Title page

The bereavement outcomes of carers of patients with high grade glioma: Experiences of support before and after the death

Elizabeth A. Lobb[1,2,3], Georgia K.B. Halkett[4], Emma McDougall[4], Rachel Campbell[5], Haryana Dhillon[5,6], Jane L. Phillips[3, 7] Anna K. Nowak[8,9]

[1]Calvary Health Care Kogarah, Sydney, New South Wales

[2]School of Medicine, The University of Notre Dame, Sydney, New South Wales.

[3]Faculty of Health, University of Technology, Ultimo, New South Wales

[4]Curtin School of Nursing, Faculty of Health Sciences, Curtin University, Bentley, Western Australia

[5]University of Sydney, Faculty of Science, School of Psychology, Psycho-Oncology Cooperative Research Group, Sydney, Australia.

[6]Centre for Medical Psychology & Evidence-based Decision-making, Sydney, Australia

[7]School of Nursing, Faculty of Health, Queensland University of Technology

[8]Medical School, University of Western Australia, Nedlands, Western Australia.

[9]Department of Medical Oncology, Sir Charles Gairdner Hospital, Nedlands, Western Australia.

Running title: Bereaved carers of patients diagnosed with high grade glioma

Corresponding author

Professor Elizabeth Lobb, ORCID 0000-0002-3917-1208
Calvary Health Care Kogarah, Kogarah, 2217.
New South Wales, Australia.
Phone: +61 2 9553 3093 Fax: +61 2 9553 3159.
E-mail Liz.Lobb@ health.nsw.gov.au

ORCID IDs

Elizabeth Lobb, ORCID 0000-0002-3917-1208
Georgia Halkett, ORCID 0000-0003-4065-4044
Emma McDougall, ORCID 0000-0001-5085-001X
Rachel Campbell, ORCID 0000-0002-5013-8361
Haryana Dhillon ORCID 0000-0003-4039-5169

Jane L. Phillips ORCID 0000-0002-3691-8230
Anna K. Nowak ORCID 0000-0002-9317-9526

Abstract

Carers of people with High Grade Glioma (HGG) completed a survey assessing their anxiety, depression and grief in addition to open-ended questions exploring their experiences of support pre and post death (n=25). One third reported borderline or clinical levels of anxiety, depression and grief related distress. Given the poor prognosis and rapid deterioration of patients with HGG the findings highlight the importance of sensitive communication about prognosis early in the disease trajectory, information tailored to disease stage, the initiation of a referral to psychological support services, and timely discussions about the preferred place of care and death.

Key words: bereaved carers, high grade glioma, emotional, financial, practical and informational support needs

Introduction

Patients with High Grade Glioma (HGG) experience a range of neurological symptoms including aphasias, ataxia, immobility, cognitive and personality changes (Osoba et al., 2000). The functional implications of these symptoms can range from causing minimal disruption to the patient being fully care-dependent.

Caring for someone with a brain cancer is unique. The caregiver often faces significant challenges coping with the persons' cognitive, personality and functional changes in addition to general cancer-related caregiving issues. The cognitive changes and, in particular, personality and behavioural changes often associated with HGG cause a shift in family roles and relationships not regularly seen with other cancers that can occur from the time of diagnosis rather than solely at the end of the disease trajectory. These daily challenges impact adversely on the patient and carer's quality of life bringing increased carer stress and carer burden. (Catt et al., 2008; Davies & Higginson, 2003; Munoz et al., 2008). A HGG diagnosis is particularly stressful for carers because the prognosis is dire and life expectancy short (Schmer et al., 2008). It is unsurprising these carers report increased levels of distress over time, decreased quality of life and many unmet needs compared to carers of patients with cancers with a better prognosis (Janda et al., 2006; Janda et al., 2007; Munoz et al., 2008).

While caregivers report changes in their role and care-related tasks occur following a cancer diagnosis and when the disease progresses (Thomas et al., 2002), this role transition often occurs more rapidly after a HGG diagnosis. Carers of advanced cancer patients experience substantial loss in their self-identity, give up significant parts of their lives including work, and may move houses to care (Ugalde et al., 2012). They are also unable to take time out to look after themselves or accept help in caring (Ugalde et al., 2012).

Caregivers of people who die soon after diagnosis experience greater levels of depression than those caring for people with a long illness trajectory (Given et al., 2004). In some cases clinically significant levels of depression are directly related to care-receivers or symptomology (Given et al., 2004). Some situational factors, cognitions, and coping factors have been previously found to be associated with grief complications; these include pessimistic thinking, stressful life events in the life of the caregiver (Tomarken et al., 2008), pre-bereavement mental distress including depression (Schulz et al., 2008) and perceived lack of social support after the person's with HGG death (Schulz et al., 2006).

It is known that overall, caregivers are at significantly greater risk of getting sick or dying after the death of their spouse or family member (Christakis & Iwashyna, 2003). Bereavement issues previously demonstrated in caregivers of patients with limited life expectancy include anxiety, depression, prolonged grief disorder, and demoralisation (Hudson et al., 2012).

While grief is considered a normal reaction to loss, and includes diverse cognitive, social, behavioural as well as physiological and somatic responses (Stroebe et al., 2008), we expected that, given the stress associated with diagnosis, treatment and caring for someone with a disease with a poor prognosis, like HGG, a higher proportion of bereaved carers would report clinically significant distress.

Aim

This exploratory study aimed to describe the bereavement experiences and support needs across various domains (emotional, practical, information and financial) of carers who had participated in a randomised controlled trial (RCT). The Care-IS trial (n=188) was conducted in Australia and encompassed a nurse-led, tailored, home-based education and support program for carers of people with HGG (Halkett et al., 2015). Australian and New Zealand Clinical Trials Registration: ACTRN12612001147875.

The CARE-IS intervention was focused on improving carer preparedness and reducing carer distress for up to 12 months after commencing combined chemotherapy. The intervention did not focus on bereavement outcomes for the carer after the patient died. Therefore comparisons are not made between the intervention and control group in this manuscript.

Materials and Methods

Design

All carers who participated in the RCT in either the intervention or the control group were invited to complete a follow-up survey a minimum of 8 weeks and a maximum of 3 years post-death of the person with HGG. This timeframe allowed us to capture the experiences of as many bereaved carers as possible.

Measures

The bereavement survey ('survey') included: Hospital Anxiety and Depression Scale (HADS); Core Bereavement Items (CBI); and, qualitative questions around participants' support needs.

Hospital Anxiety and Depression Scale (HADS) is widely used in both cancer patients and carers to assess anxiety and depression, with demonstrated reliability in carers (α = 0.84-0.89) (Gough & Hudson, 2009; Hudson & Hayman-White, 2006; Hudson et al., 2010). It consists of 14 items that generate sub-scores for anxiety and depression, by summing the 7 items corresponding to each subscale. Scores >10 indicate clinical anxiety or depression and scores between 8-10 indicate borderline anxiety and depression (Zigmond & Snaith, 1983).

Core Bereavement Items (CBI) assess grief experiences and core bereavement phenomena for individuals who have experienced the recent death of a significant other (Burnett et al., 1997). It is a valid and reliable measure (α = .95) (Holland et al., 2013) consisting of 17 items, rated on a 4-point Likert scale (0=never to 3=a lot of the time/always/continuously). The CBI generates a total score (range 0-51, α = 0.9) and three subscale scores: (1) Images and Thoughts (7 items; range 0-21, α = 0.74), (2) Acute Separation (5 items; range 0-15, α = 0.77), and, (3) Grief (5 items; range 0-15, α = 0.86), with higher scores indicating higher bereavement-related distress.

Open-ended questions: The survey also contained open-ended free text questions enquiring about support needs during the caring period (emotional, practical, information, financial) and after the death of the person with HGG. Carers were asked about the perceived helpfulness of this support (indicated on a 1-10 scale with 1-3 representing "not helpful", 4-7 "moderately helpful" and 8-10 "extremely helpful") and what could have been done to improve support. Participants were also asked about preferred place of death including: (1) Did your relative/friend die in the place they wanted to? (2) Was the place of death where you would have preferred? (3) Did you have the support you needed to allow your relative/friend to die in the place of their choice? Participants were also asked "What supports helped you cope with your relative/ friends death? If any, please describe below." Demographic data included time spent caring; time since the death of the person with HGG; other care responsibilities; current employment status and whether they had children at home.

Data analysis

Data analyses were conducted using the Statistical Package for the Social Sciences (SPSS) Version 24. Descriptive statistics (i.e. median, inter-quartile range, and range) were calculated for each quantitative outcome variable as well as the proportion of respondents reporting clinically significant anxiety/depression and distress. Mann-Whitney U tests were performed to explore differences in the distribution of the HADS depression and anxiety, and CBI scores between:, (a) those who spent above and below the median number of months caring for their relative and, (b) those whose relative died ≤ versus >12 months prior to survey completion.

Content analysis (Elo & Kyngas, 2008) was conducted on the free-text questions that explored the following areas: supports carers received, supports needed and preferred place of death. The purpose of content analysis was to organise and elicit meaning from the qualitative data collected and to draw realistic conclusions. To ensure rigorous analysis, data coding was completed independently by three researchers [EL,GH, EM], results were then discussed and consensus achieved to ensure the validity of the findings (Bengtsson, 2016). Reporting was informed by the consolidated criteria for reporting qualitative research checklist (COREQ)(Tong et al., 2007).

Results

Forty-nine eligible (carers) participants were contacted via phone and 33 consented to be sent the survey. Nine participants were unable to be contacted, seven participants did not consent, and 25 completed surveys were returned. Table 1 summarises participant demographics.

The average time spent caring for someone with HGG was 14 months (SD 7.22; range 5 – 36 months). Almost half the carers (n = 10) had provided care for 12 months or less. The average time since death was 18 months (SD 11.47; range 4 – 36). For almost half the carers (n = 12) the death had occurred under 10 months from diagnosis.

Table 1. *Participant demographics*

Gender		
	Male	5 (24%)
	Female	20 (76%)
Age		*M*=62.08 yrs
	35-50	2 (8%)
	51-65	13 (52%)
	66-80	10 (40%)
Group		
	Intervention	14 (56%)
	Control	11(44%)
State		
	WA	19 (76%)
	NSW	6 (24%)
Time spent caregiving (months)		*M*=14.34
	0-6	4 (16%)
	7-12	6 (24%)
	13-18	11 (44%)
	19-24	1 (4%)
	25-36	3 (12%)
Time since the death of care recipient (months)		*M*=18.32
	2-6	5 (20%)
	7-12	7 (28%)
	13-18	1 (4%)
	19-24	4 (16%)

25-36	8 (32%)
Relationship to care recipient	
Husband or male partner	5 (20%)
Wife or female partner	19 (76%)
Daughter	1 (4%)
Employment status	
Full-time	5 (20%)
Part-time	2 (8%)
Retired	12 (48%)
Unemployed	3 (3%)
Other	2 (8%)
Caring for others at home	
No	23 (92%)
Parent	1 (4%)
Grandchild/ren	1 (4%)
Children at home	
No children	7 (28%)
0	11 (44%)
1	3 (12%)
2	3 (12%)
3	1 (4%)
Country of birth	
Australia	11 (44%)
UK and Ireland	9 (36%)
Asia	2 (8%)
Africa	1 (4%)
America	1 (4%)
New Zealand	1 (4%)

Note: *'Other' refers to Asia (N=2), Africa, America and New Zealand.

Anxiety, depression and bereavement-related distress

HADS and CBI scores are summarised in the supplementary file (Appendix 1). HADS anxiety scores from 28% of carers indicated clinical level anxiety and from 12% (indicated borderline clinical anxiety. HADS depression scores from 4% of participants indicated clinical depression and 16% indicated borderline clinical depression. One respondent reported borderline anxiety *and* depression, one reported clinical anxiety *and* depression, and two reported borderline depression *and* clinical anxiety.

Compared to the baseline assessments performed for the RCT (taken within approximately 2 months of diagnosis of HGG of care recipient), 16% reported improved depression and 40% improved anxiety (i.e. change in category from clinical to borderline or borderline to low); 4% reported stable depression and 16% reported stable anxiety (i.e. did not change category); 12% reported worse depression and 16% reported worse anxiety (i.e. shifted from low to borderline or borderline to clinical).

Grief

There were no significant differences in anxiety, depression, or bereavement-related distress scores between caregivers (a) whose relative had died less versus more than 12 months prior; or, (b) who spent more or less than the median number of months providing care. (See Appendix 1 Supplementary Tables).

Qualitative findings

Support during caregiving

Table 2 highlights participants' perceived helpfulness of the supports received during caregiving.

Table 2

Perceived helpfulness of supports received during caregiving* (n=25)

Area of support	Not at all helpful	Moderately helpful	Extremely helpful
Emotional	1 (4%)	9 (36%)	15 (60%)
Information	2 (8%)	12 (48%)	11 (44%)
Practical	6 (24%)	6 (24%)	13 (52%)
Financial	13 (52%)	4 (16%)	8(32%)

**This question refers to any support received during caregiving, i.e., not support specific to the Care-IS intervention*

Overall support

In response to a question about which health professionals provided carers overall support from during the care period: 14 reported their general practitioner (GP); 14 nominated either cancer or palliative care nurses; 11 specialist doctors (either oncologist, neuro-surgeon or "specialist"); and, 13 a specialist palliative care service.

Emotional support prior to death

The most frequently accessed emotional support was from a counsellor/psychologist (n=13) followed by family and friends (n=6). There was wide variability in the level of support carers received from others as exemplified in the following quotes.

"My family members could have helped. I didn't have any real help until it was too late and mum had to go to hospice because she was unable to move." (P189, control, 8 months bereaved).

"*I had quite a bit of support from my family (none from [patient's]). Neighbours and some friends. I attended my psychologist regularly. [Patient] had some counselling for his aggression"* (P038, 36 months bereaved).

When asked how they could have been better emotionally supported some carers identified routine availability of psychological counselling would have provided better emotional support:

> *Didn't really receive any emotional support except from friends and family and research nurse. Perhaps a psychologist should have been provided for us through palliative care. I was probably too busy to see one anyway if one had been provided.* (P2003, 10 months bereaved)

One participant described a single case worker would have been helpful:

> *A single case worker assigned to us as a couple, who could co-ordinate all the services, advice, financial aid available etc would have helped. We grappled in the dark trying to understand the services available to us.* (P120, 10 months bereaved)

Others wanted more contact from services and one carer indicated earlier preparation for the *"Terminal nature of the condition"* (P081, 32 months bereaved) would have been beneficial.

Information support about prognosis and disease progression

Information support was mostly from the oncology specialist or GP with particular reference to the poor disease trajectory and progression which many described as "honest" and "accurate". The benefit of access to health professionals, communication, and the need for more neuro-oncology care co-ordinator roles was highlighted in comments such as:

> *Neuro-oncology clinical coordinator always kept us informed and answered our questions. It was an important role which made visits to GP almost unnecessary and kept communication between us and the oncologist going. There should be more people filling this role in Australia.* (P2003, 10 months bereaved)

Carers also wanted more explicit information on the disease trajectory, prognosis and dying process stating: *"Preparing me earlier for the terminal nature of his condition"* (P081, 32 months bereaved), *"Possibly some better understanding of how quickly the end would come"* (P079, 24 months bereaved) and:

> *The first meeting with the oncology support nurse I asked what to expect (no sugar coating) was told [patient] would "go out" the way he "came in" with regards to his ability to care for himself. This may sound blunt, but it was accurate. I found the loss of*

> *my husband's ability to communicate the way an intelligent, articulate adult does, the saddest part of this illness. I lost the person, long before he died. Emotionally that was the hardest. No help or support could have made that easier …* (P133, 10 months bereaved)

Practical support prior to the death

Practical needs included personal care for the care recipient (e.g. showering); more specialist home nursing; respite and transport support: *"We found the most difficult aspect was getting [patient] to appointments. It was almost impossible to move him out of the house …… I didn't know where to turn to for help"* (P2003, 10 months bereaved) and "f*ormal respite care was very inflexible and difficult to change to meet my needs. Very bureaucratic system."* (P196, bereaved 9 months).

When asked about unmet practical support needs, one carer highlighted both they and the care recipient were not eligible for services:

> *Because I was a 'young' carer I didn't qualify for respite or cleaning help and because mum was only 60 she didn't either. This is seriously wrong and didn't allow me to have any mother/daughter time with her before she died. I was robbed of that in her final months because I had to be her constant carer, I had to shower her, get her on and off the toilet, wipe her, feed her, everything because we were in the gap in the system where she wasn't old enough for {Name} help and I wasn't old enough for [support for carers] help. In short the system is broken and there is not enough help for carers or carees.* (P189, 8 months bereaved)

Others found the transition from active treatment to palliative care difficult when communication and follow-up with the oncology team ended: *"No contact was made by {patient's name} oncologist/medical team from {hospital name} while we were at the palliative care. I understood that a changeover of care was made but a little attention would be helpful"* (P2016, 4 months bereaved)

Financial support prior to death

A number of carers indicated accessing financial support was challenging and not knowing their carer entitlements was a major barrier: *"We were fortunate we were ok… we would [have] spent overall at least $70,000 on everything from diagnosis."* (P038, 36 months bereaved) and:

> *Centrelink is a minefield. Found out after my husband died we could have been receiving more financial support. Often the staff did not know the rules themselves. Grateful for what we got, but we had to cash in retirement funds, insurance, etc to survive.* (P062, 34 months bereaved)

One participant highlighted the delay in processing of financial support eligibility. Assets assessment was done after death and while they were assessed as 0% all costs were funded – when they were in a financial situation to pay. They noted the inadequacy of any payments to cover items such as medications, transport, parking, dressings and continence pads:

> *Assets Assessment' by government were not processed before he died so we were assessed at 0% so all care home costs were refunded (other than daily standard charge) ruling in legislation. The system needs to be more efficient in processing in a timely manner to avoid this.* (P133, 10 months bereaved).

Supports during bereavement

Participants highlighted a range of supports received during bereavement across domains (see table 3). However, some participants also indicated receiving “no support” or “not needing any” in free text responses, illuminating the nuanced experiences of participants. (see Table 3).

Table 3. *Specific* **s***upport received during bereavement (n=25)*

Type of support received	
Emotional Support	
Psychologist/counsellor	8
Family	13
Social support	13
Health professional (Doctor, nurse, social worker)	1
GP	6
Community home care service	1
Research nurse	0
No support received/required	2
Practical Support	
Family	4
Social support	4
Community home care	1
No support received/ required	10
Financial Support	
Superannuation	1
Department Veteran Affairs	1
Cancer Council	1
Centrelink bereavement allowance	3
Financial advisor	3
Superannuation	1
Family/friends	2
No support received/required	7
Information Support	
Community home care service	5
Psychologist/counselling	1
Own research e.g., Internet/ books	5
Family/friends	2
No support received/required	5

Emotional supports during bereavement

The majority of participants (n=18) reported family and friends provided emotional support during bereavement: *"Just having friends and family who listened and cared about how I was feeling- work colleagues saw and handled my melt downs and still do!"* (P2051, 6 months bereaved).

Participants reported accessing formal supports as needed: *"Family and friends and knowing I could see the GP if necessary. Supporting our daughter has been quite hard she now has mental health plan, organised by GP which is helping*" (P196, 9 months bereaved).

Many cited accessing a counsellor or psychologist and memorial services provided by facilities: *"I was very pleased the care home had a memorial service at the end of the year it was lovely to reconnect with other residents and staff"* (P133, 10 months bereaved) and:

> *I seek counselling and my GP assessed me and provided me with a Mental Health Care Plan. I am now seeing a psychologist for 6 sessions. But this is just recently i.e., in the past 3 weeks. The first two months without counselling was difficult.* (P2016, 4 months bereaved)

Information support during bereavement

Few participants reported that they sought or required information support after the death of the patient. Some gained access to information from websites and the internet, *"[I] can get all the info I need online from reputable websites"* (P196, 9 months bereaved). Whilst others received information packs from palliative care services or funeral homes: "*[Residential care service] sent the information about what to do in terms of organising the funeral, whom and what organisation to notify about [patient's] passing. This information has been really helpful."* (P2016, 4 months bereaved)

Seven carers reported receiving no or very little information, "*Needed to enquire myself*" (P092, 30 months bereaved) or that it was not required.

Practical support during bereavement

Family and friends helped carers cope after their relative's death through provision of meals, help with paperwork, funeral preparation, and advice. The importance of engaging in activities was highlighted by participants:*"... getting out in the bush, volunteering which led to job in tutoring environment"* (P071, 30 months bereaved) and *"putting into place the things that I had told [patient] I was going to do. We did a lot of dancing together and I told him I'd start a month after he died line dancing."* (P107, 22 months bereaved). Ten reported they either received no practical support or did not need any. Several carers received the government bereavement payment or financial support from government departments. Others sought help from a financial advisor, accountant, or bank manager. For several family and friends helped cover funeral costs.

> *Family helped me financially. Had a short period of bereavement pension, but it's hard to get the paperwork in quickly enough to receive the entire 3 months of payment. Reduced cost of utilities helped. We were able to pay off our mortgage with [patients'] superannuation. I work full time, but am a low income earner.* (P2003, 10 months bereaved)

Seven reported no financial support was received or required. Several commented on difficulty with paperwork to access financial support: *"Having to sort out all our finances and taking complete control of it took up a lot of time and energy. Just because you have joint accounts means absolutely nothing- everything had to be put in my name."* (P107, 22 months bereaved).

Additional supports to help cope after the death

Some carers suggested legal and financial advice would have helped: e.g., *"Better support from banks and any organisation that I had to change over to my name*" (P107, 22 months bereaved). Others included; a longer period of bereavement support from Centrelink, practical help with gardening and housework, and referral to counsellors: *"Possibly talking to others -counselling, practical support at home"* (P2060, 14 months bereaved). Some indicated a loss of family support after the death was difficult for them. One carer commented they would have liked: "*Contact from all the agencies who had been part of the journey and who I heard nothing from in the month post him passing."* (P062, 34 months bereaved). One carer expressed a need for: *"More information for what is available to me, written down as I wasn't taking things in verbally for quite some time."* (P115, 24 months bereaved).

Others reported their grief was too intense to know what they needed or what, if anything, could have helped at that time: *"It's hard to say as I wasn't in a position at the time any way I was heavily medicated etc"* (P2055, 6 months bereaved) and "*None as it is unpredictable and ongoing. Grief comes in waves when least expected"* (P055, 33 months bereaved).

One bereaved carer provided a summary of their grief experiences:

> *Time does indeed lessen grief, however I wasn't prepared for the sheer intensity of the grief that I experienced after [patient] died. Physically and emotionally, it took up my life. However, my children are grown up and have their own lives and children to consider. So it was up to me to sort everything out. I had to spend a lot of time sorting out joint accounts and also going through files…* (P107, 22 months bereaved*).*

Preferred place of death

Four carers indicted they did not know if their relative died in the place they wanted to as it had not been discussed. Two patients wanted to die at home, but the carer felt they had no choice but to go to hospital or hospice care as the physical demands of caring made staying at home impossible: *"Would have preferred to be home, but that was not possible. Palliative care and respect. I think it was as good as any death is. I felt part of a 'family.'"* (P133, 10 months bereaved)

Eight patients died in hospital either by choice or circumstances: *"I could not look after him at home and hospice nurses (it took 2 nurses 24x 7) could pick him up off the floor if he fell. I couldn't do that myself, living alone with him"* (P120, 10 months bereaved).

Eight carers said their relative died at home as they wanted. Twenty carers said they had the support to allow their relative to die in the place of their choice whilst several felt they had no choice because of the nature of the disease or felt unsupported to make a choice.

Finally, carers commented how the loss of the patient's ability to communicate was the most difficult part of caring. Others felt they "fell between the gaps" in terms of eligibility for home support: "*[Patient] died in hospital instead of home as we couldn't get practical help. We were unable to have mum cared for at home like we all would have preferred"* (P189, 8 months bereaved).

The perceived value of palliative/hospice care rather than staying at home until death was appreciated by one carer:

> *… whilst I would have liked to take [patient] home to spend the rest of his life at home before he passed away, it would have been impossible for me to do so considering [patient's] illness. I really appreciate and am grateful for what the nurses and doctors at [palliative care facility] have done for [patient]. The support given was second to none!* (P2016, 4 months bereaved).

Discussion

This study builds on previous research which highlighted that bereaved carers of people with HGG found late-stage caregiving is all consuming and taxing because those they care for often experience complex symptoms with cognitive, behavioural, and physical disabilities negatively affecting daily life functioning (Piil & Jarden, 2018) and a systematic review which concluded there was limited evidence on how bereaved caregivers prefer to be supported, warranting further study (Piil et al., 2019). We explicitly asked bereaved carers how they could be supported in several domains (e.g. emotional, practical, information, and financial) in addition to assessing their anxiety, depression and grief experiences. This discussion is structured around Moore et al.'s (2013) systematic review of the palliative and supportive needs of people with HGG and their carers which identified the need for clear avenues of communication with treating professionals, identification of health services needs and resources and psychological and social support.

A systematic review (Moore et al., 2013) identified the need for consistent, well-delivered information around disease sequelae and treatment, clear avenues of communication with treating professionals, identification of health services needs and resources and psychological and social support.

Similar to other studies our bereaved carers preferred to be referred to palliative care early and information was mostly provided by oncology specialists or primary physicians (GP). This reflects previous findings that while people with HGG and their caregivers are supported mainly by neuro-oncologists for most of the disease phase, end-of-life is managed predominantly by general practitioners and specialists in palliative care (Heese et al., 2013). However, the caregivers in our study felt they could have been better supported with more information on the disease, its short prognosis, and the dying process. Notably, these are information needs in retrospect. An earlier study of carers of people with HGG found they wanted information on prognosis and treatment but giving such information at times of stress such as prior to initial surgery was suboptimal (Lobb et al., 2011). Additionally, treatment for HGG is often initiated rapidly leaving little time to absorb information or make treatment choices.

However, one study reported only half of physicians and nurses or health care workers feel comfortable talking about end of life and symptoms with patients (Sizoo et al., 2012). Previous studies highlighted the importance of communication with patients and carers about the illness and carers need opportunities to have conversations about their expectation of the patient's impending death which is often perceived to be unspoken by health professionals (Adelbratt & Strang, 2000). The participants in our study emphasised the importance of well-delivered information around disease sequelae early and prior to cognitive decline in the patient. As previously indicated these are preferences expressed in retrospect, and it is unclear whether carers would have been receptive to these conversations while the patient was under active treatment.

It may be that separate patient and carers consultations need to be held to discuss the dying process and an opportunity offered for bereaved families to communicate after the patient has died [32]. Such information would allow timely conversations with the patient about their preferred place of death as well as preparing both patients and carers for the journey ahead. If initiated too early patients and carers may experience end of life discussions as irrelevant or inappropriate or as destroying hope. If left too late there is a risk the patient will be unable to contribute actively because of progressive neurological symptoms (Piil & Jarden, 2018).

Many carers in this study reported not knowing the person's preference for place of death. Finding the most appropriate time for these conversations is emotionally challenging. However, caregivers in a previous study emphasised conversations must take place sooner rather than later (Tong, Sainsbury & Craig, 2007). It has been recommended that systematic pre-bereavement planning and careful communication about the services offered by palliative care bereavement support centres may improve access to support among bereaved family caregivers (Kirby et al., 2018). Satisfaction with the physician providing end of life care, the absence of transitions in health care settings, and the patient's ability to communicate at end of life are factors important for a dignified death.

Carers reported on their need for practical and social support, such as respite and this was mainly provided by palliative care services and friends. Many wanted greater access to respite care and practical support for household activities. One study has suggested the responsibilities of caring extend beyond household duties to constantly watching over the patient to avoid harm (Piil & Jarden, 2018) . Hence, a supportive social network is a valuable support for the person providing care. Carers also wanted access to practical support so that they could spend quality time with their family members. However access to these services were not without financial burden.

Almost half the carers reported receiving no financial support and few carers received the Government bereavement payment. Knowing where to go and difficulty with paperwork were the main barriers. Many out of pocket expenses such as costs of continence pads and medications were not covered. Many indicated the need for more information on services available for financial support, respite care, personal and practical care. We found that financial stress was particularly concerning for this group as often the patient was unable to recommence work and the carer had to give up employment due to intensive caring demands. Proactive information provision on financial issues and accessing government agencies has previously been recommended (Catt et al., 2008). Our data indicate there is a need for simplified and streamlined access to information about financial support, as well as, the application and review process to reduce the burden on carers both before and after the patient's death. Several participants reported that they did not receive the financial support they required until after the patient died. Carers also highlighted the difficulty they experienced in organising bank accounts after the patient died. It is imperative service providers address these issues at a policy and systems level.

Whilst one third of our participants reported borderline or clinical levels of anxiety, depression and grief related distress the bereaved carers in our study sought emotional support while caring from psychologists or counsellors and family members. However, routine referral to psychological counselling for themselves, family, and patient may have provided better emotional support both in coping during the illness and after death. Our findings support a recent study of eight bereaved caregivers that a supportive social network of family, friends and work colleagues is crucial support for the person providing care and in the bereavement phase (Piil & Jarden, 2018).

Recommendations for clinicians

Given the poor prognosis and rapid deterioration of people with HGG our study highlights the importance of sensitive communication with caregivers about prognosis early in the disease trajectory, information tailored to the stage of the disease, the initiation of a referral to grief support services, and timely discussions about the preferred place of care and death. The provision of tailored written information on the availability of support services such as respite, financial support (in particular assistance completing the paperwork) and bereavement support services should be offered routinely to caregivers. The distress associated with diagnosis, treatment and caring for someone with a disease with a poor prognosis referral for anticipatory grief support from the time of diagnosis is encouraged. Not all bereaved carers will require referral for formal mental health support, however, given the isolation and burden of caring reported in this study referral to community based support such as Compassionate Communities is recommended.

Limitations

The limitations of this exploratory analysis were the small sample size, The sample may also be subject to self-selection bias as carers who were most distressed or alternatively least distressed may have opted not to participate in the survey (Breen et al., 2021).

Conclusion

As the majority of patients experience communication deficits near death, discussion early in the disease trajectory of the patient's preferences regarding treatment in the end of life phase is recommended (Sizoo et al., 2012). Future research needs to sensitively explore the preferences of people with HGG and their caregivers about the timing for a discussion about their preferences for the place of death so that support services can be put in place in a timely and appropriate manner.

Caring for people with HGG is an emotionally and physically exhausting experience for many carers. The experiences of bereavement in this study indicate gaps in financial, information, psychological and practical support for carers. Ensuring provision of information and resources early to prepare for deterioration is essential, as is simplifying the procedures to access financial and practical support. Without change carers will continue to fall through the cracks, unable to access the best support available to them.

Acknowledgement: We thank the bereaved carers who participated in this study. The study was funded by a Grant from Cancer Australia APP1105307. A/Prof Georgia Halkett is currently receiving a Cancer Council of WA Research Fellowship.

Ethical approval: Ethics approval was gained from Curtin University and participating tertiary hospitals. 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: Consent was obtained from all participants included in the study.

Author contributions: Conception and design of the study (GKBH; EAL; AKN; JLP); acquisition of data (EM); analysis and reporting of data (RC, EM, EAL, GKBH); drafting the manuscript (EAL; GKBH; AKN, EM, JLP; AN; HD, RC).

Disclosure statement: The authors declared no conflicts of interest with respect to the research, authorship, and/or publication of this article.

References

Adelbratt, S., & Strang, P. (2000). Death anxiety in brain tumour patients and their spouses. *Palliative Medicine*, *14:*, 499–507.

Bengtsson, M. (2016). How to plan and perform a qualitative study using content analysis. *NursingPlus Open*, *2*, 8-14.

Breen, L. J., Johnson, A. R., O'Connor, M., Howting, D., & Aoun, S. M. (2021). Challenges in Palliative Care Research on Family Caregivers: Who Volunteers for Interviews? *Journal of Palliative Medicine*, *24*(1), 112-115. https://doi.org/10.1089/jpm.2019.0672

Burnett, P., Middleton, W., Raphael, B., & Martinek, N. (1997). Measuring core bereavement phenomena. *Psychological Medicine*, *27*(1), 49-57. https://doi.org/10.1017/s0033291796004151

Catt, S., Chalmers, A., & Fallowfield, L. (2008). Psychosocial and supportive-care needs in high-grade glioma. *Lancet Oncology*, *9*, 884-891.

Christakis, N. A., & Iwashyna, T. J. (2003). The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. *Social Science and Medicine*, *57*(3), 465-475. https://doi.org/10.1016/s0277-9536(02)00370-2

Davies, E., & Higginson, I. (2003). Communication, information and support for adults with malignant cerebral glioma: a systematic literature review. *Supportive Care in Cancer*, *11*, 21-29.

Elo, S., & Kyngas, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, *62*(1), 107-115. https://doi.org/10.1111/j.1365-2648.2007.04569.x

Given, B., Wyatt, G., Given, C., Sherwood, P., Gift, A., DeVoss, D., & Rahbar, M. (2004). Burden and depression among caregivers of patients with cancer at the end of life. *Oncol Nurs Forum 31*, 1105-1117.

Gough, K., & Hudson, P. (2009). Psychometric properties of the Hospital Anxiety and Depression Scale in family caregivers of palliative care patients. *Journal of Pain and Symptom Management*, *37*(5), 797-806. https://doi.org/10.1016/j.jpainsymman.2008.04.012

Halkett, G. K., Lobb, E. A., Miller, L., Phillips, J. L., Shaw, T., Moorin, R., Long, A., King, A., Clarke, J., Fewster, S., Hudson, P., Agar, M., & Nowak, A. K. (2015). Protocol for the Care-IS Trial: a randomised controlled trial of a supportive educational intervention for carers of patients with high-grade glioma (HGG). *BMJ Open*, *5*(10), e009477. https://doi.org/10.1136/bmjopen-2015-009477

Heese, O., Vogeler, E., Martens, T., Schnell, O., Tonn, J. C., Simon, M., Schramm, J., Krex, D., Schackert, G., Reithmeier, T., Nikkhah, G., Sabel, M., Steiger, H. J., Schlegel, U., Loffler, M., Weller, M., Westphal, M., & German Glioma, N. (2013). End-of-life caregivers' perception of medical and psychological support during the final weeks of glioma patients: a questionnaire-based survey. *Neuro-Oncology*, *15*(9), 1251-1256. https://doi.org/10.1093/neuonc/not089

Holland, J. M., Nam, I., & Neimeyer, R. A. (2013). A psychometric evaluation of the core bereavement items. *Assessment*, *20*(1), 119-122. https://doi.org/10.1177/1073191112446656

Hudson, P., Remedios, C., Zordan, R., Thomas, K., Clifton, D., Crewdson, M., Hall, C., Trauer, T., Bolleter, A., Clarke, D. M., & Bauld, C. (2012). Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. *Journal of Palliative Medicine*, *15*(6), 696-702. https://doi.org/10.1089/jpm.2011.0466

Hudson, P. L., & Hayman-White, K. (2006). Measuring the psychosocial characteristics of family caregivers of palliative care patients: psychometric properties of nine self-report instruments [Research Support, Non-U.S. Gov't]. *Journal of Pain and Symptom Management*, *31*(3), 215-228. https://doi.org/10.1016/j.jpainsymman.2005.07.010

Hudson, P. L., Remedios, C., & Thomas, K. (2010). A systematic review of psychosocial interventions for family carers of palliative care patients. *BMC Palliative Care*, *9*, 17. https://doi.org/10.1186/1472-684X-9-17

Janda, M., Eakin, E., Bailey, L., Walker, D., & Troy, K. (2006). Supportive care needs of people with brain tumours and their carers. *Supportive Care in Cancer*, *14*(11), 1094-1103.

Janda, M., Steginga, S., Langbecker, D., Dunn, J., Walker, D., & Eakin, E. (2007). Quality of life among patients with a brain tumor and their carers. *Journal of Psychosomatic Research*, *63*(6), 617-623.

Kirby, E., Kenny, K., Broom, A., MacArtney J, & Good, P. (2018). The meaning and experience of bereavement support: A qualitative interview study of bereaved family caregivers. *Palliat Support Care*, *16*(4), 396-405.

Lobb, E., Halkett, G., & Nowak, A. (2011). Patient and caregiver perceptions of communication of prognosis in high grade glioma. *Journal of Neuro-Oncology*, *104*(1), 315-322.

Moore G, Collins, A., Brand, C., Gold, M., Lethborg, C., Murphy, M., Sundararajan, V., & J, P. (2013). Palliative and supportive care needs of patients with high-grade glioma and their carers: A systematic review of qualitative literature. *Patient Education and Counseling*, *91*, 141-153.

Moore, G., Collins, A., Brand, C., Gold, M., Lethborg, C., Murphy, M., Sundararajan, V., & Philip, J. (2013). Palliative and supportive care needs of patients with high-grade glioma and their carers: a systematic review of qualitative literature. *Patient Education and Counseling*, *91*(2), 141-153. https://doi.org/10.1016/j.pec.2012.11.002

Munoz, C., Juarez, G., & Munoz, M. (2008). The quality of life of patients with malignant gliomas and their caregivers. *Social Work in Health Care*, *47*, 455-478.

Osoba, D., Brada, M., Prados, M., & Yung, W. (2000). Effect of disease burden on health-related quality of life in patients with malignant gliomas. *Neuro-Oncology*, *2*, 221-228.

Piil, K., & Jarden, M. (2018). Bereaved Caregivers to Patients With High-Grade Glioma: A Qualitative Explorative Study. *Journal of Neuroscience Nursing*, *50*(2), 94-99. https://doi.org/10.1097/JNN.0000000000000348

Piil, K., Juhler, M., Jakobsen, J., & Jarden, M. (2016). Controlled rehabilitative and supportive care intervention trials in patients with high-grade gliomas and their caregivers: a systematic review. *BMJ Support Palliat Care*, *6*(1), 27-34.

Piil, K., Nordentoft, S., Larsen, A., & Jarden, M. (2019). Bereaved caregivers of patients with high-grade glioma: a systematic review. *BMJ Support Palliat Care*, *9*(1), 26-33. https://doi.org/10.1136/bmjspcare-2017-001386

Schmer, C., Ward-Smith, P., Latham, S., & Salacz, M. (2008). When a family member has a malignant brain tumour: the caregiver perspective. *Journal of Neuroscience Nursing*, *40*, 78-84.

Schulz, R., Boerner, K., & Hebert, R. S. (2008). Bereavement after caregiving In M. Stroebe, R. Hannson, H. Schut, & W. Stroebe (Eds.), *Handbook of Bereavement Research and Practice*. American Psychological Association.

Schulz, R., Boerner, K., Shear, K., Zhang, S., & Gitlin, L. N. (2006). Predictors of complicated grief among dementia caregivers: A prospective study of bereavement. *American Journal of Geriatric Psychiatry*, *14*, 650-658.

Sizoo, E. M., Pasman, H. R., Buttolo, J., Heimans, J. J., Klein, M., Deliens, L., Reijneveld, J. C., & Taphoorn, M. J. (2012). Decision-making in the end-of-life phase of high-grade glioma patients. *European Journal of Cancer*, *48*(2), 226-232. https://doi.org/10.1016/j.ejca.2011.11.010

Stroebe, M. S., Hansson, R. O., Schut, H. E., & Stroebe, W. E. (2008). *Handbook of bereavement research and practice: Advances in theory and intervention* American Psychological Association.

Thomas, C., Morris, S. M., & Harman, J. C. (2002). Companions through cancer: the care given by informal carers in cancer contexts. *Social Science and Medicine*, *54*(4), 529-544. http://www.ncbi.nlm.nih.gov/pubmed/11848273

Tomarken, A., Holland, J., Schachter, S., Vanderwerker, L., Zuckerman, E., Nelson, C., Coups, E., Ramirez, P. M., & Prigerson, H. (2008). Factors of complicated grief pre-death in caregivers of cancer patients. *Psycho-Oncology*, *17*(2), 105-111. https://doi.org/10.1002/pon.1188

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups *International Journal for Quality in Health Care,*, *19*(6), 349-357.

Ugalde, A., Krishnasamy, M., & Schofield, P. (2012). Role recognition and changes to self-identity in family caregivers of people with advanced cancer: a qualitative study. *Support Care Cancer* *20*(6), 1175-1181. https://doi.org/10.1007/s00520-011-1194-9

Zigmond, A. S., & Snaith, R. P. (1983). Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand.*, *67*(6), 361-370.

Supplementary Table A. Median scores on anxiety, depression and grief in those who spent less than versus more than the median number of months (i.e. 14 months) caregiving.

	Number of months spent caregiving		U	P value
	Below median (< 14 months) n = 14	Above median (> 14 months) n = 11		
Outcome measure (score range)	Md (IQR)	Md (IQR)		
HADS Anxiety (0-21)	6 (4-12)	7 (5-11)	68.5	.639
HADS Depression (0-21)	4 (2-7)	6 (2-7)	66.0	.545
CBI Total Score (0-51)	30 (21-33)	25 (23-35)	70.0	.701

Supplementary Table B. Median scores on anxiety, depression and grief in those whose relative died less than versus more than 12 months previously.

	Number of months since patient death		U	P value
	< 12 months n = 12	> 12 months n = 13		
Outcome measure (score range)	Md (IQR)	Md (IQR)		
HADS Anxiety (0-21)	6 (4-10)	8 (4-12)	65.0	.477
HADS Depression (0-21)	45 (1-8)	4 (2-7)	76.0	.913
CBI Total Score (0-51)	28 (23-33)	29 (23-35)	74.0	.828

* Higher equals worse for all outcome measures. CBI = Core bereavement items; HADS = Hospital Anxiety and Depression scale; IQR = Interquartile range; Md = median; U = test statistic Mann-Whitney U test.

Supplementary Table C. Median CBI total and subscale scores in those who reported borderline versus clinical levels of anxiety assessed via HADS.

	HADS Anxiety	
	Borderline anxiety (scores 8-10) n = 3	Clinical anxiety (scores > 10) n = 7
CBI scores (score range)	Md	Md
CBI total score (0-51)	38	31
CBI images and thoughts subscale (0-21)	14	11
CBI acute separation subscale (0-15)	11	8
CBI grief subscale (0-15)	13	10

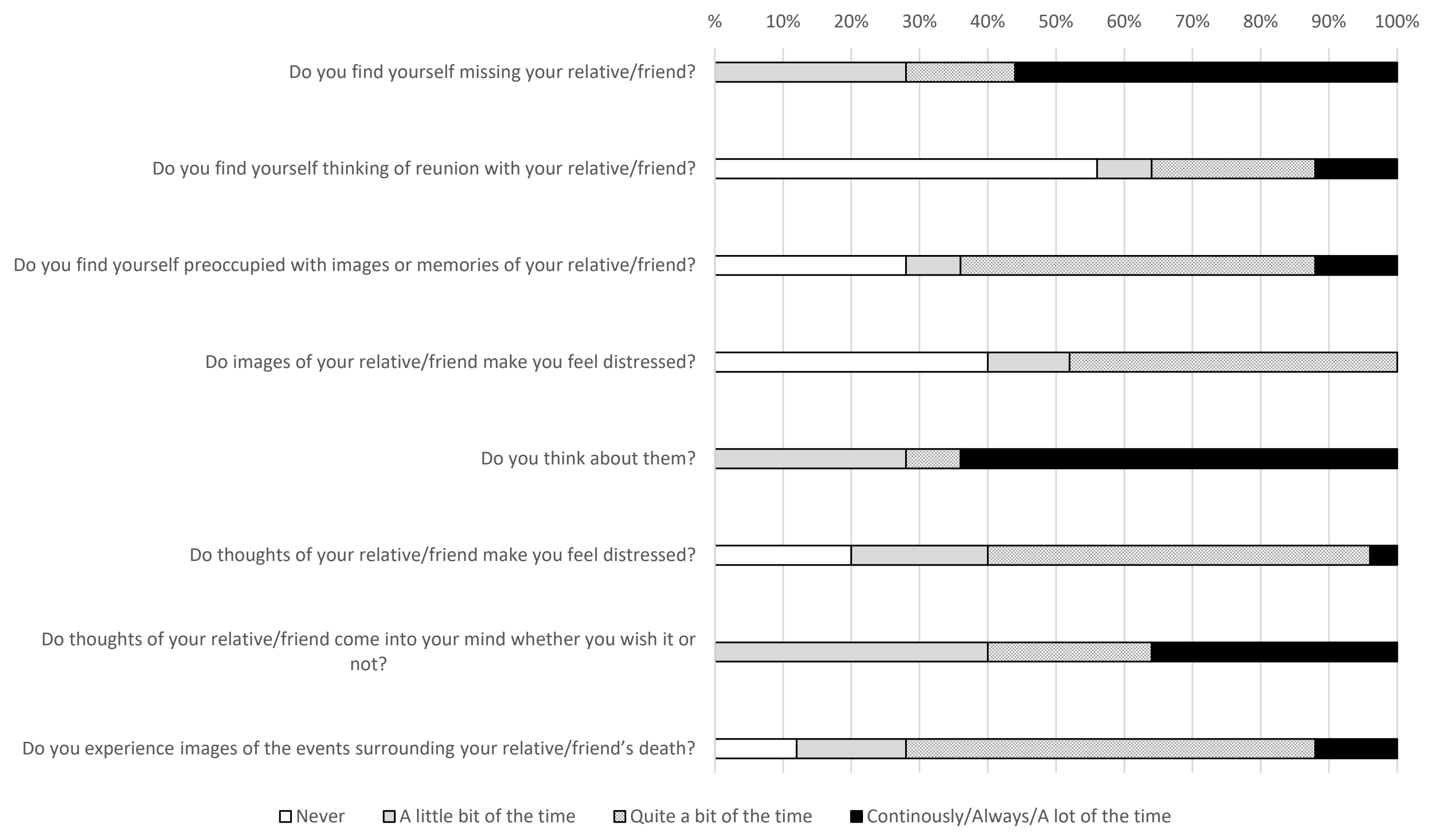
* Higher equals higher bereavement related distress for all CBI subscales. CBI = Core bereavement items; HADS = Hospital Anxiety and Depression scale; Md = median.

Supplementary Table D. Median CBI total and subscale scores those who reported borderline versus clinical levels of depression assessed via HADS.

	HADS Depression	
	Borderline depression (scores 8-10) n = 4	Clinical depression (scores > 10) n = 1
CBI scores (score range)	Md	Md
CBI total score (0-51)	32	42
CBI images and thoughts subscale (0-21)	12	19
CBI acute separation subscale (0-15)	8	13
CBI grief subscale (0-15)	11	10

* Higher equals higher bereavement related distress for all CBI subscales. CBI = Core bereavement items; HADS = Hospital Anxiety and Depression scale; Md = median.

Supplementary Figure A. Proportion of respondents reporting bereavement-related distress at time of survey completion (Core bereavement items 1 to 8)



Supplementary Figure B Proportion of respondents reporting bereavement related distress at time of survey completion (Core bereavement items 9 to 17)