Do carer's levels of unmet needs change over time when caring for patients diagnosed with high grade glioma and how are these needs correlated with distress?

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Running title: Carers' levels of distress over time

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Acknowledgements

Abstract

Purpose: To determine how carer needs changed longitudinally and understand associations between unmet needs and distress.

Methods: Family carers of patients with high grade glioma (HGG) were recruited. Carers completed questionnaires during patients' chemoradiotherapy (T1), three (T2) and six months (T3) including: the Distress Thermometer; General Health Questionnaire-12; the Partner and Carer Supportive Care (PCS) Needs Scale and its supplement the Access to Services Needs Scale, and the Brain Tumour Specific Supportive Care Needs Scale. Linear latent growth models were applied.

Results: The Time 1 questionnaire was completed by 118 carers; 70 carers provided responses at Time 3. While the mean numbers of elevated (*moderate to high*) needs remained stable over time, the specific needs changed. The most frequently reported PCS needs included the impact of caring on the carer's working life or usual activities; finding more accessible parking; making life decisions in the context of uncertainty; reducing stress in the patient's life; and understanding the patient's experience. The most frequently reported need unique to carers of a brain tumor patient was for information on adjusting to cognitive changes in the patient. Other prominent needs included managing difficult aspects of the patient's behaviour and adjusting to changes in the patient's personality, both of which increased over time. Higher numbers of needs were associated cross-sectionally with higher distress levels.

Conclusion: Carers of people with HGG remain highly distressed and their needs evolve over time, indicating a requirement for ongoing evaluation of unmet needs and interventions to address carer psychological morbidities.

Introduction

High grade glioma (including Grade III anaplastic astrocytomas, oligodendrogliomas and glioblastoma (grade IV astrocyoma), 'HGG') is a rapidly terminal, progressive cancer that impacts on every aspect of a patient's life. Patients experience functional and neurological deficits, cognitive decline and behavioral and personality changes. Median survival varies along tumour type, grade, molecular markers, and treatment, but generally remains poor [1]. Indeed, for glioblastoma multiforme, the most common HGG, the median survival does not exceed 15 months even after optimal treatment strategies which include surgery, radiotherapy and chemotherapy [2].. Elderly or poor performance status patients may receive short course radiotherapy, or radiotherapy or chemotherapy alone [3] [4].

Carers looking after patients with HGG undergo a role transition from family member to carer where they need to support the patient in many activities [8, 9]. Although Piil et al. [9] reported patients and carers may work towards a shared hope and engage in health promotion activities to promote the health of the patient, this new role can impact significantly on carers' lives. They are required to be actively involved in the patients' lives, communicate with health professionals around treatment decision-making and provide transportation. Carers also need to learn to manage the patients' symptoms (e.g. seizures), side effects, and mobility issues and oversee oral chemotherapy treatment [8]. As a result carers experience increased levels of distress and burden [10-14] and reduced quality of life [15].

Several studies have explored levels of distress experienced by patients with HGG [16, 17], but fewer have examined carer distress. Trad et al. [18] reported that mean carer distress on the Distress Thermometer (DT) (maximum score = 10) at diagnosis was 5.9 (SD=1.8, n=32) and increased to 7.6 (SD=1.3, n=14) at time of recurrence. Choi et al. [19] reported that half of carers for HGG patients experienced low levels of depressive symptoms from diagnosis across the disease trajectory and the other half had high scores indicating that carers were at risk for clinical depression at the time of diagnosis and continued to be at risk, although scores did reduce over time. Anxiety scores showed a similar pattern with some carers remaining anxious throughout the disease trajectory. These investigators also found that more depressive symptoms were associated with higher scores for anxiety and burden, lower carer age, income, social support and poorer patient functioning[19]. Our own data demonstrated that mean carer distress (measured on the DT) was 5.2/10 (SD=2.5, n=118), which was significantly higher than patients' mean distress of 4.1/10 (SD=2.9, n=116, p=.001) during chemoradiotherapy; carer distress remained high over time [20-22].

In a small study of 27 carers of patients with a primary brain tumor, 56% experienced health problems, more than 45% had increased anxiety and depression and 33% were at increased risk for psychosomatic disorders relating to distress, exhaustion and other burdens [23]. Other studies have reported that carers of patients with HGG experience poorer social functioning, mental health and higher carer burden than carers of patients with other cancers [24-26]. Sherwood et al. [27] highlighted that carer burden and distress for carers of patients with primary tumors was affected by the patient's neuropsychiatric status and burden was also increased when the carers played a role in assisting with activities of daily living. Further research by this team found that patients with problem behavior increase carer depressive symptoms[28].

Carers of brain cancer patients have high unmet needs which may change depending on tumor location, disease progression and treatment response [8, 15, 29-33]. Systematic reviews on caring for patients with brain cancer [34-36] conclude that relatives of patients with brain cancer found caring "overwhelmingly exhausting" [34], care needs were high [35] and were associated with hope, emotional support, managing symptoms and side effects, and accessing support and information [36]. Carers required information about providing day-to-day care, managing patient behavior and coping with personality and/or cognitive changes [34]. However, additional studies are required to identify how the supportive care needs of both patients with brain cancer and their carers change over time and whether these needs are linked to high distress levels.

We previously reported that the top five unmet needs for carers of HGG patients at the time patients were receiving chemoradiotherapy were: accessing prognostic information; accessing financial support and government benefits; accessible hospital parking; impact of caring on usual life and reducing stress in the patients' life. Our recent work also demonstrated that carer distress and psychological morbidity (anxiety and depression) is highest most proximal to diagnosis, but remains high over time, with distress and psychological morbidity being highly correlated [22]. However, it is unknown whether high levels of distress in carers of HGG patients are directly related to high unmet needs. . The aim of the current study was to therefore determine how carer unmet needs change longitudinally and understand associations between unmet needs and distress, in order to inform and tailor service delivery and education at the time of most need.

Methods

Ethics approval was gained from Curtin University and participating tertiary hospitals. A longitudinal study design collected survey data at three time points: during chemoradiotherapy (T1), three (T2) and six (T3) months later. Data collection methods were described in our previous publications [20, 21].

Recruitment

Family carers of patients diagnosed with HGG were recruited from neurosurgical, radiotherapy or medical oncology departments at four national sites. Eligible participants were identified by their medical practitioner. Patients, and their carer, were eligible if they were aged 18 years or older and the patient was diagnosed with Grade III-IV HGG (including Grade III anaplastic astrocytomas, oligodendrogliomas and glioblastoma), and commencing chemoradiotherapy. Exclusion criteria were an inability to complete questionnaires for language, literacy or physical reasons.

Demographic variables

Information was collected at baseline on gender, age, relationship to patient, education level, employment prior to and after diagnosis, financial impact of diagnosis, length of time caring, and number of dependent people in the home. Information on employment status and financial impact was collected at each time point.

Measures of psychological impact

The DT [37] and the 12-item version of the General Health Questionnaire (GHQ-12) [38] measured psychological impact. The DT is a validated visual analogue scale (0-no distress to 10-extreme distress) used by participants to self-report how distressed they have felt over the past week [37]. The DT has been used in carer populations where scores of 5-6 indicate moderate distress and greater than 7 indicate high distress [38].

The GHQ-12 is a validated psychometric scale which measures levels of self-reported anxiety and depression [39]. The GHQ-12 has been found to have high reliability in carers (Cronbach's alpha = 0.89). A 0-3 Likert score was employed for each item and a total calculated (range 0-36). The higher the overall score, the higher the level of anxiety and depression. Scores between 16 and 20 reflect evidence of "psychological distress", while scores of greater than 20 reflect "severe psychological distress" [39, 40].

Carer needs

Unmet needs were identified using the Partner and Carer Supportive Care Needs Scale, a supplement needs scale for Access to Services [41], and the Brain Tumor Specific Supportive Care Needs Scale [30]. The Partner and Supportive Care Needs Scale is a valid and reliable 44 item scale designed for carers of cancer patients to assess unmet needs. The four domains include Health Care Service Needs, Psychological and Emotional Needs, Work and Social Needs, and Information Needs. The supplementary Access to Services needs scale includes 16 items on parking, transport, monetary allowances, information, counselling. The Brain Tumor specific needs scale (11 items) is structurally similar and designed to be co-administered with the Partner and Supportive Care Needs Scale and has been designed and validated in a brain tumor carer population [15].. Items in the Brain Tumor specific needs scale include adjusting to change in the cognitive, personality, behaviour, physical and self-care needs of the patient.

Each of the unmet needs items measure 'No need' or 'Some need' and 'Some need' is then identified further as low, moderate or high need. A need was considered elevated at moderate or high levels, and the sum of elevated needs within each of the three scales gave the total number of elevated needs. These totals were included in the growth models described below. Needs totals were divided into three categories according to the mean number of elevated needs in the sample respectively: for the Access to Services needs scale, the categories were: no, 1-2, and 3 or more elevated needs and for the Supportive care needs scale, the categories were: no, 1-10, and 10 or more elevated needs. The top needs were determined as those with the highest percentages of carers indicating the need was elevated i.e. at a moderate/high level.

Data analysis

The highest to lowest needs for each Carer needs scale were determined. The associations between numbers of elevated needs in each category and distress levels were determined, with numbers of needs included as continuous variables. Findings are reported as significant with a p value <0.05.

Descriptive statistics, correlation coefficients, t-tests and linear regression were performed using SPSS v21. Linear latent growth models were fitted in Mplus7 to model the change in numbers of needs, DT and GHQ-12scores over time and variables associated with that change. Full information maximum likelihood (FIML) methods were applied to account for missing values due to carer withdrawal. FIML has been shown to give similar results to multiple imputation methods for continuous outcomes [42]. Initially, the trend over time in levels of the dependent variable was estimated before subsequently including explanatory variables in the

model. Variables significantly correlated with the dependent variable were identified in univariable analyses ($p<.10$). These were then included in the model and backward elimination applied to identify the most parsimonious multivariable model. Sensitivity analyses revealed the final models were robust to the order in which variables were excluded.

Growth or change over time in a dependent variable is represented in latent growth models by means of an intercept and a slope term. In our models, the intercept represents the mean score at T1 (during chemoradiotherapy), and the linear slope represents the mean change in the dependent variable scores from T1 to T3. Associations are estimated between explanatory variables and the intercept and the slope respectively, allowing for variables to be associated with initial levels of the dependent variable as well as associated with the rate of change in that variable over time. Findings are reported as significant with a $p<0.05$.

Results

165 dyads were eligible and approached for consent. Baseline data for patients and carers has been reported separately [20, 21]. The T1 questionnaire was completed by 118 carers (71.5% response rate), with 70 providing data up to T3 (59.3% response rate). Ten did not provide further data because the patient died (2 before T2 and 8 before T3), and 38 withdrew. For seven withdrawals, the patient died within 2 months of the missing data time point. We have previously reported that carers who did/did not withdraw did not differ significantly for patient survival, ECOG performance, demographic variables, baseline DT and GHQ-12 scores [22].

Table 1 summarises patient and carer demographics at baseline [20, 21]. Mean age for the carers was 53 years (SD=13.6, Range = 21-89) and mean age for the patients was 56 (SD=13.3, Range = 18-86). The majority of patients (92%) had grade IV astrocytoma, as chemoradiotherapy was the standard of care for this patient group. A small group of patients with grade III gliomas (7%) and anaplastic glioma NOS (1%) were recruited as they were treated with combined chemoradiotherapy due to concerns that biopsies had undersampled contrast-enhancing disease, participation in a clinical trial, or absence of IDH1 mutation.

Do carers experience change in levels of unmet needs over time, and do those needs change?

Trends in the numbers of elevated carer needs were investigated across the three time points (Table 2). Results from the growth curve models indicated the mean numbers of elevated needs remained stable over time, with non-significant slope terms (PCS, $p=.09$; ATS, $p=.99$; BrTSC $p=.34$).

Partner and Carer Supportive Care Needs

Most carers reported at least one area of need (low, moderate or high) on the supportive care needs scale at each time point: 112/118 (95%) at T1, 85/90 (94%) at T2 and 63/70 (90%) at T3. The mean number of items out of a possible maximum of 44 for which the carers expressed an elevated (*moderate to high*) need only decreased by one over time: 10 at T1 (M=9.8, SD=10.4), nine at T2 (M=8.7, SD=9.8) and eight at T3 (M=8.2, SD=8.9). When high and moderate needs were assessed separately (see supplementary Table) it was noted for many of the items that while there was a decline in high needs over time, there was a commensurate reciprocal increase in moderate needs in the domains which had previously been high needs. However, as demonstrated in Table 3 through evaluating elevated needs some needs did decrease over time. The most frequently reported needs across all three time points included the impact of caring on the carer's working life or usual activities (on average across the three time points 34% of carers expressed this need; need ranked 4th, 1st and 12.5th at T1, T2 and T3 respectively); the need to find more accessible parking (33%), making life decisions in the context of uncertainty (32%), reducing stress in the patient's life (32%) and understanding the patient's experience (32%; Table 3).

Access to Services Needs

The percentages of carers who reported at least one area of access to services need (low to high) were 74%, 66% and 47% at T1, T2 and T3 respectively. Overall, carers reported very few elevated *(moderate to high)* needs in this category (T1, M=1.7, SD=3; T2, M=1.5, SD=2.6; T3, M=1.7, SD=2.8). Table 4 shows the frequency of specific elevated needs at each time point in this category. On average, easy car parking at the hospital or clinic was the most frequently reported ATS need across all three time points (30%). This was followed by the need for counselling services (14%), monetary allowance for travel (13%), treatment and equipment expenses (13%), drop in-counselling support and service (12%), relaxation classes (11%), transport service to and from the hospital or clinic (11%), 24-hour telephone support and cancer advisory service (10%) and brochures about services and benefits for patients with cancer (10%).

Brain Tumor Specific Supportive Care Needs

The percentages of carers who reported at least one area of brain tumor specific need (low to high) across the three time points remained at 69% (T1, n=81; T2, n=61; T3, n=48). Carers reported elevated *(moderate to high)* needs for only one to two areas (out of possible 11) (T1, M=1.4, SD=2.3; T2, M=1.8, SD=2.6; T3, M=1.6, SD=2.3). The most frequently reported

need across all time points was for information on adjusting to cognitive changes in the patient (33%), increasing from 27% at T1, to 33% at T2, and 38% at T3. Other prominent needs which are somewhat unique to the experience of carers of a brain tumor patient included managing difficult aspects in the patient behaviour (19%) and adjusting to changes in the patient's personality (17%), both of which increased over time (see Table 5).

Are changes in distress and psychological health associated with carer unmet needs?

We previously demonstrated how carer distress, as measured by the DT and GHQ-12 respectively, changed over time and identified factors associated with changes in carers' psychological status[43]. In this manuscript, we assessed the associations between changes in these two measures of psychological distress and the numbers of elevated needs of each type, in separate growth curve analyses controlling for the demographic and other variables found to be significantly associated with change in our previous modelling.

Although higher numbers of partner and caregiver supportive care needs at T1 were associated with higher DT scores at T1 (b=0.076, s.e.=0.022, p=.001), they were not associated with differential trends in distress scores between T1 and T3 (b=-0.014, s.e.=0.016, p=.4). Similarly, the numbers of access to services needs (b=0.203, s.e.= 0.080, p=.011) and brain tumor specific needs (b=0.248, s.e.=0.120, p=.039) were associated with DT scores at T1, but neither access to services needs (b=-0.048, s.e.=0.055, p=.4) nor brain tumor specific needs (b=0.014, s.e.=0.089, p=.9) impacted on changes in distress. Thus, whilst numbers of elevated needs correlated cross-sectionally with distress at T1, they did not moderate changes in distress, i.e. changes in distress that occurred from T1 to T3 did so irrespective of the numbers of unmet needs carers experienced.

Similar growth curve analyses were performed to assess whether changes in psychological distress as measured by the GHQ-12 were associated with unmet needs. Time since diagnosis, found to be significantly associated with GHQ-12 slope in our previous study [43], was controlled for in all models. The numbers of supportive care needs at T1 were associated with higher GHQ-12 scores at T1 (b=0.260, s.e.=0.045, p<.001), but a steeper decline in scores from T1 to T3 (b=-0.096, s.e.=0.030, p=.001), i.e. carers with high numbers of supportive care needs were likely to start with higher distress levels but by T3, distress levels were similar to those of carers who initially reported lower numbers of elevated supportive care needs (Figure 1A).

For the access to services needs, the number of needs at T1 was also associated with higher GHQ-12 scores at T1 (b=0.499, s.e.=0.172, p=.004); however, was not associated with changes

in distress from T1 to T3 (b=-0.070, s.e.=0.107, p=.5). Carers with high initial needs had higher GHQ-12 levels and, whilst these levels dropped over time, so did those of carers with lower needs at T1 (Figure 1B).

The numbers of brain tumor specific needs at T1 were associated with higher GHQ-12 scores at T1 (b=1.126, s.e.=0.216, p<.001), but not with changes in scores from T1 to T3 (b=-0.094, s.e.=0.157, p=.55). Thus, the slight decline in distress over time was consistent for carers regardless of their initial numbers of elevated brain tumor specific needs (Figure 1C). These results indicate that those with higher initial numbers of access to services needs and brain tumor specific needs consistently experienced relatively higher psychological distress than other carers (Figures 1B and 1C).

Discussion

The experience of caring for someone with HGG is not static, and while some patients remain clinically stable over six months, around 50% of Grade IV astrocytoma patients who receive chemoradiotherapy have progressed within six months of treatment start [2]. A six-month period was chosen for this study, recognising that after this point the proportion of deceased patients would increase, with a commensurate increase in missing data. Nevertheless, we anticipated that carer psychological, service and information needs would evolve over this period.

Carers have high numbers of unmet needs across all domains, which change over time

Previous literature highlights that carers of brain cancer patients have high unmet needs [8, 15, 29-33]. The overall numbers of needs of each of the three types (PCS, ATS and BrTSC) experienced by carers did not decline over the 6 month period; however, the specific needs changed. As some needs were met or became less relevant, others became more prominent. Over time the most important needs carers reported continued to be split between needs relating to the carer's well-being and those related to caring for the patient. This finding was similarly reported for carers of cancer patients who also completed the PCS 12 months post diagnosis [44]. As patients in our sample had incurable diagnoses and the requirement for extensive carer involvement was immediate, carers had begun to consider the impact on their lives immediately and continued to do so more as the patients' health declined. Of note, accessibility of parking and transport is very important to this group because patients often have significant physical disability.

We also highlight the needs of this population relative to carers of patients with other cancers. Girgis et al. [44] reported that at 6 months post diagnosis 50% of their sample of carers for patients with different cancer types had at least one, 36% had at least three, and 29% had at least five elevated needs. In contrast, 80% of carers in our sample had at least one unmet need, 71% had at least three and 59% had at least five unmet needs, using the same scale. This suggests that proportionally more carers of patients with HGG experience elevated needs when compared with carers of other cancer groups, highlighting the need for additional resourcing for this group of carers.

The highest needs relating specifically to caring for someone with brain cancer was obtaining information on adjusting to cognitive changes in the patient, and this need increased over time. Janda et al. [30] similarly reported this as the highest need for carers of patients diagnosed with a primary brain tumor. Furthermore, it has been reported that neurocognitive symptoms and personality changes in brain cancer patients lead to a change in the relationship and carers needing to take total responsibility [8, 9, 36]. This can then lead to an increase in carer burden with carers needing to deal with changes in the patient's neuropsychiatric status and play a role in assisting with activities of daily living [27]. Currently, cancer services have few resources specifically addressing patient cognitive decline and reducing its impact on carers. This may be an area in which service providers with experience in the management of patients with dementia or head injury could assist in developing appropriate services for brain cancer patients and their carers. Other related needs included managing patient behavior and adjusting to patient personality changes. These needs could be better addressed by ensuring access to medical liaison psychiatry or psycho-oncology services to address patient insight, carer education, and if appropriate the medical management of behavioral concerns.

Carer distress and psychological morbidity was associated with unmet needs

In our previous manuscript [43] we demonstrated that from 1 month after diagnosis, distress levels remained high and did not attenuate significantly over the study period for both the GHQ-12 and the DT. We have now added to this understanding by identifying that carers who report the greatest number of elevated needs of any kind consistently experience the most distress and psychological morbidity as measured by both the DT and GHQ-12. (The only exception to these consistent differences were the GHQ-12 scores which reduced slightly over time in carers with the highest PCS needs, so that distress levels were similar at the last time point in this high need group to those of carers with fewer of these general needs.) Whilst it is possible that having a higher number of unmet needs drives distress, it is also plausible that the

most distressed carers consistently report a higher number of needs. Hence, it is important that additional effort is targeted towards both addressing carer unmet needs as well as trying to reduce carer distress. In carers of patients with renal cell cancer, unmet information needs were also associated with increased anxiety and depression [45]. In carers of patients with ovarian cancer, optimism and social support were stronger predictors of carer psychological wellbeing than unmet needs, although unmet needs were also associated with distress [46]. Furthermore, in carers of patients with head and neck cancer, increasing resilience was associated with less depression and anxiety, suggesting that carer psychological morbidity may be related to psychological traits and coping styles [47]. An RCT conducted with carers of HGG patients (n=56 patient-carer dyads) demonstrated that caregiver mastery was improved and health-related quality of life was maintained when carers received a structured intervention consisting of psychoeducation and cognitive behavioural therapy [48]. Further study is needed to understand the complex relationships between carer distress and psychological morbidity, unmet needs, coping styles, self-efficacy, and mastery in this carer population. Interventions that reduce carer distress and also improve their preparedness to care or mastery need to be developed and tested for carers of patients with HGG.

Limitations

This study investigated participants over a six-month period, but we acknowledge that it may have also been informative to target key clinical events, such as time of disease recurrence. The questionnaire time points were selected to balance the information obtained with participant burden. Completion rates declined over time, as anticipated in a group who are juggling competing demands of caring with personal and work duties. However, participant withdrawal was accounted for during data analysis and neither carer nor patient characteristics differed between those who continued or withdrew. Additional data collection after six months would have provided further insight into carers' distress and needs; however, we were cognisant of the difficulties of maintaining compliance and chose to stop at 6 months to reduce participant burden and accounting for the high attrition due to deterioration in patient health.

Conclusion

Our findings support and confirm previous work demonstrating that carers of HGG patients continue to have high levels of distress and needs for six months post chemoradiotherapy in the context of a different healthcare system to previous reports. These needs changed over time and related to both caring for the patient and looking after themselves. Our findings have

implications for service delivery, some of which can be readily implemented. It is important that screening for distress and determining carer needs not be limited to the early post-diagnostic period; these carers remain highly distressed and their needs evolve over time, indicating a requirement for ongoing evaluation of unmet needs and vigorous attempts to address them, as well as vigilance and intervention for carer psychological morbidities. Carers of people with HGG have specific needs around cognitive, behavioral, and personality changes in the person they care for which increase over time and are relatively unique to this population. These problems can be difficult to manage, and resourcing for cognitive, psychological and psychiatric assessment and management must be an integral part of brain tumor services. Furthermore, carers of this population group require ongoing information and support to assist them in caring for the patient. Further research needs to be conducted to develop interventions that not only reduce carer distress, but also improve their preparedness to care or mastery. We are currently conducting a randomised controlled trial to determine whether a nurse-led intervention focusing on addressing carers' needs improves their preparedness to care and reduces their levels of distress [49, 50].

Table 1 Patient and Carer Baseline Characteristics

Patient demographics (n=116)		
Variable	Category	n (%)
Gender	Male	82 (70.7%)
	Female	34 (29.3%)
Diagnosis	WHO Grade IV anaplastic astrocytoma	107 (92%)
	WHO Grade III anaplastic astrocytoma	5 (4%)*
	Grade III anaplastic oligodendroglioma	3 (3%)*
	Anaplastic glioma NOS	1 (1%)
Patient self-reported ECOG Status	0	37 (31.9%)
	1	41 (35.3%)
	2	27 (23.3%)
	3	8 (6.9%)
	4	2 (1.7%)
Carer demographics (n=118)		
Variable	Category	n (%)
Gender	Male	32 (27%)
	Female	86 (73%)
Relationship to patient	Spouse/Partner	96 (81%)
	Other (e.g. parent, child)	22 (19%)
Level of Education (n=116)	High school	51(44%)
	Post-secondary education	65 (56%)
Employment (n=116)	**Pre-diagnosis**	**Post diagnosis**
Full time	41 (35%)	21 (18%)
Part time	30 (26%)	25 (22%)
Unemployed	6 (5%)	16 (14%)
Retired	28(24%)	31 (27%)
Self employed	4(3%)	4 (3%)
Homemaker	5(4%)	4 (3%)
Disability pension/stress leave/unable to work	2 (2%)	6 (5%)
Carer's leave	-	9 (8%)
		n (%)
Employment status changes (n=115)	Stayed the same	85 (74%)
	Reduced hours or stopped	30 (26%)
Financial effect of diagnosis (n=115)	No or slight effect	69 (60%)
	Significant effect	46 (40%)
Time since diagnosis (n=116)	One month or less	25 (22%)
	1-2 months	50 (43%)
	More than 2 months	41 (35%)

*Combined chemoradiotherapy was not considered standard care for grade III anaplastic oligodendroglioma or anaplastic astrocytoma at the time the study was conducted; however, a small number of patients with these histologies receive combined chemoradiotherapy on clinical indications, such as diagnosis made on biopsy only in the presence of radiological characteristics in keeping with grade IV glioma, or participation in a clinical trial with randomisation to chemoradiotherapy.

Table 2: Percentages of carers with elevated unmet needs by time

Partner and Carer Supportive Care needs			
Of 44 listed needs:	**T1** **% (CI)** **(n=117)**	**T2** **% (CI)** **(n=89)**	**T3** **% (CI)** **(n=69)**
At least one elevated need	79.5(72-87)	76.4 (67-85)	76.8 (67-87)
At least three elevated needs	71.0(63-79)	60.7(50-71)	60.9(49-73)
At least five elevated needs	59.0(50-68)	51.7(41-62)	50.7(38-63)
At least 10 elevated needs	35.0(26-44)	34.8(25-45)	37.7(26-49)
Access to Services needs			
Of 16 listed needs:	**Time 1 n(CI)** **(n=117)**	**Time 2** **n(CI)** **(n=94)**	**Time 3 n(CI)** **(n=70)**
At least one elevated need	51.3(42-60)	50.0(40-60)	50.0(38-62)
At least three elevated needs	19.7(12-27)	18.1(10-26)	21.4(12-31)
At least five elevated needs	11.9(6-17)	9.6(4-16)	14.3(6-23)
At least 10 elevated needs	2.6(0-5)	2.1(0-5)	2.9(0-7)
Brain Tumor Specific Supportive Care Needs			
Of 11 listed needs:	**Time 1 n(CI)** **(n=116)**	**Time 2** **n(CI)** **(n=89)**	**Time 3 n(CI)** **(n=70)**
At least one elevated need	45.7(36-55)	49.4(39-60)	42.9(31-55)
At least three elevated needs	21.6(14-29)	27.0(18-36)	30.0(19-41)
At least five elevated needs	10.3(5-16)	16.9(9-25)	12.9(5-21)

T1: Time 1; T2: Time 2; T3: Time 3. Elevated needs: Moderate-high level need.

Table 3: Partner and Carer Supportive Care Elevated needs over time

	Time 1 ranking % of participants with elevated needs; (95% CI) N=116-118		Time 2 ranking % of participants with elevated needs; (95% CI) N=88-90		Time 3 ranking % of participants with elevated needs; (95% CI) N=68-70	
Finding more accessible hospital parking	1	37.6 (28.7 - 46.5)	3	34.8 (24.7-44.9)	7.5	27.5 (16.7 - 38.4)
Finding out about financial support and government benefits for you and/or the person with cancer	2	37.4 (28.4 - 46.4)	9.5	27.0 (17.6 – 36.4)	16.5	23.2 (13.0 - 33.4)
Accessing information about the person with cancer's prognosis, or likely outcome	3	36.8 (27.9 - 45.6)	9.5	27.0 (17.6 - 36.4)	16.5	23.2 (13.0 - 33.4)
The impact that caring for the person with cancer has had on your working life, or usual activities	4	36.2 (27.3 - 45.1)	1	40.0 (29.7 - 50.3)	12.5	24.6 (14.2 - 35.1)
Reducing stress in the person with cancer's life	5	35.1 (26.2 – 44.0)	4.5	32.6 (22.7-42.5)	7.5	27.5 (16.7 - 38.4)
Accessing information on what the person with cancer's physical needs are likely to be	6	32.5 (23.9 - 41.1)	18	21.4 (12.7 - 30.0)	18	21.7 (11.8 - 31.7)
Feeling confident that all the doctors are talking to each other to coordinate the person with cancer's care	7	31.6 (23.1-40.2)	29	17.1 (9.0 - 25.1)	7.5	27.5 (16.7 - 38.4)
Managing concerns about the cancer coming back	8.5	31.0 (22.5 - 39.6)	4.5	32.6 (22.7 - 42.5)	12.5	24.6 (14.2 - 35.1)
Working through your feelings about death and dying	8.5	31.0 (22.5 - 39.6)	8	30.0 (20.4 - 39.7)	15	24.3 (14.0 – 34.6)
Having opportunities to discuss your concerns with the doctors	10	29.9 (21.5 - 38.3)	26	18.0 (9.8 - 26.11)	12.5	24.6 (14.2 - 35.1)

Obtaining the best medical care for the person with cancer	11.5	28.4 (20.1 - 36.8)	7	31.5 (21.6 - 41.3)	7.5	27.5 (16.7 - 38.4)
Addressing fears about the person with cancer's physical or mental deterioration	11.5	28.4 (20.1 - 36.8)	13.5	24.4 (15.4 - 33.5)	7.5	27.5 (16.7 - 38.4)
Making decisions about your life in the context of uncertainty	13	28.5 (20.1 - 36.8)	2	35.6 (25.5 - 45.6)	2	31.4 (20.3 - 42.6)
Accessing information about the benefits and side-effects of treatments so you can participate in decision making about the person with cancer's treatment	16	28.2 (19.9 - 36.5)	11	25.8 (16.6 - 35.1)	7.5	27.5 (16.7 - 38.4)
Understanding the experience of the person with cancer	18	27.6 (19.3 - 35.8)	6	31.8 (21.9 - 41.7)	1	35.7 (24.2 - 47.2)
Balancing the needs of the person with cancer and your own needs	21	23.9 (16.1 - 31.8)	12	24.7 (15.6 – 33.9)	3	30.0 (19.0 - 41.0)
Adapting to changes to the person with cancer's working life, or usual activities	24	23.1 (15.3 - 30.8)	13.5	24.4 (15.4 - 33.5)	4	29.0 (18.0 – 40.0)

Elevated needs: Moderate to high level of need indicated by carer. Top 10 needs identified at each time point included in the table. Needs within top 10 at time 2 and/or time 3 are also listed at Time 1 to demonstrate how needs changed over time. Items with the same percentages of carers at the time point have been given a ranking at the midpoint of those tied items.

Table 4: Access to Services Elevated needs over time

	Time 1 ranking		Time 2 ranking		Time 3 ranking	
	% of participants with elevated needs; (95 CI) N=116-118		% of participants with elevated need; (95 CI) N=87-90		% of participants with elevated need; (95 CI) N=68-70	
Easy car parking at the hospital or clinic	1	35.0 (26.3 - 43.8)	1	28.9 (19.3 - 38.4)	1	27.1 (16.5 - 37.8)
Brochures about services and benefits for patients with cancer	2	16.4 (9.5 - 23.2)	11	6.7 (1.4 - 11.9)	13.5	5.7 (0.1 - 11.3)
Transport service to and from the hospital or clinic	3	16.2 (9.5 - 23.0)	13.5	5.6 (0.7 - 10.4)	9.5	11.4 (3.8 - 19.1)
Monetary allowance for travel, treatment and equipment expenses	4	15.5 (8.8 - 22.2)	5	11.5 (4.7 - 18.3)	6.5	11.6 (3.9 - 19.3)
Counselling services (eg. counsellor, psychologist, social worker, nurse specialist) at the hospital or clinic for your family/partner	5	12.8 (6.7 – 19.0)	12.5	15.6 (7.9 - 23.2)	2.5	12.9 (4.8 - 20.9)
Library of books and videos about cancer and related issues	6	12.0 (6.0 - 17.9)	8	9.0 (2.9 - 15.1)	13.5	5.7 (0.1 - 11.3)
Relaxation classes	7.5	10.3 (4.7 – 16.0)	4	12.4 (5.4-19.3)	9.5	11.4 (3.8 - 19.1)
Drop-in counselling and support service	7.5	10.3 (4.7 - 15.8)	3	12.5 (5.5 - 19.6)	2.5	12.9 (4.8 - 20.9)
24-hour telephone support and cancer advisory service	9	9.5 (4.1 - 14.9)	9	7.8 (2.1 - 13.4)	6.5	11.6 (3.9 - 19.3)
Food and drink facilities in or near the clinic waiting room	10	7.7 (2.8 - 12.6)	13.5	5.6 (0.7 - 10.4)	15	4.3 (0 - 9.2)
Home cleaning service	11	6.9 (2.2 - 11.6)	6	10.1 (3.7 - 16.5)	11	8.7 (1.9 - 15.5)
Comfortable waiting room	12	6.8 (2.2 - 11.5)	7	10.0 (3.7 - 16.3)	12	7.1 (1.0 -13.3)

Home gardening service	13 5.1 (1.1 - 9.2)	10 6.7 (1.43- 12.1)	6.5 11.6 (3.9 - 19.3)
Home nursing service	14.5 4.3 (5.6 - 8.6)	15 4.4 (0.1 - 8.8)	6.5 11.6 (3.9 - 19.3)
Respite care	14.5 4.3 (5.6 - 8.6)	12.5 5.6 (0.7 - 10.5)	4 11.8 (3.9-19.6)

Elevated needs: Moderate to high level of need indicated by carer. Top 10 needs identified at each time point included in the table. Needs within top 10 at time 2 and/or time 3 are also listed at Time 1 to demonstrate how needs changed over time. Items with the same percentages of carers at the time point have been given a ranking at the midpoint of those tied items.

Table 5: Brain tumor specific supportive care elevated needs for carers

	Time 1 ranking		Time 2 ranking		Time 3 ranking	
	% of participants with elevated need; (95 CI) N=116-117		% of participants with elevated need; (95 CI) N=86-89		% of participants with elevated need; (95 CI) N=67-70	
Help in accessing state or federal assistance that the person with a brain tumor may be eligible for	1	29.6 (21.1 - 38.0)	5	20.5 (11.9 - 29.1)	2	20.9 (10.9 - 30.9)
Adjusting to changes in the mental and thinking ability of the person with a brain tumor	2	26.7 (18.6 - 34.9)	1	32.6 (22.7 - 42.5)	1	37.7 (26.0 - 49.4)
Managing difficult aspects in the behaviour of the person with a brain tumor	3	14.7 (8.1 - 21.2)	3	21.4 (12.7 - 30.0)	3	20.3 (10.6 - 30.0)
Adjusting to changes in the personality of the person with a brain tumor	4	13.8 (7.4 - 20.2)	2	22.5 (13.6 - 31.3)	6	15.7 (7.0 - 24.5)
Feeling alone in caring for the person with a brain tumor	5	12.9 (6.7 - 19.1)	4	20.9 (12.2 - 29.7)	5	17.1 (8.1 - 26.2)
Rehabilitation services for the person with a brain tumor such as occupational therapists, speech pathologists or physiotherapists	6	11.3 (5.4 - 17.2)	10	9.0 (2.9 - 15.1)	7	11.4 (3.8 - 19.1)
Changes in the ability of the person with a brain tumor to care for him/herself (such as washing and bathing oneself, cooking for oneself	7	9.6 (4.1 - 15.0)	7	12.4 (5.4 - 19.3)	4	18.6 (9.2 - 27.9)

Assistance with household management (such as planning ahead, addressing correspondence)	8	7.8 (2.8 - 12.7)	7	12.4 (5.4 - 19.3)	8	7.1 (1.0 - 13.3)
Changes in the ability of the person with a brain tumor to care for children or other dependants	9.5	6.9 (2.2 - 11.6)	11	7.9 (2.2 - 13.6)	10	2.9 (0 - 6.9)
Assistance to talk about effects of the brain tumor with others (e.g. work colleagues, employers, social groups, children)	9.5	6.9 (2.2 - 11.6)	7	12.4 (5.4 - 19.3)	9	4.3 (0 - 9.2)
Adjusting to changes in the appearance of the person with a brain tumor	11	5.2 (1.1 - 9.3)	9	10.1 (3.7 - 16.5)	11	2.9 (0 - 6.9)

As there are only 11 items, all items ranked at all time points. Elevated needs: Moderate to high level of need indicated by carer. Items with the same percentages of carers at the time point have been given a ranking at the midpoint of those tied items. Figure 1. Mean GHQ-12 score by time and number of PCS, ATS and BrTSC needs

Figure caption

Figure 1. Mean GHQ-12 score by time and number of PCS, ATS and BrTSC needs

Note. Association PCS score to GHQ-12 intercept p<.001 and GHQ-12 slope p =.001 (Fig 1a); Association ATS score to GHQ-12 intercept p =.004 and GHQ-12 slope p =.511 (Fig. 1b); Association BrTSSCN score to GHQ-12 intercept p<.001 and GHQ-12 slope p =.549 (Fig. 1c).

Conflict of Interest Statement

The authors have no conflicts of interest to declare. We have full control of all primary data and agree to allow the journal to review the data if requested.

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