Mapping the nature of distress raised by patients with high-grade glioma and their family caregivers: a descriptive longitudinal study

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Abstract

Background. Few supportive and palliative care interventions have been described for people with high-grade glioma (HGG) and their caregivers. A structured intervention, I-CoPE, which includes regular screening of patients' and caregivers' needs, was delivered as a pilot study in a tertiary neuro-oncological unit. This study prospectively described the severity and content of key concerns raised by patients and their caregivers in the 3 months following a diagnosis of HGG.

Methods. Consecutive patients and caregivers were screened for distress longitudinally using the Distress Thermometer at 3 time points. Exploration of the issues raised during screening was undertaken by the care coordinator and the issues documented. This documentation was subsequently audited to map patterns and nature of distress. The key reasons underlying distress and responses offered were grouped thematically and summarized using descriptive statistics.

Results. Thirty-two patients and 31 caregivers were recruited and underwent screening. At diagnosis, 87% of caregivers ($n = 27$) and 60% of patients ($n = 19$) reported distress scores meeting clinical significance. The predominant concerns reported by patients during screening related to existential issues such as fear of dying, whereas caregivers were more focused on practical caring responsibilities. Over time, the reasons for distress changed to include more physical health concerns for patients and more psychological concerns for caregivers.

Conclusions. This prospective longitudinal descriptive study revealed that following a new diagnosis of HGG, patients and caregivers had changing needs for support and fluctuating distress, mirroring the illness trajectory. Palliative care needs were apparent from diagnosis, and early integration of palliative care should be considered.

Keywords

caregivers | high-grade glioma | mixed-methods research | palliative care | psychosocial screening | supportive care.

People with high-grade malignant glioma (HGG) have significant supportive and palliative care needs.^{1,2} HGG patients include those with diagnoses of glioblastoma multiforme, anaplastic astrocytoma, and anaplastic oligodendroglioma. HGG remains a poor prognostic

cancer, with those with grade IV tumors having a median survival of just 14.6 months for patients treated with standard chemo-radiotherapy treatment protocols.³ Many patients negotiate multiple, often devastating physical, cognitive, and behavioral changes even early in their illness.⁴ In

particular, early cognitive decline means caregivers need specialist support, with patients frequently unable to participate significantly in decision making and planning.⁴

Patients with HGG and their caregivers have described their particular needs for improved care coordination, continuity of care, emotional support, and proactive preparatory caring advice throughout the trajectory.^{5,6} They also report a wish for individualized information based on the site of their tumor and its likely effects and the social implications such as for work and for driving. They highlight the value of such information being provided in a staged manner according to illness phase.⁵⁻⁷ Qualitative data indicate that gaps in support, information, and preparation for families exacerbate the burden of caring and suffering,^{6,8} and likely account for the high rates of distress previously reported by up to 63% of patients⁹ and 72% of caregivers.⁹

Much research to date has focused on describing the patient and caregiver experience¹⁰; however, there is developing interest in establishing best methods of providing care or trialing specialist interventions to educate and support patients and their caregivers.¹¹⁻¹⁴ This increasing focus reflects outcomes of systematic reviews, which highlight the need to find effective methods of support for patients with HGG and their caregivers.^{1,2} Such a focus also occurs in the context of a mature body of evidence suggesting integration of early palliative care for people with cancer leads to improved patient and family caregiver outcomes.¹⁵ Studies of early palliative care have not, to date, been undertaken in the HGG patient cohort. However, epidemiological data hint at the potential benefits available, with, for example, palliative care being associated with greater likelihood of death at home.¹⁶

Different approaches to responding to supportive and palliative care needs have been reported. Halkett et al have shown that distress among caregivers remains consistently high in the 6 months following a patient's HGG diagnosis, and in response, have developed a support model for family members of patients with HGG, currently under evaluation in clinical trials.¹³ Our earlier research established that the proactive assessment of needs at key points of change or transition in the illness as part of a 'needs-driven' model of care enables the effective tailoring of support including supportive as well as palliative care approaches.^{17,18}

We developed a model of supportive and palliative care for patients with HGG and caregivers (I-CoPE, Information, Coordination, Preparation and Emotional support), based on previous empirical work, that, in short, anticipates problems, and identifies and responds to them early rather than waiting until fully established to react; provides staged information according to the stage of illness reached; stipulates routine referral to palliative care services at first recurrence of cancer (at minimum); includes the family caregiver; and is based on illness or treatment milestones rather than time. Overarching the care provision is the role of the cancer care coordinator, who forms a relationship at diagnosis, checks in at regular times, conducts screening for concerns and responds accordingly, and provides staged information according to illness stage.¹⁷ In usual cancer care, the cancer care coordinator provides a point of contact, coordination of appointments, and support to patients and families. The difference in the I-CoPE model of care is the structure around such interactions, including

defined minimum regular contacts, screening, and staging of information appropriate to the illness phase.

As part of a larger study, we sought to empirically test the initial stages of this I-CoPE model of supportive and palliative care with a particular focus on patients with newly diagnosed HGG. The feasibility, acceptability, and preliminary effectiveness of I-CoPE for patients with HGG and their family caregivers has been reported elsewhere.¹⁸ This paper reports the severity and content of key concerns raised by patients and their caregivers as they completed these measures longitudinally as part of the study following a diagnosis of HGG.

Aim

The aim of this paper was to describe the severity and content of key concerns reported by patients and their caregivers identified through screening, using the Distress Thermometer, in the 3 months following a diagnosis of HGG.

Methods

Design and Setting

This was a noncontrolled, single-arm, pilot implementation study of a structured approach to the provision of supportive and palliative care for people with HGG and their family caregivers undertaken within the Neuro-Oncology service at a single tertiary center in Melbourne, Australia. Participants who provided written informed consent received the new model of supportive and palliative care (I-CoPE). The study was approved by the institutional human research ethics committee (protocol number 140/13).

Participants

Participants were adults newly diagnosed with HGG (grades 3 or 4) and their nominated family caregivers who consented to participate in the I-CoPE study.¹⁸ In addition, eligible participants were able to provide informed consent, complete written English-language instruments, and were planned for radiotherapy treatment. Patients with a disease-related speech or language deficit that precluded them from completing study questionnaires and/or providing consent to the study were excluded. Consecutive eligible patients were approached in person (along with their caregivers) during their first inpatient admission in the week following biopsy and/or resection. Subsequent interactions occurred over the telephone or, if the patient was attending the hospital for appointments, in person. Those patients without caregivers but who were otherwise eligible were included in the study.

Procedures

I-CoPE intervention

The I-CoPE intervention involved the provision of information, coordination, preparation, and emotional support over

3 key identified care transitions for people newly diagnosed HGG and their caregivers. The transition points correspond to specific points early in the patients' illness trajectory^{4,16,17} and included Transition 1: following the patient's pathological diagnosis after biopsy and/or resection in the acute hospital (I-CoPE 1); Transition 2: following discharge (7-10 days postdischarge) from the acute hospital (I-CoPE 2); Transition 3: following the completion of standard radiotherapy protocol when patients are no longer attending the acute hospital outpatient services on a daily basis, approximately 12 weeks following diagnosis (I-CoPE 3).

I-CoPE was delivered by a cancer care coordinator and consisted of the following activities: provision of information staged according to the illness stage; regular screening for needs and responses instituted, including emotional support; coordination of care as patients moved between sites and disciplines; and active engagement of family caregivers (these activities have been described in detail elsewhere).¹⁸ I-CoPE provided a framework to enable a standardized approach to the (minimum) timing of interactions, and a method to identify needs through screening using the Distress Thermometer.¹⁹

The Distress Thermometer screening tool was administered at each transition point and used as a prompt to explore patients' needs and concerns. This tool enabled screening for practical, physical, family, emotional, and spiritual/existential concerns. This tool has been shown to be successfully administered to cancer patients and their caregivers using community-based telephone outcalls^{20,21} and is well validated for use with brain cancer patients, with clearly defined cut-off scores to identify clinically relevant distress (score ≥ 4).^{12,22-24} All participants reporting a distress score of 4 or greater were offered referral to further supportive services as needed. Screening was accompanied by 1) staged information provision, 2) provision of emotional support, 3) coordination activities, and 4) active engagement of family caregivers.

I-CoPE 1 was delivered face to face in the inpatient setting, and I-CoPE 2 and 3 were delivered by phone.

Data collection

I-CoPE screening conversations conducted with patients and their caregivers were documented by the patient care coordinator using a standardized form. This form included all items listed on the Problem Checklist,¹⁹ the option of a free-text description for other concerns raised not covered by the available domains, and a standardized list of clinical responses offered by the cancer care coordinator to address concerns. In addition, the care coordinator detailed in full his or her perceptions and understandings of key concerns raised and the responses enacted.

As a mechanism to ensure fidelity of recording, a subset of interactions (1 in every 6 I-CoPE interactions) were audited by an independent researcher (AC). This involved interactions between the cancer care coordinator, the patient, and/or his or her caregiver being observed to ensure consistency of reporting.

Data analysis

Analysis of the concerns raised during screening was undertaken based on the predefined domains of the

Distress Thermometer and Problem Checklist.¹⁹ In addition, documentation of additional concerns raised not covered by these items was subjected to thematic analysis. This was undertaken initially by the researchers individually (JP, AC) with ideas raised, grouped, and subsequently categorized. The researchers then undertook a validation process to compare similarities and discuss areas of difference, thereby developing an agreed-on coding matrix and classification of themes.

Once all items were coded and themes agreed on, descriptive statistics including frequencies, counts, and percentages were generated to summarize the nature of the interactions at each time point. Consistent with the descriptive aims of this paper, variables of interest were preplanned and included the concerns elicited and clinical responses enacted. Categorical variables were defined according to the coding matrix developed during analysis. Distress Thermometer scores were also categorized into 2 groups to identify clinically significant distress.²⁵

Results

Description of Participants

Patients and caregivers were identified by treating clinicians as they presented with a new diagnosis of HGG. Of 53 potential patients admitted during the study period of 18 months, 11 were ineligible (cognition, non-English speaking, poor health) and 5 were not approached (admitted during staff leave), resulting in 37 eligible patients. Of these, 5 declined participation, giving a total of 32 patients and 31 caregivers who participated in the study and underwent screening over 12 weeks following a new diagnosis of HGG. Patients ($n = 32$) included 17 men, mean age 61 years; 14 were in some form of employment at diagnosis, and 25 had a glioblastoma multiforme (Table 1). The caregivers ($n = 31$) included 13 men, mean age 58 years, and 25 of the 31 caregivers nominated themselves as spouses/partners. Over the study 32, 29, and 28 patients, and 31, 30, and 29 caregivers received I-CoPE 1, I-CoPE 2, and I-CoPE 3, respectively. Therefore, in total, there were 89 patient and 90 caregiver I-CoPE contacts with data available for evaluation.

Severity of Distress Reported by Patients and Caregivers

The level of patient distress recorded using the Distress Thermometer fluctuated over the time course of the study, with initially elevated levels at diagnosis, dipping following hospital discharge, and increasing again as initial therapy was completed at 3 months (Fig. 1). Caregiver levels of distress gradually lessened with time. High proportions of patients and caregivers alike reported significant distress, meeting the clinically significant cutoff score of 4 or greater (see Table 2, Fig. 1). Overall, caregiver-reported distress was consistently greater than patients' and tended to be most prevalent at diagnosis. Patient distress returned to initial high levels at the end of treatment.

Table 1 Demographics of Participants

	Patients n = 32	Carers n = 31
Age mean (range), y	60.4 (28-82)	57.3 (28-85)
Male sex	17	13
Marital status		
-Married/de facto	19	22
-Never married	4	3
-Divorced/separated/widowed	9	6
Education level		
-Secondary education	9	13
-Tertiary or equivalent qualifications	11	17
-Not recorded	2	1
Employment at time of diagnosis		
-Full time	9	13
-Part time	5	5
-Retired/home caring/other	18	13
Tumor type ^a		
-Grade 4	25	
-Grade 3	7	
Tumor site		
-Parietal	8	
-Temporal	9	
-Frontal	10	
-Multifocal	2	
-Cerebellum/brainstem	3	
Concurrent medical condition	12	7
Relationship to patient		
-Spouse/partner		25
-Child/offspring		5
-Parent		1
-Friend		1

^aIncludes glioblastoma multiforme, anaplastic astrocytoma, and anaplastic oligodendroglioma.

Nature of Concerns Over Time

Detailing the nature and frequency of concerns raised by patients and caregivers during I-CoPE screening reveals that patient and caregiver needs were often distinct. Concerns raised by patients were predominantly in the spiritual or existential domain (33% of all concerns), such as fears of the unknown, fears of death and dying, and a stated desire to maintain quality of life. Physical and health-related concerns were minimal at diagnosis but became a greater focus through treatment (Table 3).

"What will happen to me? How do you die of a brain tumor?" Patient 7 [existential concern]

"I don't know how she will cope when I'm gone." Caregiver 23 [existential concern]

"It is really scary to know I could have a seizure." Patient 21 [physical-/health-related concern]

"Every time the steroid dose goes down, I start to feel really tired." Patient 12 [physical concern]

Meanwhile, the concerns raised by caregivers were most frequently in the practical (34% of all concerns) and emotional (29% of all concerns) domains.

"The appointments are just so confusing and change all the time. We just don't know where we're supposed to be." Caregiver 4 [practical concern]

"He is just so positive. I feel I need to be strong for him but I'm struggling." Caregiver 17 [emotional concern]

It was interesting to note that at the earlier times, caregivers' focus was on practical concerns about caring responsibilities and treatment questions, whereas by I-CoPE3, emotional concerns (38% of all concerns) such as worry about how their loved one was coping were most prevalent. Similarly, by I-CoPE 3 there was a marked increase in caregivers' concerns around the family including impacts on children and how to discuss the cancer with family.

Fig. 1 Patient- and Caregiver-Reported Distress Over Time I-CoPE indicates information, coordination, preparation and emotional support.

Table 2 Patient- and Caregiver-Reported Distress

	I-CoPE 1 Mean ^a ± SD	I-CoPE 2 Mean ^a ± SD	I-CoPE 3 Mean ^a ± SD
Patients	5.1 ± 3.1	3.3 ± 2.1	5.0 ± 2.8
	(range: 0-10)	(range: 0-7)	(range: 0-8)
	n = 32	n = 29	n = 28
% recording distress level ≥ 4	60%	55%	40%
Caregivers	6.0 ± 2.1	4.8 ± 1.7	4.0 ± 1.9
	(range: 0-10)	(range: 0-7)	(range: 0-8)
	n = 31	n = 30	n = 29
% recording distress level ≥ 4	89%	77%	59%

Abbreviation: I-CoPE, information, coordination, preparation and emotional support.

^aHigher scores indicate greater distress/level of concern (range = 0-10), with a score greater than or equal to 4 considered significant distress.²⁵

Nature of Responses and Referral Outcomes

The types of responses and referral outcomes resulting from all I-CoPE screening interactions are detailed in Fig. 2. Supportive counseling was the most common response (34% of all responses provided). Such counseling included, for example, discussion of how to talk to families about the diagnosis, financial resources and support available for caregivers, and employment plans. All patients and caregivers received the I-CoPE information resources, but additional information or coordination tasks that were required are presented in Fig. 2.

Discussion

This longitudinal descriptive study mapped patient- and caregiver-reported distress in the months immediately following a new diagnosis of HGG. Results demonstrated patients and caregivers had changing needs for support and fluctuating distress, which mirrors key points in the illness course—time of diagnosis, return home, and conclusion of initial treatment regimens.

Table 3 Nature of concerns raised during I-CoPE screening

Nature of Concern(s)	I-CoPE 1		I-CoPE 2		I-CoPE 3		Total	
	Patient	Caregiver	Patient	Caregiver	Patient	Caregiver	Patient	Caregiver
Existential	43%	23%	32%	16%	15%	23%	33%	21%
Practical	28%	37%	23%	39%	12%	15%	22%	34%
Emotional	13%	28%	14%	26%	38%	38%	20%	29%
Physical	4%	5%	32%	13%	31%	0%	18%	7%
Family	11%	7%	0%	6%	4%	23%	6%	9%

Abbreviation: I-CoPE, information, coordination, preparation and emotional support.

Fig. 2 Health Care Professional Responses to Concerns Raised During I-CoPE Screening I-CoPE indicates information, coordination, preparation and emotional support.

A series of new findings deserves mention in this cohort of patient and caregiver dyads mapped over time. First, the levels of distress of patients and caregivers differed. Patients' distress fluctuated, reducing on return home to increase again when treatment concluded, perhaps reflecting fatigue with daily therapy or the available time to fully reflect on the realities of the diagnosis and its attendant implications. Caregivers' distress remained clinically significant although gradually reduced and centered on different concerns as time progressed. These differences between groups and the changes over time have also been previously documented by Halkett and colleagues, who found that caregivers of patients with HGG reported consistently high levels of distress, which could not be predicted.⁸ Similarly, other groups have highlighted that the needs of patients with HGG and their caregivers both change in intensity and focus over time.^{26,27} The dynamic nature of needs reinforces the importance of repeated

screening or monitoring at key times to identify and address emerging concerns.⁸

Second, the proportions of clinically significant patient distress were high (53% to 63%) relative to earlier studies with HGG patients that have reported prevalence rates of 29% to 52%.^{12,22–24} This may reflect methodological differences in measurement tools used and their manner of administration. In this study, the high levels of distress recorded at I-CoPE 1 were noted during a long consultation (mean duration 45 minutes¹⁸), delivered face to face with the experienced cancer care coordinator. It is possible that in the context of such an intensive interaction, patients are more willing to express concerns and vulnerabilities.

Third, and consistent with earlier studies with advanced cancer patients, using the Distress Thermometer¹⁹ as a tool primarily of communication facilitated the initiation of conversations that may not otherwise have occurred. The I-CoPE model incorporating screening enabled a

conversation and voicing of concerns that were not necessarily broached in the usual medical consultation, where the focus was on treatment for the cancer. Cancer treatment and access to best available treatments is required by all patients and families. Delivery of the I-CoPE model also allowed other concerns to emerge alongside cancer treatment discussions. Exploration of concerns raised in I-CoPE delivery simultaneously facilitated the building of rapport and a relationship at the same time as assisting coordination of treatment and care navigation throughout the illness. It also enabled the mobilization of appropriate psychosocial supports.^{28–30}

Finally, screening using the Distress Thermometer in the context of I-CoPE delivery revealed a series of concerns that may typically be classified as the core focus of palliative care. The existential concerns of patients and caregivers were very significant and prevalent at diagnosis. Discussions around the meaning of illness and fear of the future are core activities of palliative care. Yet data suggest palliative care is rarely engaged at time of diagnosis of HGG for such patients, even for those with poor prognostic disease. The content of distress as highlighted in this study adds yet further impetus to the growing body of evidence suggesting integration of palliative care earlier in the illness course.¹⁵

There are some study limitations that must be mentioned. The numbers of patients and caregivers are small, consistent with the pilot nature of the study. The findings of this study may not be generalizable to a broader population, and could represent a more distressed group who were motivated to engage in a supportive intervention study. This study had no control arm, with all patients and caregivers accessing the intervention, which may have influenced their reporting of concerns. Furthermore, it was a single-center study of English-speaking participants, again precluding broad generalizability of the results. Nevertheless, as an exploratory study seeking to understand the care needs and concerns over time, we believe it has highlighted some important areas for further examination, most particularly, the patterns over time of distress and its cause(s).

Patients with HGG and their family caregivers have high levels of concern that differ in content from each other, and over time. While patients initially have a higher proportion of existential concerns at diagnosis, for family caregivers the initial focus is on practical issues. These concerns change in severity and content with the illness course. The Distress Thermometer used as a screening tool within the I-CoPE model of care is an effective way to identify and explore these concerns. Based on the content of these concerns, early referral to palliative care should be considered following the diagnosis of HGG.

Funding

This work was supported by a grant from the Australian Primary Health Care Research Institute, Department of Health and Ageing, Commonwealth Government of Australia.

Acknowledgments

The model of supportive care tested in this study was developed based on a program of work supported by the Victorian Cancer Agency, Australia.

Conflict of interest statement. None declared.

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