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

Authors

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

Affiliations

[1]Psycho-Oncology Cooperative Research Group, School of Psychology, Faculty of Science, The University of Sydney, Sydney, New South Wales, Australia

[2]Centre for Medical Psychology & Evidence-based Decision-making, School of Psychology, Faculty of Science, The University of Sydney, Sydney, New South Wales, Australia

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

[4]Caring Futures Institute, College of Nursing and Health Sciences, Flinders University, Adelaide, South Australia, Australia

[5]Centre for Online Health, The University of Queensland, Brisbane, Queensland, Australia

[6]Centre for Health Services Research, The University of Queensland, Brisbane, Queensland, Australia

[7]School of Clinical Medicine, UNSW Medicine and Health, University of New South Wales, Kensington, New South Wales, Australia

[8]Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital, Randwick, New South Wales, Australia

[9]Sydney Youth Cancer Service, Nelune Comprehensive Cancer Centre, Prince of Wales Hospital, Randwick, New South Wales, Australia

[10]South West Sydney Clinical School, UNSW Medicine, University of New South Wales, Liverpool, New South Wales, Australia

[11]Liverpool and Macarthur Cancer Therapy Centres, Liverpool, New South Wales, Australia

[12]Ingham Institute for Applied Medical Research, Liverpool, New South Wales, Australia

[13]School of Applied Psychology & Menzies Health Institute of Queensland, Brisbane, Queensland, Australia

[14]Medical School, University of Western Australia, Crawley, Western Australia, Australia

[15]School of Medicine and Public Health, University of Newcastle, Newcastle, New South Wales, Australia

[16]NHMRC Clinical Trials Centre, University of Sydney, Sydney, New South Wales, Australia

[17]Griffith Centre for Mental Health, Griffith University, Queensland, Australia

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

[19]Oliva Newton-John Cancer and Wellness Centre, Austin Hospital, Heidelberg, Victoria, Australia

[20]Division of Cancer Services, Princess Alexandra Hospital, Woolloongabba, Queensland, Australia

[21]School of Medicine, University of Queensland, Brisbane, Queensland, Australia

[22]IMPACCT Research Centre, Faculty of Health, University of Technology, Sydney, NSW, Australia

*Corresponding to: Dr Mona M Faris, Room 325, Brennan-MacCallum Building, University of Sydney, Sydney, NSW, 2006, Australia; Telephone: +61 2 8627 5222; Email:

mona.faris@sydney.edu.au

3

Abstract

Background

We aimed to define levels of unmet supportive care needs in people with primary brain tumour and 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-SF34 during adjuvant chemoradiation therapy. Participants were allocated to one of three categories: *no need* ('no need' for help on all items), *low need* ('low need' for help on at least one item, but no 'moderate' or 'high' need), or *moderate/high need* (at least one 'moderate' or 'high' need indicated). Clinical capacity to respond to the proportion of patients needing to be prioritised was assessed.

Results

Overall, 13% (n=5) were categorised as *no need*, 23% (n=27) *low need*, and 64% (n=74) *moderate/high need*. At least one *moderate/high need* was reported in the physical and daily living domain (42%), and 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 one item but 'high' need was not selected for any item) and *high need* (at least one 'high' need indicated). Results revealed 24% (n=28) *moderate need* and 40% (n=46) *high need.* Those categorised 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.

Keywords

Brain tumour, high-grade glioma, unmet need, screening, health service

Introduction

Brain tumours 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 tumours (~62%).[3] Brain cancer and its treatment can cause debilitating side-effects, including physical, behavioural, 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 tumour and treatments; a lack of financial assistance/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 tumour (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 most costly 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 need involves identifying patients' needs, how much help they are seeking, and appropriate support to address these needs.[12] However, in Australia, there are no standardised models or systematic approaches implemented to identify and address unmet needs in those affected by brain cancer in routine clinical care.[13]

6

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 (SCNS) tool (SCNS-SF34), called 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 which 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 need.[19] Stepped care frameworks are effective and cost-efficient models of healthcare delivery, using a hierarchy of

7

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 provider 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 operationalise levels of need (i.e., steps) to guide timely assessment

and intervention by prioritising patients.

Several approaches have been used to categorise level of unmet need using responses to

the SCNS-SF34. A binary approach, dichotomising unmet need as "no need" (i.e., not applicable

and satisfied) versus "some need" (i.e., 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 categorising

participants' unmet need 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

haematological cancer. In 72%, unmet needs were assessed >12 months since diagnosis. Based

on responses to the SCNS-SF34, respondents were categorised as having: a) *no needs* for people

reporting 'no need' for help on all items; b) *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, c)

moderate/high needs where a 'moderate' or 'high' need was indicated on at least one item.

8

Categorising level of unmet need in this way has the potential to identify and prioritise patients requiring more specific interventions, or specialised 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 tumours (e.g., 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 four tertiary hospitals across two Australian states. Eligible individuals were aged ≥18 years, 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 non-participation 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 NSW (HREC # 2008/08/092), and registered in 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 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 34-

item SCNS-SF34.[18,17] Needs were assessed across five domains: psychological; physical and

daily living; health system and information; patient care and support; and sexuality. While

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.

[Table 1 here]

The BRAINS program brings together a diverse group of experts in brain tumour

management. Members consist of researchers who work in the field of brain tumour; 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.

Operationalising step allocations

Using patient supportive care needs data assessed by the 9-items included in SCNS-ST9

from the HGG cohort study,[5,6] 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

10

group of multidisciplinary experts in the care of PwBT, similar to other studies utilising expert opinion to develop recommendations for clinical practice.[27,28] By examining the proportion of patients categorised 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 categorisation 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%), mean time from diagnosis was 1.3 months (range 0-6). Most people reported having a partner (83%), who was typically their primary carer (78%).

[Table 2 here]

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

[Table 3 here]

The distribution of responses across these categories was skewed, with approximately two thirds categorised as having *moderate/high need*. Discussion with our expert group focused on feasibility of implementing these categories within oncology services considering practical implications on workflow. It was agreed, while the aim is to assess and provide support to all people with HGG indicating some need, prioritising 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 re-classified 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.

12

Level of unmet need was relatively evenly spread across the severity range for the physical and daily living domain. Patients categorised as *high need* were more likely than those categorised as *moderate need* to report needing assistance navigating the health system and accessing health information.

[Table 4 here]

Discussion

Four step allocations were operationalised based on level of unmet need: *no need*, *low need*, *moderate need*, and *high need*. Based on a prior study categorising 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 categorised 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, while Boyes et al. focused on individuals with haematological cancer. The clinical trajectory of selected haematological cancers is commonly characterised as a chronic disease.[26] In primary brain cancer, especially HGG, disease progression is often rapid and characterised by a decline in functional, emotional, and/or

13

cognitive functioning prior to death. Distress is higher in PwBT compared to individuals with other cancer diagnoses,[29] and higher levels of distress associated with higher unmet need.[30] Additionally, most participants in Boyes et al. were >12 months post-diagnosis whilst in this sample, 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 while 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 categorised 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 organisational level toward addressing high unmet needs, particularly in clinical settings with limited healthcare resources.

Using Boyes' et al.[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 individuals with most severe needs are rapidly prioritised in health care systems with finite resources. While all patients indicating *some* level of need will receive a

14

triage conversation to review identified needs, PwBT reporting high needs are prioritised for urgent follow-up enabling support to be delivered in a timely way.

In this cohort, 40% were categorised 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 sub-acute 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 optimise 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 standardise 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 prioritise triage conversations and referrals. We acknowledge 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 prior to implementation remains an important priority in psycho-oncology research and clinical practice.[13,35]

15

There are some limitations of the current study. Despite HGG (Grades III-IV) comprising the majority of adult malignant primary brain tumours, 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 tumour 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 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 to females and those from a culturally and linguistically diverse background, limiting generalisability 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 tumour on cognition, therefore, assistance from healthcare providers 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 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 tumour (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

16

finalised. We also aim to assess variability of need according to patient factors (e.g., ECOG status, relationship status) which has the potential to help health care providers identify those more likely to have high unmet need.

In conclusion, this study operationalised 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 categorisation 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 health care 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 KB Halkett.

17

Allied Health (HOTTAH) grant provided by the Clinical Oncology Society of Australia.

Conflict of Interest: 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 the manuscript, was not involved in the editorial review or decision to publish the manuscript.

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 COGNO Annual Scientific Meeting, Brisbane, QLD, Australia, Oct 16-18, 2022.

Author contributions:

Mona M. Faris, PhD (Conceptualization; Methodology; Writing – original draft; Writing – review & editing), Haryana M. Dhillon, PhD (Funding acquisition; Project administration; Supervision; Writing – original draft; Writing – review & editing), Rachel Campbell, PhD (Formal analysis; Writing – review & editing), Georgia K.B. Halkett, PhD (Funding acquisition;

Investigation; Writing – review & editing), Raymond J. Chan, PhD (Writing – review & editing), Helen M. Haydon, PhD (Writing – review & editing), Ursula M. Sansom-Daly, PhD (Writing – review & editing), Eng-Siew Koh, MD (Writing – review & editing), Tamara Ownsworth, PhD (Writing – review & editing), Anna K. Nowak, PhD (Writing – review & editing), Brian Kelly, PhD (Writing – review & editing), Robyn Leonard, BLArch (Writing – review & editing), Kerryn E. Pike, DPsych (Writing – review & editing), Dianne M. Legge, MApSc (Writing – review & editing), Mark B Pinkham, BM BCh (Writing – review & editing), Meera R. Agar, PhD (Writing – review & editing), The BRAINS Program Group (Writing – review & editing), Joanne Shaw, PhD (Supervision; Writing – original draft; Writing – review & editing).

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.

19

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

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*. 2003/10/01 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

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. 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. Accessed 26

June, 2023. https://www.pocog.org.au/content.aspx?page=brains_landing

15.   Vodermaier A, Linden W, Siu C. Screening for emotional distress in cancer patients: a

systematic review of assessment instruments. *JNCI*. 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.   PHN Mental Health Flexible Funding Pool Programme Guidance: Stepped Care (2019).

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. *JCO 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*. 2022/03/01 2022;30(3):1981-1992.

23.   Sakamoto N, Takiguchi S, Komatsu H, 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;47(12):1157-1161.

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*. 2016/08/01 2016;24(8):3589-3599.

33.   Butow P, Shaw J, Shepherd HL, et al. 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;18:1077-1089.

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.

23

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. Accessed 25 July, 2023. https://www.aans.org/en/Patients/Neurosurgical-Conditions-and-Treatments/Brain-Tumors#:~:text=More%20than%20150%20different%20brain,or%20the%20brain's%20immedia te%20surroundings

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*. 2016/03/01 2016;127(1):91-102.

38.   Masya L, Shepherd HL, Butow PN, et al. 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.

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 tumour
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

Table 2: Patient characteristics at T1 (N = 116)

Patient Characteristics	T1
Age (years) (n= 110)	
Mean (SD)	56 (13.3)
Median (IQR)	58.5 (15)
Time since diagnosis (months) (n= 115)	
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[a]	20 (17.2)
TAFE[b] certificate/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/separated	12 (10.3)
Widowed	3 (2.6)
Missing	1 (0.9)

Country of birth, No. (%)	
Australia	67 (57.8)
Other[c]	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[d]	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[e] , 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)

Abbreviations: SD, Standard Deviation; IQR, Interquartile Range
[a] In the Australian education system, Year 12 marks the final year of formal schooling.
[b] Technical and Further Education (provider of vocational education and training)
[c] 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 of America.
[d] 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.
[e] Eastern Cooperative Oncology Group (level of physical dependency)

Table 3: Proportion of participants (N = 116) categorised as having no, low, or moderate/high

needs, overall and by SCNS-ST9 domains

	Step 1	Step 2	Step 3
	No need[a]	Low need[b]	Moderate/high need[c]
	No. (%)	No. (%)	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 one item, but did not select 'moderate' or 'high' need for any item.
[c] Selected 'moderate' or 'high' level need for help for at least one item.

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

	Step 1	Step 2	Step 3	Step 4
	No need[a]	Low need[b]	Moderate need[c]	High need[d]
	No. (%)	No. (%)	No. (%)	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 one item, but did not select 'moderate' or 'high' need for any item.

[c] Selected 'moderate' need for help for at least one item, but did not select 'high' need for any item.

[d] Selected 'high' need for at least one item.