvataneni et al. sample was 1.6 (range 0-28) years. Given these findings, further prospective longitudinal studies are needed to examine how the needs of primary brain tumor patients change across the entire disease trajectory.

Overall, this study found relatively low awareness of, referral to or use of supportive services, particularly considering the levels of unmet need. While most patients were aware of at least one service within each category, awareness of individual services varied considerably. In the health professional services category, at least 80% of participants reported being aware of four of the seven services. Awareness of health professional services was much higher than awareness of support services, where only one service out of 10 was known by 80% or more of participants. Awareness of practical services (one item of nine known by at least 80%) and information sources/services (one item out of six known by 80%) was also much lower. Our results concur with those of Burns et al. [40], who found that advanced cancer patients had greater recognition of allied health professionals compared to other supportive services, programs and institutions. These differences in awareness of services may reflect the general population's greater familiarity with services offered by health professionals such as physiotherapists and speech therapists, compared with services targeted towards people affected by cancer or brain tumors. Sources of information about services may

influence this awareness, as patients receive information about community services largely from informal and commercial services [40].

Differences in service use across categories largely reflect differences in awareness, and likely also differences in access. For example, physiotherapy services are routinely offered in most Australian hospitals following surgery, whereas patients must know support groups are available and take action to find a group and physically attend. Other access barriers may be financial [41], geographical or otherwise related to the burden of attendance [41], suggesting alternative modalities (eg telephone, internet-based services) of services should be explored. Negative attitudes towards psychosocial support on the part of patients and health professionals may also have influenced service utilization. Approximately half of distressed cancer patients do not access, or refuse, psychosocial services [42-44], and some individuals see accepting such a referral as a sign of personal weakness or outside their expectations for how a cancer patient should act [44]. Interventions to encourage cancer patients to communicate with health professionals about challenging issues [23] and to seek support [45] have been developed, but greater implementation of these interventions in practice may be needed. Health professionals also play a central role in overcoming stigma and encouraging patient utilization of needed services [46]. Our results suggest health professionals more commonly referred patients to other health professionals compared to support services, despite average levels of patients' need being very similar for physical and psychosocial issues. The reasons for this are not known, but a recent systematic review reported that health professionals' negative perceptions of psychosocial care, not knowing enough about psychosocial services, and organizational issues were key barriers to their referral of patients to psychosocial care [47]. It has previously been suggested that the fragmented health care system may lead to a diffusion of responsibility regarding whose role it is to refer patients to support [48] and organizational change may be needed to overcome this. However, professional education for clinicians in discussing patients' psychosocial issues and information about available services may also facilitate discussion about psychosocial issues and referral to support services.

Limitations

Recommendations for further research arise from the limitations from our study. The patient consent rate of 43% (overall response rate of 18.9%) may be evaluated as positive given this was a cancer registry-based study [49], with no prior contact between patients and the research team. The population-based sampling method used increases the generalizability of the results, although verification of these findings in a larger, national study is recommended. This study may also have underestimated the unmet needs of this sample. Although actions were taken to enable the participation of patients with neurological and/or cognitive impairments (e.g. conducting data collection by interview rather than paper-based survey; allowing proxy participation), that three quarters of the sample reported full function at baseline suggests more disabled patients (potentially with correspondingly higher levels of unmet needs) may not have participated.

Triangulation of data regarding referrals and service utilization is also recommended, with data collected both from patients and from health services longitudinally. Further validation and assessment of the psychometric properties of the service utilization survey is also required. As our data were collected by patient self-report or from a proxy, it is possible that patients did not accurately recall the services they were offered or used, were influenced by social desirability bias,

or that they took up some referrals at a later point. Furthermore, although the use of carer proxy ratings enabled the participation of more impaired patients (improving the representativeness of the sample), the accuracy of data regarding supportive care needs and service utilization is not known. Some studies suggest carer proxies may report slightly poorer outcomes than patients do when patients have poorer performance status [24,50], but other studies have found no systematic differences [25,51]. This study suggests that there is a small relationship between unmet needs and service use for some domains and some time points, but the small sample size limits the conclusions which can be drawn. Given that some statistically significant associations were shown, further investigation into these relationships in future studies is warranted.

Conclusion

Despite guidelines emphasising the need for the provision of psychosocial care and referral to information, practical assistance and allied health care services, many brain tumor patients have unmet needs and are not aware of services available. That this has been demonstrated among patients during the early diagnosis/treatment period, when contact with health services is perhaps the highest it will be for any point across the disease trajectory, is particularly concerning. Given the comparatively low referral to and use of psychosocial support services, health professional training in psychosocial needs assessment and communication about these issues may be needed.

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Conflict of Interest: The authors declare that they have no conflict of interest.

Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent: Informed consent was obtained from all individual participants included in the study.

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Table 1: Patients' demographic, disease and treatment characteristics

Characteristic	Number	%
Male	23	57.5
Marital status		
Married/living together	35	87.5
Other (divorced, widowed, never married)	5	12.5
Education		
Junior high school (grade 10) or less	12	30.0
Senior high school (grade 12) or less	9	22.5
Trade certificate, technical college, diploma	10	25.0
University degree (Bachelor or higher)	9	22.5
Work status		
Employed (full time, part time or casual)	10	25.0
Retired/full-time home duties/carers	18	45.0
Permanently ill/disabled/unable to work	12	30.0
Income		
< \$40,000/year	13	32.5
\$40,000-<\$80,000/year	13	32.5
≥\$80,000/year	11	27.5
Don't know or do not wish to answer	3	7.5
Location (using ASGC ^a remoteness categories, based on postcode)		
Major city	22	55.0
Inner regional	14	35.0
Outer regional	4	10.0
Tumor malignancy (self-report)		
Malignant	24	60.0
Benign	14	35.0
Don't know	2	5.0
Tumor type (self-report)		
Glioblastoma	16	40.0
Meningioma	9	22.5
Astrocytoma	3	7.5
Oligodendroglioma	2	5.0
Other/don't know	10	25.0
Tumor laterality (self-report)		
Left	19	47.5
Right	15	37.5
Both/don't know	6	15.0
Tumor lobe (QCR ^b record) ^c		
Frontal	10	32.3
Temporal	9	29.0
Parietal/occipital	4	12.9
Sub-cortical	3	9.7
Meninges	4	12.9
Other	1	3.2
Treatments received (tick all that apply)		
Surgical debulking	35	87.5
Radiotherapy	23	57.5
Chemotherapy	24	60.0
Cancer Grade (QCR ^b record, WHO criteria) ^d		
Low grade (grade I or II)	12	43.4

High grade (grade III or IV)	15	55.6
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^a ASGC: Australian Standard Geographical Classification

^b QCR: Queensland Cancer Registry

^c Tumour lobe was only available for 27 participants

^d WHO: World Health Organization criteria; cancer grade was only available for 27 participants

Table 2: Change in supportive care needs scores over time

	Baseline		Follow-up		Change	p-value
	N	Mean (SD) ^a	N	Mean (SD)	Mean (SD)	
Supportive care needs						
Psychological needs	40	45.8 (25.1)	32	35.6 (27.5)	-8.8 (14.3)	0.001*
Health system & information needs	40	37.9 (17.4)	32	27.8 (16.5)	-9.9 (22.4)	0.014*
Physical needs	40	47.9 (26.3)	32	38.9 (27.6)	-7.5 (22.7)	0.044*
Patient care & support needs	40	30.4 (13.2)	32	13.0 (16.4)	-15.9 (16.6)	<0.001*
Sexuality needs	35	34.8 (28.6)	28	29.2 (35.3)	-6.3 (31.0)	0.244
Brain tumor specific needs	40	32.5 (19.6)	32	21.9 (16.1)	-9.5 (15.1)	0.001*

^a SD: Standard deviation

* p<0.05

Table 3: Five most prevalent supportive care needs at each time point

	Top 10 (general or brain tumor-specific) items at baseline	N (%) reporting moderate/high unmet needs ^a	Top 10 (general or brain tumor-specific) items at follow-up	N (%) reporting moderate/high unmet needs ^a
1	Concerns about the worries of those close to you	27 (69.2)	Lack of energy/tiredness	16 (50.0)
2	Not being able to do the things you used to do	25 (62.5)	Not being able to do the things you used to	16 (50.0)
3	Lack of energy/tiredness	24 (60.0)	Anxiety	15 (46.9)
4	Uncertainty about the future	21 (52.5)	Feeling like you are not the same person you were before the brain tumor	15 (46.9)
5	Feeling like you are not the same person you were before the brain tumor	20 (50.0)	Uncertainty about the future	14 (43.8)

Physical need
 Psychological need
 Brain tumor specific

^a Proportions differ with the same number of patients due to missing data

Table 4: Awareness of, referral to and use of services

Service	Aware N (%)	Referred N (% among those aware)	Utilized N (% among those aware)	Would have used if aware N (% among not aware)
Information sources & services	Mean number used: 1.34 (SD 1.18)			
Information booklets on diagnosis	18 (56.3)	14 (82.4)	15 (83.3)	9 (81.8)
Information on your diagnosis available on the internet	28 (87.5)	4 (22.2)	15 (57.1)	0
Brain tumor or cancer telephone lines	17 (53.1)	4 (44.4)	5 (31.3)	7 (58.3)
Brain tumor awareness or information forums/seminars	11 (34.4)	3 (37.5)	4 (36.4)	9 (64.3)
Cancer Council Queensland	16 (50.0)	4 (25.0)	3 (18.8)	10 (100)
Brain Tumour Support Service	0	0	0	10 (71.4)
Brain Tumour Alliance Australia	0	0	0	10 (71.4)
Health professionals	Mean number used: 2.13 (SD 1.60)			
Care coordinator	16 (50.0)	11 (84.6)	12 (75.0)	8 (80.0)
Physiotherapist	30 (93.8)	17 (77.3)	18 (60.0)	0
Occupational therapist	26 (81.3)	14 (70.0)	13 (50.0)	2 (66.7)
Speech therapist/pathologist	31 (96.9)	16 (84.2)	14 (46.7)	0
Rehabilitation service/ specialist	16 (50.0)	6 (60.0)	5 (33.3)	1 (25.0)
Exercise physiologist	6 (18.8)	0	0	10 (55.6)
Dietician or nutritionist	27 (84.4)	7 (46.7)	6 (22.2)	1 (33.3)
Support services	Mean number used: 0.88 (SD 1.31)			
Face-to-face support group	12 (37.5)	2 (25.0)	1 (8.3)	10 (66.7)
Telephone support group	11 (34.4)	3 (50.0)	3 (30.0)	8 (57.1)
Online support group	9 (28.1)	1 (20.0)	2 (25.0)	6 (35.3)
Peer support group	8 (25.0)	3 (42.9)	1 (12.5)	14 (77.8)
Religious support	19 (59.4)	3 (27.3)	7 (36.8)	1 (11.1)
Coping workshop/program	8 (25.0)	1 (33.3)	1 (20.0)	10 (55.6)
Counseling service	20 (62.5)	4 (36.4)	6 (30.0)	4 (80.0)
Psychologist	26 (81.3)	6 (46.2)	6 (26.1)	1 (33.3)
Psychiatrist	25 (78.1)	0	0	1 (33.3)
Neuro-psychologist/ neuro-psychiatrist	7 (21.9)	1 (33.3)	1 (16.7)	11 (73.3)
Practical assistance	Mean number used: 1.31 (SD 1.60)			
Social worker/ welfare worker	25 (78.1)	8 (57.1)	7 (28.0)	3 (75.0)
Patient Travel Subsidy Scheme	15 (46.9)	11 (91.7)	11 (73.3)	3 (42.9)
Accommodation assistance	15 (46.9)	7 (63.6)	8 (53.3)	4 (66.7)
Financial counselor/advisor	15 (46.9)	0	3 (21.4)	4 (57.1)
Wig & turban service	9 (28.1)	0	0	3 (37.5)
Look Good Feel Better program	8 (25.0)	2 (33.3)	3 (37.5)	4 (36.4)
Community health nurse/ home nursing service	28 (70.0)	5 (41.7)	5 (18.5)	1 (50.0)
Respite care	27 (84.4)	1 (3.7)	2 (7.4)	0
Palliative care	24 (60.0)	3 (33.3)	3 (13.0)	0

SD: Standard deviation

Differences in totals reflect missing data

Table 5: Estimated influence of supportive care need and distress variables on categories of service use among 32 participants with primary brain tumors by linear regression

Outcome	Predictor	Time point	Unstandardize d B ^a	SE ^b	Standardized Beta	R square	p-value
Number of information sources/ services used	Health system & information needs	Baseline	-0.002	0.013	-0.023	0.001	0.900
	Health system & information needs	Follow up	0.010	0.013	0.142	0.020	0.440
	Brain tumor-specific needs	Baseline	0.018	0.011	0.285	0.081	0.114
	Brain tumor-specific needs	Follow up	0.028	0.012	0.377	0.142	0.033*
Number of support services used	Distress	Baseline	0.184	0.077	0.401	0.160	0.023*
	Distress	Follow up	0.154	0.079	0.334	0.111	0.062
	Psychological needs	Baseline	0.024	0.008	0.487	0.237	0.005*
	Psychological needs	Follow up	0.026	0.007	0.549	0.302	0.001*
	Brain tumor-specific needs	Baseline	0.038	0.010	0.560	0.313	0.001*
	Brain tumor-specific needs	Follow up	0.035	0.013	0.431	0.186	0.014*
Number of health professionals used	Physical needs	Baseline	0.032	0.010	0.513	0.263	0.003*
	Physical needs	Follow up	0.017	0.010	0.295	0.087	0.102
	Brain tumor-specific needs	Baseline	0.032	0.014	0.379	0.144	0.032*
	Brain tumor-specific needs	Follow up	0.031	0.017	0.308	0.095	0.087
Number of practical assistance used	Patient care & support needs	Baseline	0.015	0.025	0.107	0.012	0.559
	Patient care & support needs	Follow up	0.008	0.018	0.087	0.008	0.636
	Brain tumor-specific needs	Baseline	0.019	0.015	0.231	0.053	0.203
	Brain tumor-specific needs	Follow up	0.017	0.018	0.175	0.031	0.339

^a Mean change in number of services used for each point in needs/distress scores

^b SE: Standard error

* p<0.01

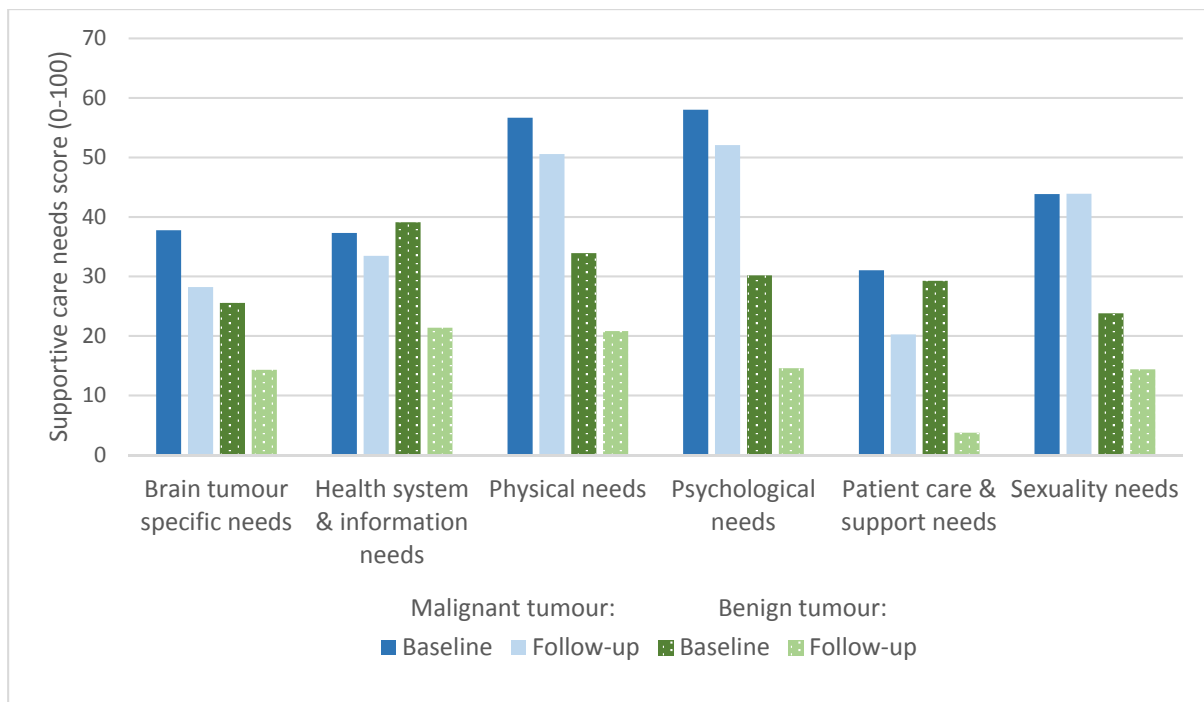


Figure 1 Change in supportive care needs scores over time: for malignant (n=24) & benign (n=14) brain tumor patients (n=2 unsure of malignancy excluded)

Figure created in MS Excel

Appendix 1: Service Utilization Survey Items

Information sources and services:

- Information booklets on your diagnosis from organizations such as the Cancer Council or Brain Tumour Alliance Australia
- Information on your diagnosis available on the internet
- Brain tumor or cancer information telephone lines
- Brain tumor awareness or information forums or seminars
- Cancer Council Queensland Brain Tumour Support Service
- Brain Tumour Alliance Australia

Health professionals:

- Brain tumor or cancer care coordinator
- Physiotherapist
- Occupational therapist
- Speech therapist or pathologist
- Rehabilitation service or specialist
- Exercise physiologist
- Dietician or nutritionist

Support services:

- Face-to-face support group
- Telephone support group
- Online support group
- Peer support program
- Religious support, such as a chaplain
- Workshop/program on coping with your diagnosis
- Face-to-face or telephone counseling service
- Psychologist
- Psychiatrist
- Neuro-psychologist or neuro-psychiatrist

Practical assistance:

- Social worker or welfare worker
- Patient Travel Subsidy Scheme
- Accommodation assistance
- Financial counselor or advisor
- Wig and turban service
- Look Good Feel Better program
- Community health nurse or home nursing service
- Respite care
- Palliative care