







Unmet needs in people with high-grade glioma: defining criteria for stepped care intervention

Mona M. Faris , PhD,^{1,*} Haryana M. Dhillon , PhD,^{1,2} Rachel Campbell , PhD,¹ Georgia K.B. Halkett , PhD,³ Annie Miller, DipBus,⁴ Raymond J. Chan, PhD,⁵ Helen M. Haydon , PhD,^{6,7} Ursula M. Sansom-Daly, PhD,^{8,9,10} Eng-Siew Koh , MD,^{11,12,13} Tamara Ownsworth, PhD,¹⁴ Anna K. Nowak, PhD,¹⁵ Brian Kelly, PhD,¹⁶ Robyn Leonard, BLArch,¹⁷ Kerryn E. Pike, DPsych,^{14,18,19} Dianne M. Legge, MAppSc,^{3,20} Mark B. Pinkham, BM, BCh,^{21,22} Meera R. Agar, PhD,²³ The BRAINS Program Group, Joanne Shaw, PhD¹

¹Psycho-Oncology Cooperative Research Group, School of Psychology, Faculty of Science, The University of Sydney, Sydney, NSW, Australia

²Centre for Medical Psychology & Evidence-Based Decision-Making, School of Psychology, Faculty of Science, The University of Sydney, Sydney, NSW, Australia

³Curtin School of Nursing/Curtin Health Innovation Research Institute, Faculty of Health Sciences, Curtin University, Bentley, WA, Australia

⁴Community advisory group, Psycho-Oncology Cooperative Research Group, The University of Sydney, Sydney, NSW, Australia

⁵Caring Futures Institute, College of Nursing and Health Sciences, Flinders University, Adelaide, SA, Australia

⁶Centre for Online Health, The University of Queensland, Brisbane, QLD, Australia

⁷Centre for Health Services Research, The University of Queensland, Brisbane, QLD, Australia

⁸School of Clinical Medicine, UNSW Medicine and Health, University of New South Wales, Kensington, NSW, Australia

⁹Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital, Randwick, NSW, Australia

¹⁰Sydney Youth Cancer Service, Nelune Comprehensive Cancer Centre, Prince of Wales Hospital, Randwick, NSW, Australia

¹¹South West Sydney Clinical School, UNSW Medicine, University of New South Wales, Liverpool, NSW, Australia

¹²Liverpool and Macarthur Cancer Therapy Centres, Liverpool, NSW, Australia

¹³Ingham Institute for Applied Medical Research, Liverpool, NSW, Australia

¹⁴School of Applied Psychology & Menzies Health Institute of Queensland, Brisbane, QLD, Australia

¹⁵Medical School, University of Western Australia, Crawley, WA, Australia

¹⁶School of Medicine and Public Health, University of Newcastle, Newcastle, NSW, Australia

¹⁷Brain Cancer Collective, NHMRC Clinical Trials Centre, University of Sydney, Sydney, NSW, Australia

¹⁸Griffith Centre for Mental Health, Griffith University, Queensland, Australia

¹⁹School of Psychology & Public Health and John Richards Centre for Rural Ageing Research, La Trobe University, Victoria, Australia

²⁰Olivia Newton-John Cancer and Wellness Centre, Austin Hospital, Heidelberg, VIC, Australia

²¹Division of Cancer Services, Princess Alexandra Hospital, Woolloongabba, QLD, Australia

²²School of Medicine, University of Queensland, Brisbane, QLD, Australia

²³Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT) Research Centre, Faculty of Health, University of Technology, Sydney, NSW, Australia

*Correspondence to: Mona M. Faris, Psycho-Oncology Cooperative Research Group, School of Psychology, Faculty of Science, The University of Sydney, Camperdown, NSW 2006, Australia (e-mail: mona.faris@sydney.edu.au).

Abstract

Background: We aimed to define levels of unmet supportive care needs in people with primary brain tumor and to reach expert consensus on feasibility of addressing patients' needs in clinical practice.

Methods: We conducted secondary analysis of a prospective cohort study of people diagnosed with high-grade glioma ($n = 116$) who completed the Supportive Care Needs Survey-Short Form during adjuvant chemoradiation therapy. Participants were allocated to 1 of 3 categories: *no need* ("no need" for help on all items), *low need* ("low need" for help on at least 1 item, but no "moderate" or "high" need), or *moderate/high need* (at least 1 "moderate" or "high" need indicated). Clinical capacity to respond to the proportion of patients needing to be prioritized was assessed.

Results: Overall, 13% ($n = 5$) were categorized as *no need*, 23% ($n = 27$) *low need*, and 64% ($n = 74$) *moderate/high need*. At least 1 *moderate/high need* was reported in the physical and daily living domain (42%) and the psychological (34%) domain. In recognition of health system capacity, the *moderate/high need* category was modified to distinguish between *moderate need* ("moderate" need indicated for at least 1 item but "high" need was not selected for any item) and *high need* (at least 1 "high" need indicated). Results revealed 24% ($n = 28$) *moderate need* and 40% ($n = 46$) *high need*. Those categorized as *high need* indicated needing assistance navigating the health system and information.

Conclusions: Using four step allocations resulted in 40% of patients indicating *high need*. Categories may facilitate appropriate triaging and guide stepped models of healthcare delivery.

Brain tumors are relatively rare, with approximately 4 per 100 000 people affected annually worldwide (1). Compared to improved overall cancer survival rates, brain cancer survival has

improved marginally, from 20% to 22%, over 30 years (2). High-grade gliomas (HGG, Grade III-IV) comprise the majority of adult malignant primary brain tumors (~62%) (3). Brain cancer and its

Received: January 19, 2024. Revised: April 3, 2024. Accepted: April 27, 2024

© The Author(s) 2024. Published by Oxford University Press.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial License (<https://creativecommons.org/licenses/by-nc/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited. For commercial re-use, please contact journals.permissions@oup.com

treatment can cause debilitating side-effects, including physical, behavioral, cognitive, and psychological symptoms (4). Previous research identified many concerns and unmet needs in people with HGG. These include feeling like a different person; physical side-effects related to both the tumor and treatments; a lack of financial assistance or advice; changes in cognitive ability; barriers to accessing rehabilitation services; and a lack of information on new research and treatment options (5,6). After those with lung cancer, people with brain tumor (PwBT) have a higher prevalence of symptom burden and concerns and more severe problems, relative to other cancer types (7). Additionally, PwBT commonly experience a poorer sense of wellbeing and quality of life (8), with 16%-48% reporting clinical levels of anxiety or depression (9). The high symptom burden results in higher health service costs for individuals and the healthcare system, rendering it one of the costliest cancers (\$1.7 million/person) (10). Such findings highlight the potential benefit of routine screening for symptoms to facilitate timely access to appropriate supportive care (11). Assessing unmet needs involves identifying patients' needs, how much help they are seeking, and appropriate support to address these needs (12). However, in Australia, there are no standardized models or systematic approaches implemented to identify and address unmet needs in those affected by brain cancer in routine clinical care (13).

To address this gap, the Brain cancer Rehabilitation, Assessment, Interventions for survivorship Needs (BRAINS) program was developed to support best practice in survivorship and supportive care to those affected by brain cancer in Australia (14). The program aims to facilitate assessment and management of unmet needs in PwBT and to increase uptake of screening in routine practice (15). Given cognitive changes potentially arising due to brain cancer and treatment (16), a brief screening measure is important. We have previously demonstrated the sensitivity and specificity of a brief version of the 34-item Supportive Care Needs Survey-Short Form (SCNS-SF34), a 9-item tool called SCNS-Screening Tool (SCNS-ST9), to screen for unmet needs in PwBT (17). The SCNS-ST9 retains the same 5-point Likert response scale and original five SCNS-SF34 domains but with two items each, except for one domain that has one item (17,18). A secondary data analysis from a prospective cohort study (5,6) was performed at two timepoints (during chemoradiation and 3 months later) for 116 people with HGG completing SCNS-SF34. Only three (<5%) individuals with unmet needs on SCNS-SF34 were missed using the SCNS-ST9 at each time point (17), demonstrating the sensitivity and specificity of this brief tool to screen for unmet needs in people with HGG.

Given the SCNS-ST9's sensitivity and specificity, the question remains how best to use this screening tool to allocate supportive care resources. Many PwBT in need of supportive interventions do not receive assistance as needs often outstrip availability of clinicians with expertise in the care of PwBT (13). This barrier may be addressed through use of a stepped model of healthcare delivery to triage patients based on the severity of their needs. Stepped care is defined as evidence-based delivery of health interventions tailored to individual needs (19). Stepped care frameworks are effective and cost-efficient models of healthcare delivery, using a hierarchy of interventions of increasing intensity (20). Our team is developing a stepped care model to implement psychosocial screening as part of routine care, with patients who indicate *some* level of need on the SCNS-ST9 having a triage conversation with a healthcare professional to discuss screening results and appropriate support. However, timing of the triage conversation and type of support offered will depend

on the level of need indicated on screening. To develop a stepped model of care, we must first operationalize levels of need (ie, steps) to guide timely assessment and intervention by prioritizing patients.

Several approaches have been used to categorize the level of unmet need using responses to the SCNS-SF34. A binary approach, dichotomizing unmet need as "no need" (ie, not applicable and satisfied) versus "some need" (ie, low, moderate, and high; moderate and high) has been used (21,22). Alternatively, quantitative approaches have been used, such as creating domain scores by summing the responses on the 5-point Likert scale per domain and a total scale score by summing all domain scores (23-25). Both approaches fail to determine how much and how urgently help is needed. For example, using the latter approach, a total score does not identify how many unmet needs have been endorsed nor magnitude of need. Another approach to categorizing participants' unmet needs with explicit operational definitions of categories was demonstrated in a study by Boyes et al. (26), who examined the prevalence of supportive care needs in those with hematological cancer. In 72%, unmet needs were assessed more than 12 months since diagnosis. Based on responses to the SCNS-SF34, respondents were categorized as having: 1) *no needs* for people reporting "no need" for help on all items; 2) *low needs* for those who indicated "low need" for help on at least one item, but did not select "moderate" or "high" need for any; and 3) *moderate/high needs* where a "moderate" or "high" need was indicated on at least one item. Categorizing levels of unmet need in this way has the potential to identify and prioritize patients requiring more specific interventions or specialized care. Given the complex needs of PwBT, particularly those with HGG, it is unclear how levels of unmet need would map onto these categories. We aimed to explore whether this approach would be suitable for people with HGG to define step allocations. We also aimed to assess the appropriateness of these categories by mapping existing unmet needs reported in the cohort study to these categories after seeking input from experts in brain tumors (eg, healthcare professionals, researchers).

Method

Study design

We conducted a secondary analysis of a prospective cohort study of people with HGG (5,6). Briefly, people with HGG were recruited by their treating clinician or cancer care coordinator from outpatient clinics (neurosurgical, radiation oncology, medical oncology) from 4 tertiary hospitals across 2 Australian states. Eligible individuals were aged 18 years or older, diagnosed with Grade III-IV glioma, scheduled to begin adjuvant chemoradiation, with capacity to complete questionnaires in English. A total of 165 participants were assessed as eligible, with 127 consenting to participate, and 116 completing baseline surveys (91% response rate). Reasons for nonparticipation included physical or emotional stress, disinterest, hospital admission, and poor cognitive health. The study was approved by the Human Research Ethics Committees (HREC) of Sir Charles Gairdner Hospital (HREC #2006-146), Curtin University (HREC #03/2007), and Cancer Institute New South Wales (NSW) (HREC #2008/08/092) and registered in the Australian New Zealand Clinical Trials Registry (ANZCTR). All participants provided informed consent.

Participants completed questionnaires at 3 timepoints: during adjuvant chemoradiation therapy and 3 and 6 months later (5,6), but only data collected during adjuvant chemoradiation was used in the current analysis. Questionnaires were completed by

Table 1. Response categories used in SCNS-ST9 for indicating perceived level of need

Level of need response category	Definition
No need—not applicable	This was not a problem for me as a result of having a brain tumor
No need—satisfied	I did need help with this, but my need for help was satisfied at the time
Low need	This item caused me concern or difficulty. I had little need for additional help
Moderate need	This item caused me concern or difficulty. I had some need for additional help
High need	This item caused me concern or difficulty. I had a strong need for additional help

the patient, with carers able to assist or complete questionnaires on their behalf. Additional patient-reported outcome measures were completed (5,6); only those relevant to the current analysis are described here, namely, the SCNS-SF34 (17, 18). Needs were assessed across five domains: psychological; physical and daily living; health system and information; patient care and support; and sexuality. Although participants completed the 34-item survey, we only examined items included in the SCNS-ST9. Participants indicated their level of need for help for all items over the last month using response options presented in Table 1.

The BRAINS program brings together a diverse group of experts in brain tumor management. Members consist of researchers who work in the field of brain tumor; healthcare professionals who provide care to PwBT, psycho-oncology, supportive and palliative care, survivorship; and patient advocates. Members of the program meet regularly to oversee the program of research.

Operationalizing step allocations

Using patient supportive care needs data assessed by the 9 items included in SCNS-ST9 from the HGG cohort study (5,6), the level of unmet need was mapped onto categories published in Boyes et al. (26) We planned, a priori, to discuss levels of need and step allocations with a working group of multidisciplinary experts in the care of PwBT, similar to other studies using expert opinion to develop recommendations for clinical practice (27,28). By examining the proportion of patients categorized as having *no needs*, *low needs*, and *moderate/high needs*, they judged the clinical capacity in managing patients who indicated *some* level of need, such that those with more severe need will be triaged rapidly and receive more intensive supportive care than those with less severe need. The group of experts met on two separate occasions (mean number of attendees = 12) to discuss categorization of unmet need. Refinement of step allocation was applied after review by this group.

Results

Characteristics of the 116 participants are presented in Table 2. Most (71%) were male with a mean age of 56 years (range 18-86) and had been diagnosed with Grade IV HGG (94%); the mean time from diagnosis was 1.3 months (range 0-6 months). Most people reported having a partner (83%), who was typically their primary carer (78%).

Prevalence of unmet needs

Participants were classified into one of three categories (26) based on self-reported level of unmet need (Table 3). Overall, 13%

Table 2. Patient characteristics during adjuvant chemoradiation therapy (T1) (N = 116)

Patient characteristics	T1
Age (years) (n = 110) ^a	
Mean (SD)	56 (13.3)
Median (IQR)	58.5 (15)
Time since diagnosis (months) (n = 115) ^a	
Mean (SD)	1.3 (1.1)
Median (IQR)	1.0 (1)
Sex, no. (%)	
Male	82 (71.0)
Female	34 (29.0)
Education, no. (%)	
Year 10 or below	34 (29.3)
Year 12 ^b	20 (17.2)
TAFE ^c certificate or diploma, business college	31 (26.7)
University or postgraduate	29 (25.0)
Missing	2 (1.8)
Marital status, no. (%)	
Married	95 (81.9)
Never married	5 (4.3)
Divorced or separated	12 (10.3)
Widowed	3 (2.6)
Missing	1 (0.9)
Country of birth, no. (%)	
Australia	67 (57.8)
Other ^d	48 (41.4)
Missing	1 (0.9)
Rurality, no. (%)	
Major city	73 (62.9)
Inner regional	10 (8.6)
Outer regional	7 (6.0)
Remote	3 (2.6)
Very remote	1 (0.9)
Unclassifiable	22 (19.0)
Language other than English spoken at home, no. (%)	
Yes ^e	11 (9.5)
No	103 (88.8)
Missing	2 (1.7)
Has a carer, no. (%)	
Carer is their partner	91 (78.4)
Carer is not their partner	18 (15.5)
No	6 (5.2)
Caring for someone else in home, no. (%)	
Yes	21 (18.1)
No	94 (81.0)
Missing	1 (0.9)
Financial effect of diagnosis, no. (%)	
No or slight effect	64 (55.2)
Significant effect	49 (42.2)
Missing	3 (2.6)
ECOG performance status ^f no. (%)	
0	37 (31.9)
1	41 (35.3)
2	27 (23.3)
3	8 (6.8)
4	1 (0.9)
Missing	2 (1.8)

^a SD = standard deviation; IQR = interquartile range.

^b In the Australian education system, Year 12 marks the final year of formal schooling.

^c Technical and further education (provider of vocational education and training).

^d Country of birth if born outside of Australia: Bahamas, Bangladesh, Colombia, Croatia, Egypt, England, France, Holland, Hong Kong, India, Ireland, Italy, Kenya, Macedonia, Malaysia, Netherlands, New Zealand, Scotland, Singapore, South Africa, United States.

^e Languages other than English spoken in the home: Bengali, Cantonese, Chinese, Croatian, Dutch, Italian, Macedonian, Spanish. One participant did not specify the non-English language spoken.

^f Eastern Cooperative Oncology Group (level of physical dependency).

(n = 5) of participants were categorized as having *no need*, 23% (n = 27) as *low need*, and 64% (n = 74) as *moderate/high need*. Across SCNS-ST9 domains, 42% of participants indicated at least one

Table 3. Proportion of participants (N = 116) categorized as having no, low, or moderate/high needs, overall and by SCNS-ST9 domains

	Step 1 No need ^a No. (%)	Step 2 Low need ^b No. (%)	Step 3 Moderate/ high need ^c No. (%)
Overall (across 9 items)	15 (13)	27 (23)	74 (64)
Domains	—	—	—
Psychological	53 (46)	23 (20)	40 (34)
Fears about cancer spreading	—	—	—
Uncertainty about future	—	—	—
Health system and information	62 (54)	19 (17)	35 (30)
Being informed about your test results as soon as feasible	—	—	—
Being informed about things you can do to help yourself to get well	—	—	—
Physical and daily living	33 (29)	34 (29)	49 (42)
Lack of energy/tiredness	—	—	—
Not being able to do the things you used to do	—	—	—
Patient care and support	86 (74)	17 (15)	13 (11)
Reassurance by medical staff that the way you feel is normal	—	—	—
Hospital staff acknowledging and showing sensitivity to your feelings and emotional needs	—	—	—
Sexuality	85 (73)	13 (11)	18 (16)
Changes in sexual relationships	—	—	—

^a Selected “no” need for help for all items.

^b Selected “low” level need for help for at least 1 item, but did not select “moderate” or “high” need for any item.

^c Selected “moderate” or “high” level need for help for at least 1 item.

moderate/high need in physical and daily living domains, followed by the psychological domain (34%) and health system and information domain (30%). Relatively few reported *moderate/high needs* in the patient care and support (11%) and sexuality (16%) domains.

The distribution of responses across these categories was skewed, with approximately two-thirds categorized as having *moderate/high need*. Discussion with our expert group focused on the feasibility of implementing these categories within oncology services considering practical implications on workflow. It was agreed that although the aim is to assess and provide support to all people with HGG indicating some need, prioritizing and instituting management for such a high proportion of patients may not be feasible within resource-constrained services. After discussion, the *moderate/high need* category was modified to differentiate between “moderate” and “high” need. We defined the *moderate need* category as responses where “moderate” need for help was indicated for at least one item but “high” need was not selected for any. The *high need* category was defined as responses where a “high” need for help was indicated for at least one item.

The same 116 participants were reclassified into one of four categories based on level of unmet need. Overall, 13% (n = 15) of participants were classified as having *no need*, 23% (n = 27) *low need*, 24% (n = 28) *moderate need*, and 40% (n = 46) *high need* (Table 4). Across most SCNS-ST9 domains, a higher proportion of participants reported “no need” compared to “low,” “moderate,” or “high” need, particularly in the patient care and support and sexuality domains. The level of unmet need was relatively evenly spread across the severity range for the physical and daily living

domain. Patients categorized as *high need* were more likely than those categorized as *moderate need* to report needing assistance navigating the health system and accessing health information.

Discussion

Four step allocations were operationalized based on level of unmet need: *no need*, *low need*, *moderate need*, and *high need*. Based on a prior study categorizing unmet need of people with other cancer types (*no need*, *low need*, *moderate/high need*) (26), we employed the same categories to define step allocations for people with HGG during chemoradiation therapy, modifying *moderate/high need* to differentiate between moderate or high unmet need.

Mapping unmet needs from HGG participants in a cohort study to the three categories outlined in Boyes et al. (26) revealed differences in distribution of the prevalence of need. Overall, the proportion of participants categorized as having *moderate/high need* in our study was 64% compared to 51% in research by Boyes and colleagues. This difference may be attributed to clinical characteristics of the samples as distress and unmet need varies across cancer diagnoses. We focused on unmet needs of people with HGG, whereas Boyes et al. focused on individuals with hematological cancer. The clinical trajectory of selected hematological cancers is commonly characterized as a chronic disease (26). In primary brain cancer, especially HGG, disease progression is often rapid and characterized by a decline in functional, emotional, and/or cognitive functioning before death. Distress is higher in PwBT compared to individuals with other cancer diagnoses (29), and higher levels of distress are associated with higher unmet need (30). Additionally, most participants in Boyes et al. were more than 12 months post-diagnosis, whereas in this sample, the mean length of diagnosis was 1.3 months, with needs likely to vary across the trajectory (13). The measures used may have contributed to differences in proportions of unmet need, with Boyes et al. using the SCNS-SF34, whereas we used the SCNS-ST9. At a domain level, however, our findings were comparable with Boyes et al. (26). The most common areas in which participants indicated needing support were psychological and physical aspects of daily living domains both in this study (34% and 42%, respectively) and in Boyes et al. (35% and 35%, respectively). These results reflect the unmet need frequently reported by people living with poorer prognosis cancers such as lung (31) or pancreatic malignancies (32). When we differentiated between participants with moderate and high need, those categorized as *high need* commonly reported needing assistance navigating the health system and information. These findings provide evidence to guide the provision of supportive care services and resource allocation at an organizational level toward addressing high unmet needs, particularly in clinical settings with limited health-care resources.

Using Boyes et al.’s (26) original criteria, our results indicate that approximately two-thirds of participants would require immediate clinical review. Revising the *moderate/high need* category provides further granularity between moderate and high level of unmet need. Our modified criteria ensure that individuals with the most severe needs are rapidly prioritized in health-care systems with finite resources. Although all patients indicating *some* level of need will receive a triage conversation to review identified needs, PwBT reporting high needs are prioritized for urgent follow-up, enabling support to be delivered in a timely way.

Table 4. Proportion of participants (N = 116) categorized as having no need, low need, moderate need, or high need, overall and by SCNS-ST9 domain

	Step 1 No need^a No. (%)	Step 2 Low need^b No. (%)	Step 3 Moderate need^c No. (%)	Step 4 High need^d No. (%)
Overall (across 9 items)	15 (13)	27 (23)	28 (24)	46 (40)
Domains	—	—	—	—
Psychological	53 (46)	23 (20)	24 (21)	16 (14)
Fears about cancer spreading	—	—	—	—
Uncertainty about future	—	—	—	—
Health system and information	62 (53)	19 (16)	11 (10)	24 (21)
Being informed about your test results as soon as feasible	—	—	—	—
Being informed about things you can do to help yourself to get well	—	—	—	—
Physical and daily living	33 (28)	34 (29)	30 (26)	19 (16)
Lack of energy/tiredness	—	—	—	—
Not being able to do the things you used to do	—	—	—	—
Patient care and support	86 (74)	17 (15)	9 (8)	4 (3)
Reassurance by medical staff that the way you feel is normal	—	—	—	—
Hospital staff acknowledging and showing sensitivity to your feelings and emotional needs	—	—	—	—
Sexuality	85 (73)	13 (11)	11 (10)	7 (6)
Changes in sexual relationships	—	—	—	—

^a Selected “no” need for help for all items.

^b Selected “low” level need for help for at least 1 item, but did not select “moderate” or “high” need for any item.

^c Selected “moderate” need for help for at least 1 item, but did not select “high” need for any item.

^d Selected “high” need for at least 1 item.

In this cohort, 40% were categorized as having a high need. This may reflect their new diagnosis of HGG and initial screening for unmet need. Identifying and addressing need early may reduce level of need over time, with rescreening to identify unresolved or new needs and to improve outcomes for PwBT. Also, these participants were recruited from an acute care setting, so the prevalence of need may be higher in subacute settings as access to supportive care services and a clinical team may be limited.

Knowing proportions likely to require support commensurate with each step can inform health service planning and optimize supportive care interventions. For example, when screening for anxiety and depression in people with cancer, 30% reported symptoms consistent with psychological disorders. The findings from implementation of a clinical pathway designed to standardize psychological care within oncology services reflected rates of psychological disorders reported in the literature (33,34). Communicating expected rates of psychological distress to staff located within services implementing this clinical pathway enabled them to plan for and prioritize triage conversations and referrals. We acknowledge that not all cancer services will have sufficient resources to address all unmet needs, and alternative models of care should be considered (13). Identifying and addressing potential barriers before implementation remains an important priority in psychoncology research and clinical practice (13,35).

There are some limitations of the current study. Despite HGG (Grades III-IV) comprising the majority of adult malignant primary brain tumors, brain cancers are heterogeneous (36). In this study, only those diagnosed with HGG were assessed. Thus, the distribution of needs for other types of brain tumor is unknown. Additionally, in this sample, the mean time since diagnosis was 1.3 months, and participants were asked to report their unmet need within the last month. Since survivorship trajectories can vary significantly among individuals with HGG, we envisage that distribution of the types of unmet need reported will vary (6,37). For example, needs relating to fatigue, fear of recurrence, and receiving timely results may change significantly during and after treatment. Furthermore, the sample was predominantly male and

English-speaking. It is conceivable they may have different unmet need compared to female patients and those from a culturally and linguistically diverse background, limiting generalizability of our findings. Importantly, 94% of our sample had a carer. For people with HGG without carers, self-reporting their unmet needs may be difficult given the impact of brain tumor on cognition; therefore, assistance from healthcare professionals is essential.

The BRAINs program leverages an existing online portal (38) to screen and address unmet need. The next step will be to implement the step allocation algorithm within the portal to automatically allocate patients to a specific step. We also need to determine the appropriate timing of the triage conversation and to match referral type and intensity according to step allocation. Additionally, work is underway to assess the suitability and psychometric properties of a screening tool for Aboriginal and Torres Strait Islander people with primary brain tumor (Supportive Care Needs Assessment Tool for Indigenous People). It will be important to establish the suitability of the step allocation algorithm for this group once the screening tool is finalized. We also aim to assess the variability of need according to patient factors (eg, Eastern Cooperative Oncology Group (ECOG) status, relationship status), which has the potential to help healthcare professionals identify those more likely to have high unmet need.

In conclusion, this study operationalized four step allocations based on the level of unmet need indicated by patients with HGG, namely, *no need*, *low need*, *moderate need*, and *high need*. The clinical implications of these findings include the potential for development of a stepped care pathway for identifying and managing unmet need in PwBT where individuals are triaged based on the magnitude of their need. Our categorization of unmet needs has the potential to facilitate timely and appropriate support for PwBT if implemented as part of a stepped care model of health delivery, particularly in busy and/or resource-constrained healthcare systems.

Data availability

The data that supported the findings of this study cannot be shared publicly for the privacy of individuals that participated in

the study but are available on reasonable request from Mona M. Faris and Georgia K.B. Halkett.

Author contributions

Mona Faris, PhD (Conceptualization; Writing—original draft), Meera R. Agar, PhD (Writing—review & editing), Mark B. Pinkham, BM, BCh (Writing—review & editing), Dianne M. Legge, MAppSc (Writing—review & editing), Kerryn E. Pike, DPsych (Writing—review & editing), Robyn Leonard, BLArch (Writing—review & editing), Brian Kelly, PhD (Writing—review & editing), Anna K. Nowak, PhD (Writing—review & editing), Tamara Ownsworth, PhD (Writing—review & editing), Eng-Siew Koh, MD (Writing—review & editing), Ursula M. Sansom-Daly, PhD (Funding acquisition; Writing—review & editing), Helen M. Haydon, PhD (Writing—review & editing), Raymond J. Chan, PhD (Funding acquisition; Writing—review & editing), Annie Miller, DipBus (Writing—original draft; Writing—review & editing), Georgia K.B. Halkett, PhD (Funding acquisition; Resources; Writing—review & editing), Rachel Campbell, PhD (Formal analysis; Writing—review & editing), Haryana M. Dhillon, PhD (Funding acquisition; Project administration; Supervision; Writing—review & editing), the BRAINS Program Group, N/A (Writing—review & editing), Joanne Shaw, PhD (Supervision; Writing—review & editing).

List of contributors

The BRAINS Program Group: Haryana Dhillon, Joanne Shaw, Meera Agar, Thea Blackler, Raymond Chan, Georgia Halkett, Helen Haydon, Dianne Legge, Robyn Leonard, Brian Kelly, Eng-Siew Koh, Anna Nowak, Tamara Ownsworth, Kerryn Pike, Nicole Rankin, Ursula Sansom-Daly, Joel Rhee, Annie Miller, Kristi Milley, Mona Faris, Rachel Campbell, Megan Jeon, Katarzyna Lion, Hannah Banks, Thomas Carlick, Jill Chen, Tiffany Fazon, Melinda Lyne, Sian Virtue-Griffiths, Kathryn Vitangcol, Jessica Buster, Emma McDougall.

Funding

This study forms part of Brain Cancer Rehabilitation, Assessment, Intervention of Survivor Needs (BRAINS), a program funded by a Medical Research Future Fund, 2019 Brain Cancer Survivorship Grant (ID: MRFBC000016). The data used in this study were collected as part of a project that was funded by the Western Australian Cancer and Palliative Care Network, Department of Health Western Australia, and a Haematology and Oncology Targeted Therapies Allied Health (HOTTAH) grant provided by the Clinical Oncology Society of Australia. G.K.B.H is supported by a Cancer Council of WA Research Fellowship. U.M. S.-D. is supported by an Early Career Fellowship from the Cancer Institute of New South Wales (ID: 2020/ECF1163). R.J.C is supported by the Australian National Health and Medical Research Council (APP 1194051).

Conflicts of interest

The authors have no conflict of interest. Associated Professor Haryana Dhillon, who holds the position of Associate Editor for *JNCI Cancer Spectrum* and a co-author on this article, was not involved in the editorial review nor the decision to publish the article.

Acknowledgments

The funder did not play a role in the design of the study; the collection, analysis, and interpretation of the data; the writing of the manuscript; or the decision to submit the manuscript for publication.

Prior presentations: Faris M, et al. Developing a stepped care model for assessing unmet needs in people diagnosed with high-grade glioma: defining criteria for stepped care intervention. [Poster Session] 14th The Cooperative Trials Group for Neuro-Oncology (COGNO) Annual Scientific Meeting, Brisbane, QLD, Australia, October 16-18, 2022.

References

1. Ilic I, Ilic M. International patterns and trends in the brain cancer incidence and mortality: an observational study based on the global burden of disease. *Heliyon*. 2023;9(7):e18222.
2. Australian Institute of Health Welfare. *Cancer in Australia 2021*. 2021. <https://www.aihw.gov.au/reports/cancer/cancer-in-australia-2021>. Accessed February 10, 2023.
3. Davis ME. Epidemiology and overview of gliomas. *Semin Oncol Nurs*. 2018;34(5):420-429.
4. Ijzerman-Korevaar M, Snijders TJ, de Graeff A, Teunissen SCCM, de Vos FYF. Prevalence of symptoms in glioma patients throughout the disease trajectory: a systematic review. *J Neurooncol*. 2018;140(3):485-496.
5. Halkett GK, Lobb EA, Rogers MM, et al. Predictors of distress and poorer quality of life in high grade glioma patients. *Patient Educ Couns*. 2015;98(4):525-532.
6. Halkett GKB, Lobb E, Spilsbury K, Dhillon H, Nowak AK. Brain cancer patients' levels of distress and supportive care needs over time. *Psychooncology*. 2022;31(12):2074-2085.
7. Lidstone V, Butters E, Seed PT, Sinnott C, Beynon T, Richards M. Symptoms and concerns amongst cancer outpatients: identifying the need for specialist palliative care. *Palliat Med*. 2003;17(7): 588-595.
8. Marotta D, Tucker Z, Hayward EN, et al. Relationship between cognitive functioning, mood, and other patient factors on quality of life in metastatic brain cancer. *Psychooncology*. 2020;29(7): 1174-1184.
9. van der Meer PB, Dirven L, Hertler C, et al. Depression and anxiety in glioma patients. *Neurooncol Pract*. 2023;10(4):335-343.
10. CanTeen Australia. *The Economic Cost of Cancer in Adolescents and Young Adults*. 2017. www.youthcancer.com.au. Accessed February 10, 2023.
11. Trad W, Koh E-S, Daher M, et al. Screening for psychological distress in adult primary brain tumor patients and caregivers: considerations for cancer care coordination. Original Research. *Front Oncol*. 2015-September-22 2015;5:203-211.
12. Harrison JD, Young JM, Price MA, Butow PN, Solomon MJ. What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer*. 2009/08/01 2009;17(8): 1117-1128.
13. Ownsworth T, Lion K, Sansom-Daly UM, et al.; BRAINS Program Investigators. Scoping the psychological support practices of Australian health professionals working with people with primary brain tumor and their families. *Psychooncology*. 2022;31(8): 1313-1321.
14. Psycholo-oncology Co-operative Research Group. *The BRAINS Program*. https://www.pocog.org.au/content.aspx?page=brains_landing. Accessed June 26, 2023.

15. Vodermaier A, Linden W, Siu C. Screening for emotional distress in cancer patients: a systematic review of assessment instruments. *J Natl Cancer Inst* 2009;101(21):1464-1488.
16. Cramer CK, McKee N, Case LD, et al. Mild cognitive impairment in long-term brain tumor survivors following brain irradiation. *J Neurooncol*.2019/01/01 2019;141(1):235-244.
17. Campbell R, Faris M, Shaw J, et al. Exploring the clinical utility of a brief screening measure of unmet supportive care needs in people with primary brain cancer. *Neurooncol Pract*. 2023;10(5):454-461.
18. Girgis A, Stojanovski E, Boyes A, King M, Lecathelinais C. The next generation of the supportive care needs survey: a brief screening tool for administration in the clinical oncology setting. *Psychooncology*. 2012;21(8):827-835.
19. Australian Government Department of Health. PHN Mental Health Flexible Funding Pool Programme Guidance: SteppedCare;2019. <https://www.coordinare.org.au/assets/PHN-Guidance-Stepped-Care.pdf>. Accessed March 2, 2023.
20. Bower P, Gilbody S. Stepped care in psychological therapies: access, effectiveness and efficiency: narrative literature review. *Br J Psychiatry*. 2005;186(1):11-17.
21. McLouth LE, Nightingale CL, Levine BJ, et al. Unmet care needs and financial hardship in patients with metastatic non-small-cell lung cancer on immunotherapy or chemoimmunotherapy in clinical practice. *J Clin Oncol Oncol Pract*. 2021;17(8):e1110-e1119.
22. Nicklin E, Velikova G, Glaser A, et al. Long-term unmet supportive care needs of teenage and young adult (TYA) childhood brain tumour survivors and their caregivers: a cross-sectional survey. *Support Care Cancer*. 2022;30(3):1981-1992.
23. Akechi T, Kubota Y, Ohtake Y, et al. Supportive care needs and psychological distress and/or quality of life in ambulatory advanced colorectal cancer patients receiving chemotherapy: a cross-sectional study. *Jpn J Clin Oncol*. 2017;52(6):650-653.
24. Hasegawa T, Goto N, Matsumoto N, et al. Prevalence of unmet needs and correlated factors in advanced-stage cancer patients receiving rehabilitation. *Support Care Cancer*.2016/11/01 2016;24(11):4761-4767.
25. Renovanz M, Hechtner M, Kohlmann K, et al. Compliance with patient-reported outcome assessment in glioma patients: predictors for drop out. *Neurooncol Pract*. 2017;5(2):129-138.
26. Boyes AW, Clinton-McHarg T, Waller AE, Steele A, D'Este CA, Sanson-Fisher RW. Prevalence and correlates of the unmet supportive care needs of individuals diagnosed with a haematological malignancy. *Acta Oncol*. 2015;54(4):507-514.
27. Honan CA, McDonald S, Tate R, et al. Outcome instruments in moderate-to-severe adult traumatic brain injury: recommendations for use in psychosocial research. *Neuropsychol Rehabil*. 2019;29(6):896-916.
28. Wearne T, Anderson V, Catroppa C, et al. Psychosocial functioning following moderate-to-severe pediatric traumatic brain injury: recommended outcome instruments for research and remediation studies. *Neuropsychol Rehabil*. 2018;30(5):973-987.
29. Goebel S, Stark A, Kaup L, Von Harscher M, Mehdorn H. Distress in patients with newly diagnosed brain tumours. *Psychooncology*. 2011;20(6):623-630.
30. Lambert SD, Harrison JD, Smith E, et al. The unmet needs of partners and caregivers of adults diagnosed with cancer: a systematic review. *BMJ Support Palliat Care*. 2012;2(3):224-230.
31. Li J, Girgis A. Supportive care needs: are patients with lung cancer a neglected population? *Psychooncology*. 2006;15(6):509-516.
32. Beesley VL, Wockner LF, O'Rourke P, et al. Risk factors for current and future unmet supportive care needs of people with pancreatic cancer: a longitudinal study. *Support Care Cancer* 2016;24(8):3589-3599.
33. Butow P, Shaw J, Shepherd HL, et al. ADAPT Program Group. Comparison of implementation strategies to influence adherence to the clinical pathway for screening, assessment and management of anxiety and depression in adult cancer patients (ADAPT CP): study protocol of a cluster randomised controlled trial. *BMC Cancer*. Nov 7 2018;18(1):1077-1089.
34. Shepherd HL, Butow P, Shaw J, et al. *How the Implementation of the ADAPT Clinical Pathway Played Out for Staff, Services and Patients*. Wiley; 2022:76-77.
35. Rankin NM, Butow PN, Hack TF, et al. An implementation science primer for psycho-oncology: translating robust evidence into practice. 2019;1(3):e14.
36. American Association of Neurological Surgeons. *Brain Tumors*. <https://www.aans.org/en/Patients/Neurosurgical-Conditions-and-Treatments/Brain-Tumors#:~:text=More%20than%20150%20different%20brain,or%20the%20brain's%20immediate%20surroundings>. Accessed July 25, 2023.
37. Langbecker D, Yates P. Primary brain tumor patients' supportive care needs and multidisciplinary rehabilitation, community and psychosocial support services: awareness, referral and utilization. *J Neurooncol*.2016;127(1):91-102.
38. Masya L, Shepherd HL, Butow PN, et al.; ADAPT Program Group. Impact of individual, organizational, and technological factors on the implementation of an online portal to support a clinical pathway addressing psycho-oncology care: mixed methods study. *JMIR Hum Factors*. 2021;8(2):e26390.