

## Carers of patients with high-grade glioma report high levels of distress, unmet needs, and psychological morbidity during patient chemoradiotherapy

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**Background.** Few studies have explored the unmet needs of carers of people with high-grade glioma. We aimed to determine carers' levels of distress during treatment, understand their support needs and explore predictors of distress.

**Methods.** Carers of people with high-grade glioma undergoing chemoradiotherapy were recruited to this prospective, longitudinal cohort study. Carers completed the validated Supportive Care Needs Survey, Brain Tumour Specific Supportive Care Needs Scale, Distress Thermometer (DT), and General Health Questionnaire (GHQ-12). Questionnaires were administered during patients' chemoradiotherapy and 3 and 6 months later.

**Results.** We recruited 118 carers who were mainly female (72%) and caring for spouse (82%). The mean age was 53 years (SD = 13.6; range, 21–89). Thirty-one percent of carers reported moderate distress (DT score 5–6/10) and 31% reported extreme distress (score 7–10/10) during combined chemoradiotherapy. Carer distress was associated with adverse GHQ scores ( $r = 0.61$ ,  $P < .001$ ). Seventy-two percent reported a negative financial impact of caring and 51% of those previously working full-time had taken leave or reduced working hours. The top 5 moderate/high unmet needs were: accessing prognostic information; accessing financial support and government benefits; accessible hospital parking; impact of caring on usual life; reducing stress in the patients' life.

**Conclusion.** Carers reported substantial distress, and high distress levels were correlated with greater psychological impact and increased self-reporting of unmet needs. Future research should focus on interventions that aid in reducing carer distress.

**Keywords:** carers' needs, carer survey, distress, high-grade glioma, psychological impact.

Patients with high-grade glioma have a rapidly terminal and debilitating disease, which places a substantial burden on their carers. Initial standard treatment for grade IV glioma consists of surgery followed by combined chemoradiotherapy (with temozolomide), which is completed ~3 months after diagnosis, followed by subsequent adjuvant chemotherapy. Median survival for patients with grade IV glioma is around 12 months with a 2-year survival of 15%.<sup>1</sup> Caring for a person with high-grade glioma is unique because patients often experience substantial functional and neurological deficits, as well as behavioral and personality changes and cognitive decline. The rapidly progressive nature of the disease means that the carer becomes an advocate, spokesperson, and driver, and he or she spends substantial time

addressing health care needs: learning to deal with seizures, mobility issues, polypharmacy, chemotherapy, and radiotherapy.<sup>2,3</sup> This leads to a reduced quality of life<sup>4</sup> and increased stress and burden for carers.<sup>5–10</sup>

Previous research has shown that carers of advanced cancer patients experience a substantial loss in their self-identity, give up significant parts of their lives, including work, and may need to move residences to facilitate optimal care of the patient.<sup>11</sup> They also have difficulty taking time out to look after themselves or accepting help in caring<sup>11</sup> and feel increasingly isolated from their social network.<sup>12</sup> Carers of patients who die soon after diagnosis experience greater levels of depression than those caring for people with a long illness trajectory, and in some cases these

Received 8 June 2015, Advance Access publication 15 October 2015

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levels of depression are clinically significant and directly correlate to the patients' disease burden.<sup>13</sup>

Carers of people with advanced cancer face multiple challenges in the following domains: physical health problems, social and psychological needs, communication and information needs, emotional problems, service provision needs, and burdens related to responsibilities, all of which impact on daily life.<sup>14-16</sup> Boele et al reported that carers of patients with high-grade glioma have poorer levels of mental health and social functioning than carers of patients with other cancers.<sup>17</sup> Lower mental health for carers of brain cancer patients has also been reported elsewhere.<sup>18</sup> Similarly, Jacobs et al found that carer burden was significantly greater than for carers of patients with other cancers (eg, lung, breast, and prostate cancer).<sup>19</sup> Evidence also suggests that carers of brain cancer patients have a high degree of unmet supportive care needs that may differ from those of the patient.<sup>4,20</sup> Further, these needs may change over time depending on the location and progression of disease and treatment response.<sup>21</sup> There has been limited research specifically exploring the needs of carers of patients diagnosed with high-grade glioma during combined chemoradiotherapy. Their needs are likely to be somewhat different from those of carers of patients with other advanced cancers, not only due to the rapid onset of the disease and short survival period, but also due to the cognitive and behavioral changes affecting the patient, which are a specific symptom of high-grade glioma.

In our previous work we found that the point of diagnosis was a time of rapid change during which carers of people with high-grade glioma had to renegotiate roles and relationships and learn to be a carer in a short period of time.<sup>3,22,23</sup> Carers reported not knowing where or when to seek additional support or assistance, experiencing loss of employment, becoming the sole car driver, and being unable to safely leave their loved ones unattended.<sup>3,22</sup>

This study aimed to determine carers' levels of distress during chemoradiotherapy, prioritize carers' support needs, and explore predictors of distress. Our primary hypothesis was that carers of patients with high-grade glioma would have a high levels of distress. Secondary hypotheses were that high carer distress levels would be reflected in worse psychological health; and in turn, those with worse psychological health would report more unmet needs. Further, we hypothesized that distress was related to carer demographics and, in particular, that female carers, those of younger age, those with financial hardships, and those with more dependents would experience more distress. We also hypothesized that carers who described themselves as prepared and confident to care would experience less psychological impact. This manuscript describes the baseline data from carers obtained during chemoradiotherapy because this is a critical time for carers and it may be possible to implement support while patients are on active treatment. We will also publish longitudinal data for this group because their needs change over time.

## Methods

Ethics approval was gained from Curtin University and participating tertiary hospitals. Consenting carers of patients scheduled to undergo combined chemoradiotherapy for high-grade glioma were recruited consecutively from neurosurgical, radiotherapy or medical oncology outpatient departments at four national sites. Patient participants were eligible if they had grade III-IV high-grade glioma, were aged 18 years or older, and were

commencing chemoradiotherapy. Participants were excluded if they were unable to complete questionnaires for language, literacy or physical reasons. Carers were invited to participate at the same time as eligible patients.

Consenting participants completed questionnaires at 3 time points: during chemoradiotherapy and at 3 and 6 months after initial survey completion. The research assistant was available to answer any questions about the study if required. This manuscript reports on the baseline data for carers.

### Demographic Variables

Information was collected on gender, age, relationship to patient, level of education, employment status prior to and after the diagnosis, the financial impact of the diagnosis, the length of time caring for the patient, and the number of other persons in the home dependent on the respondent.

Carers were asked about their preparedness and confidence in caring for their friend or relative with the following questions: "To date, how confident do you feel about caring for your friend/relative?" and "How prepared do you feel about caring for your relative/friend in the future?". These questions were scored on a Likert scale where 1 = 'Not prepared (confident)', 3 = 'Moderately prepared (confident)', and 5 = 'Highly prepared (confident)'. They were also asked: "Have you needed to learn new skills to assist you in caring for your relative/friend?" with a yes/no response and an option to specify the skills required.

### Measures of Psychological Impact

To measure psychological impact we used the Distress Thermometer (DT) and the shortened, 12-item version of the General Health Questionnaire (GHQ-12). Psychological distress has been defined by Knapp et al as 'the unique discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent, to the person.'<sup>24</sup>

The DT is a validated visual analog scale used to self-report how distressed participants have felt over the past week.<sup>25</sup> The scale runs from 0 (no distress) to 10 (extreme distress). The DT has been used to assess carer populations and scores of 5 to 6 indicate moderate distress while scores of greater than 7 indicate high distress.<sup>26</sup>

The GHQ-12 is a validated psychometric scale used to measure self-reported levels of anxiety and depression.<sup>27</sup> This has been used in a variety of areas in general health care to measure psychological morbidity, in particular as a screening tool to identify cases of anxiety and depression. Reliability of the GHQ-12 scores in carer populations is high (Cronbach's alpha = 0.89). As this study aimed to assess the severity of psychological distress, a 0 to 3 Likert scoring system was employed for each item and a total calculated (score range = 0-36). The higher the overall score on the 12 items, the higher the measured 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."<sup>27, 28</sup>

### Carer Needs

Unmet needs were identified using the Partner and Carer Supportive Care Needs Scale (PCNS) and its supplement the Access to

Services Needs Scale,<sup>29</sup> in addition to the Brain Tumour-specific Supportive Care Needs Scale (BrTSCNS).<sup>4</sup> The PCS is a valid and reliable 44-item scale designed for carers of cancer patients (Cronbach's alpha = 0.88-0.94) to assess their levels of unmet needs. The four domains included in this questionnaire are Health Care Service Needs, Psychological and Emotional Needs, Work and Social Needs, and Information Needs. The BrTSCNS scale is an 11-item survey that has been specifically designed and validated in a brain tumor carer population.<sup>4</sup> It has a similar structure to the PCS and is designed to be co-administered with this scale.

The unmet need scales measure responses in the form of 'no need' or 'some need' in a particular area. 'No need' includes an option for having had a need that had been satisfied. 'Some need' is further identified as a low, moderate, or high level of need. In determining the numbers and areas of 'some need' for carers, these last three categories were combined. Carers with above average numbers of unmet needs were identified as those with numbers of items with 'some need' above the mean number for the sample. However, in determining the most critical needs in this sample, items were dichotomized as being of moderate or high need versus low or no need. The top needs were then determined as those with the highest percentages of carers with a moderate/high level of need.

### Data Analysis

Descriptive statistics, correlation coefficients, *t* tests, and linear regression were performed using SPSS v21. Continuous scores on DT and GHQ-12 were analyzed in the regression analyses. Each predictor was first assessed in a univariate analysis; significant predictors were then included in a multivariable regression model and backward variable selection methods used to determine the most parsimonious model.

To avoid multiple comparisons of factors affecting distress, 6 neuro-oncology health care professionals were asked to independently complete a priority hypotheses matrix to determine which relationships would be tested. Only those relationships hypothesized to be present by at least 4 health care professionals were subsequently tested.<sup>30</sup> Findings are reported as significant with a *P*-value <.05.

### Results

One-hundred sixty five patient and carer dyads were eligible and approached for consent. Ninety-four percent of the patient population had grade IV glioma and 6% had grade III glioma. The baseline patient data have been reported separately.<sup>31</sup> One-hundred twenty seven carers consented to participate in the study. One-hundred eighteen carers and 116 patients completed the baseline questionnaire. Carers were still able to participate if patients declined. Reasons given for not participating are described in the report on the patients in this study.<sup>31</sup> Missing data account for the variability in the sample sizes reported below.

The majority of carers were spouses or partners (81%) and female (73%), and the mean age was 53 years (range, 21-89; SD = 13.6) (Table 1). A minority (15%) were also responsible for the care of others in their home, in all cases these were children of the carers. For 22%, the survey was completed within a month of the diagnosis, whereas for just over a third (35%) the period

since diagnosis was longer than 2 months; this reflects variability in chemoradiotherapy start dates and referral. A quarter (26%) of the carers' employment status had changed as a result of their carer role, either as a reduction in hours or to not working at all. A majority (74%) of carers reported a financial impact of the diagnosis, with 40% reporting the impact as significant. Just over a third (37%) needed to learn new skills, these related to managing the patient's medication, physical care of the patient, and interpersonal skills (patience and tolerance). Forty-eight percent felt they were only moderately or less than moderately prepared for caring and 32% reported they were only moderately or less than moderately confident about caring for the patient.

### Psychological Impact

The mean reported level of distress on the DT was 5.2 (SD = 2.5) on a scale of 0 to 10; 32% of carers reported high distress levels (scores of 7 to 10 on the DT) and a further 31% reported moderate levels (scores of 5 to 6 on the DT).

The mean of the GHQ-12 was 15.5 (SD = 6.1); 41% of the carers scored 16 or above, indicating psychological distress, while 18% scored over 20, indicating severe psychological distress, where the presence of 'psychological distress' is a marker for depression or anxiety. Carer DT scores correlated with GHQ-12 scores (Pearson's *r* = 0.6; *P* < .001), indicating that distress coexisted with anxiety and depression in this population. Fewer than 5% of participants reported high scores on the GHQ-12 and low scores on the DT, giving a sensitivity of 88.64%.

### Predictors of Psychological Impact

The associations between a range of demographic and other possible predictors of psychological impact were tested in univariate regression models (Table 2), prior to multivariable analyses to identify the strongest predictors of these measures.

Table 3 summarizes the predictors of psychological distress. Male carers scored significantly lower on the DT than female carers (*P* = .034) and DT scores also decreased according to the age of the carer, indicating that younger carers were more distressed (*P* = .013). Mean DT scores were significantly higher for carers for whom the diagnosis had a significant financial impact (*P* < .001). Length of time since diagnosis also predicted distress levels (*P* = .011), with carers surveyed within 1 month of the diagnosis significantly more distressed than those surveyed 1 to 2 months (*P* = .004) and more than 2 months (*P* = .014) after diagnosis. Adding these 4 variables to a multivariable regression model and applying backward elimination to identify the most parsimonious model, financial impact of caring (*P* < .001), time since diagnosis (*P* = .001), and gender (*P* = .049) remained as significant predictors of DT scores. An explanation for the lack of significance of age in the multivariate model is the correlation between age and gender in this sample. The male carers were significantly older than the females (mean [SD] age60.3 [16.5] vs 50.1 [11.3] years), *t*<sub>116</sub> = 3.8, *P* < .001). Hence, in this sample, the effects of gender and age are confounded.

Significant factors identified in the univariate analyses of the GHQ-12 scores were the carers' levels of confidence (*P* = .002) and preparedness to care for the patient (*P* = .001), as well as length of time since diagnosis (*P* < .001). As hypothesized, carers who reported higher levels of preparedness and confidence to care also screened as "less likely" to be experiencing significant

**Table 1.** Sample descriptive data

Predictor Variables*		n (%)
<b>Demographics</b>		
Age (n = 118)	M = 52.9 (SD = 13.6) years; range, 21-89	
Sex (n = 118)	Male	32 (27%)
	Female	86 (73%)
Relationship to patient (n = 118)	Spouse/Partner	96 (81%)
	Other (eg, parent, child)	22 (19%)
Level of education (n = 116)	High school	51 (44%)
	Postsecondary education	65 (56%)
Employment (n = 116)	<b>Before diagnosis</b>	<b>After diagnosis</b>
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	0 (0%)	9 (8%)
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%)
Caring for anyone else in home (n = 117)	Yes	18 (15%)
	No	99 (85%)
Time since diagnosis (n = 116)	One month or less	25 (22%)
	1-2 months	50 (43%)
	More than 2 months	41 (35%)
<b>Self-report measures</b>		
Needed to learn new skills (n = 117)	Yes	43 (37%)
	No	74 (63%)
Confidence in caring (n = 117)	Not confident at all	1 (1%)
	Between not confident and moderately confident	4 (3%)
	Moderately confident	33 (28%)
	Between moderately confident and highly confident	25 (21%)
	Highly confident	54 (46%)
Preparedness to Care (n = 117)	Not prepared at all	4 (3%)
	Between not prepared and moderately prepared	12 (10%)
	Moderately prepared	41 (35%)
	Between moderately prepared and highly prepared	29 (25%)
	Highly prepared	31 (27%)

\*Missing data accounts for variability in the numbers reported.

depression and anxiety on the GHQ-12. As for the DT scores, the group surveyed within 1 month of the diagnosis reported significantly higher scores on the GHQ-12 than the 2 groups surveyed after a period of more than a month. While both confidence and preparedness to care are individually significant predictors of GHQ-12 scores, their high correlation ( $r = 0.7$ ) results in an insignificant effect in a multivariable model in which both are included. Thus, the final parsimonious multivariable model included preparedness to care ( $P = .005$ ) and time since diagnosis ( $P = .005$ ) as significant predictors of the GHQ-12 scores, with the directions of the associations as described above for the univariate analyses.

### Partner and Caregiver Needs

Almost all carers (95%,  $n = 112$ ) reported at least one unmet need (ie, low, moderate, or high level) on the PCS. On average, carers reported 17 concerns for which there was some level of unmet need (M [SD] = 17.0 [11.9]; range, 0-43). Each of the demographic variables in Table 3 was assessed in terms of its ability to predict the number of items for which the carer reported some level of need. Of these, level of education ( $P = .032$ ) and gender ( $P = .050$ ) were associated with the number of unmet needs. Carers with more than secondary education reported a significantly larger number of unmet needs on average than those with less than secondary education (M [SD] = 19.1 [12.2] vs 14.1 [10.9]),



**Table 2.** Descriptive statistics for psychological distress measures

Distress Thermometer	(n = 117*)	GHQ12	(n = 118)
Low (0–4)	44 (37%)	Low (0–10)	27 (23%)
Moderate (5–6)	36 (31%)	Typical (11–12)	11 (9%)
Extreme (7–10)	37 (32%)	More than typical (13–15)	32 (27%)
		Evidence of symptoms (16–20)	27 (23%)
		Severe symptoms (21–36)	21 (18%)
M = 5.2 (SD = 2.5; observed range, 0–10)		M = 15.5 (SD = 6.1; observed range, 4–36)	

M, Mean; SD, standard deviation; GHQ12, General Health Questionnaire. \*Missing data account for variability in the numbers reported.

while women (M [SD] = 18.4 [12.2]) may report more unmet needs on average than men (M [SD] = 13.2 [10.1]). Additionally, the numbers of unmet needs were correlated with carers' levels of confidence to care for the patient ( $r = -0.38, P < .001$ ), their preparedness to do so ( $r = -0.42, P < .001$ ), and needing new skills ( $t = -2.5, P = .016$ ). Those who had to learn new skills reported significantly more unmet needs (M [SD] = 21.1 [12.9]) than those who did not (M [SD] = 14.9 [10.8]). The mean number of items on which the carers expressed a moderate-to-high need was 10 (M [SD] = 9.6 [9.9]; range, 0–40) and the top 10 areas of moderate to high need are presented in Table 4.

Carers with an above average number of unmet needs (ie, more than 17) scored significantly higher on the DT than those with a below average number of needs (above average: M [SD] = 5.9 [2.2]; below average: M [SD] = 4.6 [2.7];  $P = .009$ ). A similar finding was seen on the GHQ-12, with carers screening higher for anxiety and depression reporting more needs (above average: M [SD] = 18.4 [6.0]; below average: M [SD] = 13.2 [5.3];  $P < .001$ ).

The 16 items regarding level of need for access to services were completed by 112 carers. A total of 87 carers (74%) indicated at least 1 unmet need in this regard, with an average of 3 unmet needs reported (M [SD] = 3.1 [3.8]; range, 0–15), and 1 to 2 moderate-to-high needs (M [SD] = 1.6 [2.8]; range, 0–15). One-third of all carers (32%,  $n = 36$ ) reported an above average number of needs for access to services. The most commonly reported need of moderate-to-high level, which was expressed by 35% ( $n = 41$ ) of the carers, was “easy car parking at the hospital or clinic.” The second, mentioned by 17% ( $n = 20$ ) of carers, was “brochures about services and benefits for patients with cancer,” and the third, mentioned by 16% of carers, was “transport service to and from the hospital or clinic” ( $n = 19$ ). The other items were indicated by 15% or less of the carers as being of moderate-to-high need to them.

A total of 81 carers (69%) indicated at least 1 unmet need on the BrTSCNS. Carers identified an average of 3 unmet brain-tumor-specific carer needs (M [SD] = 3.2 [3.3]; range, 0–11), as well as 1 to 2 such needs at a moderate to high level (M [SD] = 1.5 [2.3]; range, 0–11). Just over one-third of the 115 carers who completed all 11 items in the scale (37%,  $n = 43$ ) reported an above average number of areas for which they had some need. The top 5 needs of moderate to high level specific to carers as a result of having a friend or relative with a brain tumor are given in Table 5.

**Table 3.** Predictors of psychological distress (univariate analyses)

Variables	DT M (SD)	P	GHQ-12, M (SD)	P
Sex		<b>.034</b>		.166
Male	4.3 (2.2)		14.2 (5.5)	
Female	5.4 (2.6)		16.0 (6.3)	
Age	$r = -0.23$	<b>.013</b>	$r = -0.01$	.947
Relationship		.94		.139
Partner	5.1 (2.6)		15.9 (6.4)	
Other	5.2 (2.5)		13.7 (4.4)	
Education level		.93		.725
≤12 years	5.1 (2.4)		15.6 (6.1)	
>12 years	5.1 (2.6)		15.2 (6.3)	
Other dependents living at home		.32		.645
Yes	5.7 (2.7)		14.8 (5.1)	
No	5.0 (2.5)		15.6 (6.3)	
Drop in employment status		.27		.078
Yes	5.5 (2.9)		16.9 (7.3)	
No	4.9 (2.4)		14.7 (5.3)	
Financial effect of caring significant		<b>&lt;.001</b>		.091
Yes	6.2 (2.5)		16.7 (6.2)	
No	4.4 (2.3)		14.7 (6.1)	
Time since diagnosis		<b>.011</b>		<b>&lt;.001</b>
≤1 month	6.5 (2.3) <sup>a</sup>		19.7 (6.8) <sup>a</sup>	
1–2 months	4.7 (2.5) <sup>b</sup>		13.7 (5.6) <sup>b</sup>	
>2 months	4.9 (2.6) <sup>b</sup>		15.1 (5.3) <sup>b</sup>	
Confidence in caring	$r = -0.03$	.79	$r = -0.28$	<b>.002</b>
Preparedness to care	$r = -0.07$	.47	$r = -0.30$	<b>.001</b>
Needed to learn new skills		.33		.295
Yes	5.4 (2.7)		16.2 (6.6)	
No	5.0 (2.5)		15.0 (5.9)	

<sup>a,b</sup>Tukey pairwise comparisons, means with different letters differ significantly; means with the same letter do not differ significantly. DT, Distress Thermometer; GHQ12, General Health Questionnaire; M, mean; SD, standard deviation.

Of the 115 carers who responded to all 11 items in the scale, 37% ( $n = 43$ ) reported an above average number of unmet brain-tumor-specific needs (ie, more than 3). These carers did not report higher distress levels based on the DT (above average: M [SD] = 5.7 [2.4]; below average: M [SD] = 4.8 [2.6];  $P = .074$ ); however, their scores on the GHQ-12 were significantly higher than those with below average number of needs (above average: M [SD] = 18.6 [6.0]; below average: M [SD] = 13.6 [5.3];  $P < .001$ ).

The most prominent needs identified on both the PCS and the BrTSCNS were those concerned with financial impact. The levels of unmet need for financial information correlated with the single-item question on significant financial impact ( $P < .001$ ) and change in employment status ( $P = .025$ ).

## Discussion

Informal family carers are of critical importance for patients with high-grade glioma as these patients are often physically,

**Table 4.** Ten most commonly reported moderate-to-high needs among carers as identified on the Partner and Carer Supportive Needs Scale (PCS)

Rank	Moderate-to-high Need of Carer	%
1	PCS23: Finding out about financial support and government benefits for the carer and/or the person with cancer	37.9
2	PCS2: Accessing information about the person with cancer's prognosis, or likely outcome	37.3
3	PCS20: Finding more accessible hospital parking	37.3
4	PCS22: Impact caring has had on carer's working life or usual activities	35.9
5	PCS14: Reducing stress in the person with cancer's life	35.7
6	PCS5: Accessing information on what the person with cancer's physical needs are likely to be	32.2
7	PCS11: Feeling confident that all the doctors are talking to each other to coordinate the person with cancer's care	32.2
8	PCS31: Managing concerns about the cancer coming back	30.8
9	PCS39: Working through the carer's feelings about death and dying	30.8
10	PCS10: Having opportunities to discuss their concerns with the doctors	30.5

**Table 5.** Five most commonly reported high-to-moderate needs among carers as identified on the BrTSCNS

Rank	Moderate-to-high Need of Carer	%
1	BrTSCNS10: Help in accessing state or federal assistance that the person with the brain tumor may be eligible for	30.2
2	BrTSCNS11: Adjusting to changes in the mental and thinking ability of the person with a brain tumor	26.5
3	BrTSCNS9: Managing difficult aspects in the behavior of the person with a brain tumor	14.5
4	BrTSCNS4: Adjusting to changes in the personality of the person with a brain tumor	13.7
5	BrTSCNS8: Feeling alone in caring for of the person with a brain tumor	12.8

functionally, and cognitively dependent on their carers immediately after diagnosis.<sup>3</sup> The high levels of distress reported by carers may impact significantly on their psychological well-being and ability to continue in this demanding role.<sup>32-34</sup> This, in turn, may escalate health system costs through provision of mental health services for carers, and as distressed, unpaid family carers seek the additional support of professional, paid carers, residential care, or hospital and hospice care.

We found that the majority of carers of people with high-grade glioma reported moderate-to-high levels of distress during chemoradiotherapy. Distressed carers also reported higher levels of anxiety and depression and had more unmet needs. Our findings suggest that this group experiences greater distress than reported by other cancer carer populations. Previous studies have reported that high-grade glioma carers have lower levels of mental health and social functioning and higher levels of carer burden than carers of patients with other cancers.<sup>17,19</sup> In this study we found that DT scores in our group (M [SD] = 5.2 [2.5]) exceeded those

reported in studies of general carers (M = 3.7)<sup>25</sup>; as well as carers of people with advanced cancer (M [SD] = 4.87 [2.5]),<sup>35</sup> carers of patients receiving stem cell transplants (M [SD] = 4.7 [2.6])<sup>36</sup>; and high-grade glioma patients themselves (M [SD] = 4.1 [2.9]).<sup>31</sup> Correlation between scores on the DT and scores on the GHQ-12 in the current study suggest that distress is associated with cases of anxiety and depression in this population.

Having demonstrated high levels of distress and psychological morbidity, a key issue for service providers is to identify at-risk subpopulations who may benefit from additional intervention, particularly where there are potential modifiable stressors. Consistent predictors of significant psychological impact included being younger and female, higher levels of education, and financial impact. We also found that carers with self-reported lower preparedness and confidence to care were more likely to experience anxiety and depression.

One of the goals of this study was to assess the use of the DT as a simple screening tool for distress in carers of high-grade glioma. The DT was sensitive in identifying carers who were more likely to have significant psychological impact (using GHQ-12) and there were few false negatives. Routine clinical use of the DT in screening these carers may be helpful to identify those who need additional support, but have not clearly articulated those needs, allowing appropriate referrals to social workers, welfare officers, and psychological support to be made.

Despite the high emotional and physical burden of this diagnosis, the predominant unmet needs were for financial support and information on financial benefit eligibility. Kumthekar et al provided a detailed understanding of the costs experienced by patients receiving treatment for glioma in the United States.<sup>37</sup> In New South Wales, Australia the expected lifetime economic cost of brain cancer per person was the highest of any cancer. Estimated at \$A1 891 900 (US \$1 334 346); which included patient productivity and carer costs, healthcare expenditure, burden of disease, transfer and other financial costs.<sup>38</sup> This is considerably more than the expected lifetime cost of all cancers per person which was estimated at \$A 966 000 (\$US 681 314). In this study the need for information about financial assistance was strongly associated with changes in employment and financial impact. Forty percent of carers reported a significant financial impact, which mirrors the percentage reported by the patient group (42%).<sup>31</sup> There has been relatively limited research into the financial concerns of people with advanced cancer and their families, even less so in Australia where a nationalized health system allows for a high standard of cancer care irrespective of patient financial status, with modest copayments only for supportive care medications. We are not aware of any validated screening tools for financial concerns. Our questionnaire asked a single question on the financial impact of the diagnosis, and another on employment status. Clinicians may consider asking about employment status and the financial impact of the diagnosis to assist in screening for distress related to finances, and facilitate provision of support and information. Interestingly, previous research has shown that patients are reluctant to discuss financial issues with their doctors,<sup>39</sup> although other studies suggest that patients and carers wish the subject had been approached earlier.<sup>40</sup> Financial concerns were still a major issue despite the available assistance of a social worker at each site—a social worker's role encompasses financial concerns, other psychosocial issues, and placement issues.

The second highest unmet need was in accessing prognostic information. Delivery of prognostic information can be complex, particularly if patients' needs diverge from those of carers.<sup>23</sup> This is particularly marked in the care of patients who are cognitively impaired or dysphasic. In delivering prognostic information, it is important that communication is tailored to individual needs, that the same message is received from all members of the treating team, that the message is clearly delivered, and that strategies are employed to ensure the understanding of both patients and carers.<sup>41</sup> Further work in the delivery of prognosis in this patient group and their carers is needed.

### Strengths and Limitations

Strengths of this research include the adequate sample size and the consecutive recruitment of carers, with a majority of those approached consenting to participate. We acknowledge that recruitment occurred at a potentially challenging time point, and it is plausible that those who chose not to participate would have reported more rather than less distress and unmet needs, potentially being the group who were more distressed and overwhelmed by their situation. This study may underestimate the needs of male carers because 73% of the participants were female.

As this study covers a single time point, it does not allow us to infer causality, but rather recognize associations between factors contributing to distress and unmet needs. Further, correlations between self-report measures of preparedness and confidence to care and measures of psychological impact may be inflated due to shared method variance.

This study excluded carers who were unable to converse in English.<sup>42</sup> Culturally and Linguistically Diverse (CALD) and Non-English Speaking Background (NESB) patients and carers may have even higher unmet needs, which were not captured in this study.

### Future Directions

The most important implication for future research is the clear need for interventions to reduce the burden and psychological distress of caring on carers of brain tumor patients. If carers' confidence and preparedness to care can be improved and they feel supported, distress and psychological impacts may be reduced and they may report fewer unmet needs. The relationship between carer burden, distress, and health care system costs in this group should also be explored. A carer intervention would need to be holistic and individualized and include psychological, informational and educational support. We are currently testing an intervention that covers these aspects in a randomized controlled trial, including strategies for accessing financial support. This study also highlights the need to ask similar questions of people with cancer metastatic to the brain and their carers, who experience similar neurological symptom complexes.

### Conclusion

This is the first study that has quantitatively examined the impact of caring for brain tumor patients during chemoradiotherapy, demonstrating high levels of distress and psychological morbidity, as well as potential screening strategies that may identify those with the greatest need for intervention.

### Funding

This study was funded by the WA Cancer and Palliative Care Network, Department of Health WA, and a HOTTAH grant provided by Clinical Oncology Society Australia (COSA).

### Acknowledgments

The authors thank participants in the study, sites involved in recruitment, and Céline Fournier and Jenny Clarke for their assistance in data collection.

*Conflict of interest statement.* None declared.

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