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Exploring the clinical utility of a brief screening measure of unmet supportive care needs in people with high-grade glioma

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Abstract

Background. People living with high-grade glioma (HGG) have diverse and complex needs. Screening aims to detect patients with *some* level of unmet need requiring triaging and further assessment. However, most existing measures of unmet need are not suitable for screening in this population due to their length. We aimed to explore the clinical utility of a brief screening tool (SCNS-ST9) in people with HGG in detecting unmet needs.

Methods. Secondary analysis of data collected in a prospective cohort study of 116 people with HGG who completed the Supportive Care Needs Survey (SCNS-SF34) and a brain cancer-specific needs survey (BrTSCNS) during chemoradiation (T1) and 6 months later (T2). The SCNS-ST9 contains a subset of 9 items from the SCNS-SF34. Data analysis determined the number of individuals with unmet needs on the SCNS-SF34 and the BrTSCNS, not identified as having some level of need by the SCNS-ST9.

Results. Overall, 3 individuals (T1: 2.6% [3/116]; T2: 4.8% [3/63]) at each time point reported other unmet needs on the SCNS-SF34 that were missed by the SCNS-ST9. Domain-specific screening items missed a higher proportion of individuals (3.2%–26%), particularly in the psychological and health systems domains. Only 1 individual with brain cancer-specific needs was missed by SCNS-ST9 overall.

Conclusion. Findings demonstrate the sensitivity and clinical utility of a brief screening tool (SCNS-ST9) of unmet needs in people with HGG. Routine use of this screening tool, supported by clinical pathways, may improve access to support services, potentially reducing the burden of disease for these patients.

Keywords

brain cancer | high-grade glioma | screening | supportive care | unmet needs

High-grade gliomas (HGG; Grade III–IV Glioma) are rare cancers causing high morbidity and mortality with an overall 5-year survival rate of 22% in Australia.[1] People living with HGG can experience changes in brain structure and function due to the disease and its treatments, which cause a diverse range of symptoms, behavioral changes, and functional deficits. Brain cancer survivors commonly experience both general cancer-related symptoms including fatigue, sleep disturbance, anxiety, and depression, as well as disease-specific symptoms such as sensory-motor impairments, memory, attention and processing deficits, personality changes, and communication problems, rendering it difficult to carry out usual activities and maintain close relationships.[2–6] Previous research indicates people with HGG experience reduced quality of life, increased levels of distress, and high unmet needs at the commencement of treatment.[7] A prospective cohort study further identified support needs for: information, impacts to sense of self, physical side effects, appearance changes, financial impacts, legal assistance, and changes in cognitive ability.[8] Importantly, these support needs fluctuated over time, emphasizing the importance of longer-term follow-up.[8] Despite these complex and evolving needs, no standardized approach exists to identify and address the survivorship needs of people affected by HGG in routine clinical practice in Australia.[9]

To address this, the Brain cancer Rehabilitation, Assessment, Interventions for survivorship Needs (BRAINs) program[10] is expanding an existing electronic screening portal[11,12] to identify the unmet supportive care needs of people with primary brain tumor across the disease trajectory. Survivorship in this context refers to the period from point of diagnosis throughout the remainder of the person with brain tumor's life. This work leverages an existing program which embedded a clinical pathway for anxiety and depression into routine cancer care (ADAPT) using a stepped care model.[11,12] Within the ADAPT clinical pathway, adults with cancer are screened for psychological distress using the Distress Thermometer (DT) and directed to complete the Hospital Anxiety and Depression Scale (HADS) if they score above the cutoff (DT ≥ 4).[12] Patients are then allocated to a referral step (1–5) according to the identified severity of anxiety and depression symptoms.[12] By expanding ADAPT to facilitate routine screening for both psychological distress and unmet needs, the BRAINs program aims to ensure the support needs of those living with primary brain tumor are systematically identified and addressed through provision of evidence-based resources and supportive care interventions.

Routine screening for unmet needs, followed by further clinical assessment if detected, is an established and recommended approach in people with cancer.[13] Importantly, the purpose of screening is not to comprehensively assess unmet needs but to detect patients with *some* level of unmet need, ensuring these individuals are triaged and followed up with more comprehensive clinical assessment. Choosing patient-reported outcome measures (PROMs) for the purpose of routine screening requires a balance between adequate psychometric properties and suitable content coverage and length.[14] A previous review concluded screening measures consisting of 5–20 items have a "moderate" chance of adoption in busy clinics.[14] Although several PROMs have been developed to assess the supportive care needs of people with cancer, most include > 30 items limiting their feasibility for routine screening in clinical practice.[13] Moreover, given the cognitive changes and sensory-motor and language deficits associated with HGG and its treatments,[15–17] the brevity of screening measures is especially important in this population.

Addressing the lack of suitable screening measures for unmet need, Girgis and colleagues created a brief version of the 34-item Supportive Care Needs Survey (SCNS-SF34)[18] for use in clinical settings. The resulting measure, the SCNS-ST9, contains a subset of 9 items from the SCNS-SF34, maintains the original 5 domains, and can be used as a brief screening tool with potential for wide-scale adoption in clinical settings.[19] Although the SCNS-ST9 was psychometrically validated in a large heterogeneous sample (n = 1458) of cancer patients, only a small proportion (3%) had a brain tumor. One study examining the feasibility (i.e., participation rates, data completeness and completion errors) of using the SCNS-ST9 in clinical practice with glioma patients indicated the SCNS-ST9 was easier to implement compared to other PROMs due to its brevity, however, patients were more prone to completion errors if assistance was not provided.[20] Given the unique and complex challenges faced by brain cancer survivors, the objective of this analysis was to extend these findings by further exploring the clinical utility of the SCNS-ST9 for routine screening of unmet needs in people with HGG to determine its appropriateness for use as a screening tool in clinical practice. Specifically, the purpose was to determine whether the 9 items included in the SCNS-ST9 screening tool detect the majority of people with HGG with other unmet needs not assessed by the screening tool. A secondary objective was to explore whether the SCNS-ST9 domain-specific screening items detected the majority of individuals with other unmet needs within each domain.

Methods

Study Design

This paper reports secondary post hoc analysis of data collected in a prospective cohort study of people with HGG. The primary objective of the cohort study was to describe variation in patient self-reported distress and how this was associated with well-being and unmet supportive care needs over a 6-month period from start of combined chemoradiation therapy.[8] The study procedures have been comprehensively reported elsewhere.[7,8] In brief, participants were recruited from neurosurgical, radiation, or medical oncology outpatient departments at four tertiary neuro-oncology sites in 2 Australian states by their treating clinician or cancer care coordinator. Participants were enrolled in the study from July 2008 to December 2012. Eligible participants were people diagnosed with Grade III–IV HGG,[1] aged 18 years or older, due to start postoperative combined chemoradiation therapy. Participants were excluded if they were unable to complete questionnaires due to language, literacy, or functional (e.g., aphasia or poor performance status) reasons. Ethical approval was granted by Human Research Ethics Committees (HREC) at all participating sites [Sir Charles Gairdner Hospital (HREC # 2006-146), Curtin University (HREC # 03/2007), and Cancer Institute NSW (HREC # 2008/08/092)] and all participants provided informed consent.

Participants completed questionnaires during postoperative chemoradiation therapy (T1) and 6 months (T2) later. Questionnaires were self-completed by patients via paper and pen independently or with assistance from their carer, either in the clinic or at home, and returned via mail. Data were stored and managed according to the Australian Government National Health and Medical Research Council (NHMRC) guidelines to ensure protection of participants' privacy and anonymity.[21] The first section of the questionnaire collected self-reported sociodemographic information including age, gender, relationship status, education level, country of birth, language spoken at home, parental status, time since diagnosis, employment status, and level of self-reported physical functioning based on the Eastern Co-operative Oncology Group (ECOG) performance status ranging from 0 (fully independent) to 4 (completely disabled). Although several PROMs were administered in the broader cohort study (see[7,8] for detail), here we note only those used in this analysis:

Supportive Care Needs Survey (SCNS-SF34)—[18] consists of 34 items assessing adult cancer patients' level of need across five domains: psychological, health system and

information, physical and daily living, patient care and support, and sexuality. The subset of 9 screening items that form the SCNS-ST9,[19] assess unmet needs across these same 5 domains using 1 or 2 items. For each item, respondents are asked to indicate their level of need for help over the last month as a result of having cancer, using the following response options: "no need – not applicable," "no need – satisfied," "low need," "moderate need," and "high need." The SNCS-SF34 has demonstrated reliability and validity in cancer populations.[18] Responses were scored dichotomously into no need versus "some level of need" (i.e., low, moderate, or high need).

Brain Tumor Specific Supportive Care Needs Scale (BrTSCNS)—[22] is a validated 16-item tool developed to assess additional unmet needs specific to brain cancer patients such as changes in cognitive capacity, appearance, and feeling like a different person. The BrTSCNS has identical response options to the SCNS-SF34 and is designed to be administered together with this scale. Items were scored identically to the SCNS-SF34 items, as described above.

Distress Thermometer (DT)—[23] is a validated self-report visual analogue scale with an 11-point rating scale ranging from 0 (no distress) to 10 (extreme distress). DT scores > 4 indicate moderate to high distress.[23]

Data Analysis

Data analysis focused on patient data collected at 2 time points: during chemoradiation (T1) and 6 months (T2) later. These time points enabled exploration of patient needs at two distinct time points: during and after first-line treatment. First, to determine whether the SCNS-ST9 would capture the majority of brain cancer survivors with other unmet needs not assessed by the screening tool, patient responses at T1 and T2 were analyzed descriptively to determine the proportion (%) of individuals with other unmet needs of any level (i.e., low, moderate, or high) on the broader SCNS-SF34 unmet needs measure not identified as "having some level of need" by the SCNS-ST9. Specifically, we examined what proportion (%) of individuals with other unmet needs of any level (i.e., low, moderate, or high) on the SCNS-SF34, were missed by the 9 screening items. Second, we conducted an analysis at the domain level to explore whether the domain-specific screening items captured the majority of individuals with other unmet needs within each domain. Specifically, we examined the proportion (%) of individuals with other unmet needs on each SCNS-SF34 domain that were missed by the SCNS-ST9 screening items for that domain. Additionally, we explored what proportion (%) of individuals with brain-cancer specific needs (of any level), as assessed by the BrTSCNS, were missed by the nine SCNS-ST9 screening items.

Finally, as the ADAPT clinical pathway already includes screening for psychological distress using the DT, we also a performed supplementary analysis on T1 data to explore how many individuals with unmet needs on the SCNS-SF34 psychological domain were missed by both the DT and the two SCNS-ST9 psychological screening items (ie, "Fears about cancer spreading" and "Uncertainty about future"), and whether these individuals were captured by the seven other SCNS-ST9 screening items. The rationale for this analysis was to explore the added value of administering the two SCNS-ST9 psychological screening items, in addition to the DT, for identifying individuals with unmet need who should be triaged for further assessment and support.

All descriptive statistics were performed using IBM SPSS (Version 28).

Results

Baseline questionnaires were completed by 116 participants. All participants were diagnosed with WHO Grade III–Grade IV HGG (glioblastoma, gliosarcoma, anaplastic astrocytoma, anaplastic oligodendroglioma, or anaplastic oligoastrocytoma). As post-operative chemoradiation therapy is standard care for glioblastoma this comprised the majority of diagnoses (94%). The median age was 59 years (Mean age = 56; SD = 13.3, range = 18–86), the majority were male (71%), had a partner (82%), were born in Australia (58%), and had children (90%). Median time since diagnosis was 1 month (Mean = 1.0; SD = 1.1, range 0–6). Of the 116 baseline respondents, 37 (32%) withdrew due to progressive disease and 15 (13%) died before the 6-month survey, one (1%) did not fill in the unmet need items, resulting in 63 (54%) complete responses at T2 (6 months later). A flow diagram of study participation, questionnaire response rates, and an analysis of participant drop-out is reported elsewhere.[8] Participants lost to follow-up only differed in that they were significantly closer to time of death and reported slightly higher emotional well-being at baseline.[8] Table 1 provides participants' detailed characteristics at baseline (T1: during chemoradiation) and T2 (6 months later).

Proportion (%) of Individuals Missed by the SCNS-ST9 Screening Items

Overall, at T1 (during chemoradiation) and T2 (6 months later) only three individuals at each time point with other unmet needs were missed by the 9 SCNS-ST9 screening items (2.6% and 4.8% of the total sample, respectively; Table 2); the 3 individuals missed were not the same people at each time point. Of those missed at T1, one (0.9%) had 1 need ("*Concerns and worries about those close to you*") and 2 (1.7%) had two needs (both: "*Concerns and worries about those close to you*" and "*More choice about which cancer specialists you see*" or "*Feelings about death or dying*"). Of the individuals missed at T2, two (3%) had one need ("*Feelings about death or dying*" or "*More choice about which cancer specialists you see*") and one (1.6%) had three needs ("*Concerns and worries about those close to you*," "*Being given written information about the important aspects of your care*" and "*Being informed about cancer which is under control or diminishing [that is remission]*").

At the domain level (Table 2), the two *psychological* domain screening items missed 30 (26%) individuals at T1 and 9 (14.3%) individuals at T2 with other unmet needs in that domain; the 2 *health system and information* domain screening items missed 13 (11.2%) and 16 (25.4%) individuals at T1 and T2; the 2 *physical and daily living* domain

Table 1. Participant characteristics

	T1– during chemoradiation Number (%) N = 116	T2 – 6 mo later Number (%) N = 63
Age (years)		
Mean (SD)	55.7 (13.3)	54.0 (12.9)
Median	58.5	57.0
Range	18–86	18–79
Gender		
Male	82 (71%)	48 (76.2%)
Female	34 (29%)	15 (23.8%)
Partnered		
Yes	95 (81.9%)	53 (84.1%)
No	20 (17.2%)	10 (15.9%)
Missing	1 (0.9%)	–
Education		
Year 10 or below	34 (29.3%)	16 (25.4%)
Year 12	20 (17.2%)	12 (19%)
TAFE certificate/diploma, business college	31 (26.7%)	16 (25.4%)
University or postgraduate	29 (25%)	19 (30.1%)
Missing	2 (1.8%)	–
Country of birth		
Australia	67 (57.7%)	38 (60.3%)
Other	48 (41.4%)	25 (39.7%)
Missing	1 (0.9%)	–
Language other than English spoken at home		
Yes	11 (9.5%)	4 (6.3%)
No	103 (88.7%)	59 (93.7%)
Missing	2 (1.8%)	–
Parental status		
Yes	104 (89.7%)	56 (88.9%)
No	12 (10.3%)	7 (11.1%)
Time since diagnosis (months)		
Mean (SD)	1.3 (1.1)	0.9 (0.8)
Median	1.0	1.0
Range	0–6	0–3
Employment status before diagnosis		
Employed	73 (62.9%)	43 (68.3%)
Not employed	43 (37.1%)	20 (31.7%)
Current employment status		
Employed	36 (31.0%)	15 (23.8%)
Not employed	61 (52.6%)	34 (53.9%)
Sick leave/workers compensation	19 (16.4%)	12 (19.0%)
Missing	–	2 (3.3%)
ECOG performance status		
0	37 (31.9%)	23 (36.5%)
1	41 (35.3%)	23 (36.5%)
2	27 (23.3%)	14 (22.2%)
3	8 (6.8%)	3 (4.8%)
4	1 (0.9%)	0
Missing	2 (1.8%)	–

Table 2. Proportion of individuals with unmet needs (low, moderate, or severe) on supportive care needs survey (SCNS-SF34) missed if no need indicated on SCNS-ST9 screening items

If no need indicated on SCNS-ST9 Screening items:	***N*** (%) of individuals with other unmet needs missed	
	T1: during chemoradiation (total ***n*** = 116)	T2: 6 mo later (total ***n*** = 63)
Overall on SCNS-ST9 items	3 (2.6%[a])	3 (4.8%)
Domain: psychological	30 (26%[b])	9 (14.3%)
Fears about cancer spreading		
Uncertainty about future		
Domain: health system and information	13 (11.2%)	16 (25.4%)
Being informed about your test results as soon as feasible		
Being informed about things you can do to help yourself to get well		
Domain: physical and daily living	6 (5.2%)	2 (3.2%)
Lack of energy/tiredness		
Not being able to do the things you used to do		
Domain: patient care and support	19 (16.4%)	7 (11.1%)
Reassurance by medical staff that the way you feel is normal		
Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs		
Domain: sexuality	10 (8.6%)	2 (3.2%)
Changes in sexual relationships		

aPercentage of individuals with other unmet needs on the SCNS-SF34, not identified by the nine SCNS-ST9 screening items. Overall percentage at T2 displays corresponding percentage at T2.
bPercentage of individuals with other unmet needs within the SCNS-SF34 psychological domain, not identified by the two SCNS-ST9 psychological screening items. Percentages for other domains are corresponding percentages for other SCNS-ST9 domain-specific screening items at both time points.

screening items missed six (5.2%) and 2 (3.2%) individuals at T1 and T2; the 2 *patient care and support* screening items missed 19 (16.4%) and 2 (11.1%) individuals at T1 and T2; and the 1 *sexuality* screening item missed 10 (8.6%) and 2 (3.2%) individuals at T1 and T2.

With regard to the 16 brain cancer specific items, at T1 only 1 (0.9%) individual with a need for "*special testing and advice about mental and thinking abilities*" was missed by the nine SCNS-ST9 screening items. At T2, no individuals with brain cancer specific needs were missed by the SCNS-ST9 screening items.

Supplementary Analysis

Next, we performed supplementary analysis on T1 data to explore how many individuals with other unmet needs on the SCNS-SF34 psychological domain were missed by both the DT and the two SCNS-ST9 psychological screening items. Of those who scored below the cutoff on the DT (i.e., <4) and indicated no need on the two psychological screening items, 17 (14%) had other unmet psychological needs. The majority of these (n = 10; 59%) had one unmet psychological need. Further analysis indicated 15 (88%) of these 17 individuals were identified as having "some level of need" on the other 7 SCNS-ST9 screening items. Of the two individuals who were missed completely, 1 had 2 high level psychological needs ("*Feelings about death and dying*" and "*Concerns about the worries of those close to you*" and 1 had 1 low level psychological need ("*Concerns about the worries of those close to you*").

Discussion

This analysis indicated the SCNS-ST9 screening tool can detect the majority of people with HGG with some level of unmet need, with only three individuals (T1: *n* = 3/116, 2.6%; T2: *n* = 3/63, 4.8%) "missed" at each time point. These results support the utility of implementing this screening tool in clinical practice to assess supportive care needs and extend previous findings demonstrating preliminary feasibility of using the SCNS-ST9 in clinical practice.[20] With repeated screening and follow-up, the small proportion of individuals not detected by the SCNS-ST9 may possibly be captured subsequently particularly if their level of unmet need increased over time. However, at the domain level the proportion of individuals with unmet needs who were missed with the SCNS-ST9 was substantially higher

(3.2%–26%) and varied across domains and time points. This finding suggests the domain screening items should *not* be used separately to screen for supportive care needs within individual domains. Rather, the SCNS-ST9 screening tool should be administered in its entirety to minimize the risk of failing to detect individuals with *some* level of unmet need in any domain.

Given the findings of this analysis, the next step in our research is to implement the SCNS-ST9 screening tool into an automated electronic system to conduct pilot work to explore the acceptability of these screening items in people with primary brain tumor more broadly. This may lead to modifications to the wording of the screening items prior to implementation in clinical practice. For example, we acknowledge the wording of some items (e.g., "fears about cancer spreading") is likely inappropriate for people with HGG. The pilot testing will identify these issues and inform tailoring of item wording specific to this patient group for subsequent validation. Furthermore, the supplementary analysis conducted suggested the 2 psychological screening items could potentially be dropped from the screening tool, given the DT and 7 other screening items detected the majority of individuals missed by these items. Doing so would further reduce the length of the screening tool and possibly enhance its feasibility for routine use in clinical practice, however, only if the DT is implemented together with the SCNS-ST9. This should be explored during pilot testing with patients prior to implementation in clinical practice. Future research should also continue to explore ways to further improve the brevity of unmet need measures to enhance feasibility for use in clinical practice, including the use of computer adaptive testing (CAT) to minimize respondent burden.[24]

Incorporating the SCNS-ST9 into an automated electronic system has the potential benefit of delivering a structured approach to screening patients for psychological distress and supportive care needs; facilitating triaging to appropriate evidence-based supportive care interventions to address the identified needs; and, assisting healthcare professionals to better identify and respond to the needs of people with primary brain tumor. Screening for any level of unmet need using an automated electronic system, rather than comprehensively assessing the full range of patient needs, should minimize the impact on human resources to deliver the screening. However, the success of this electronic system will depend on widespread, equitable patient access to screening and its integration across services (tertiary, palliative, community/primary care) to ensure seamless communication and service delivery. Beyond the Australian context, this approach may lay the foundation for international change in primary brain tumor care and provide proof of concept for the implementation of similar initiatives to identify and address distress and supportive care needs in this clinical population globally.

Importantly, previous research indicates carers of people with HGG report higher distress than patients during chemoradiation,[7,25] with up to 62% of carers reporting moderate or high distress which remains consistent over time.[26] Compared to carers of people with other cancer types, those caring for people with HGG report higher levels of caregiver strain, lower levels of mental well-being and higher activities of daily living workload.[27] Carers of people with HGG also report elevated support needs, however their specific needs evolve and change over time.[28,29] The most common needs reported include impacts on their own working life or usual activities, making life decisions in the context of uncertainty, reducing stress for the patient, and understanding the patient's experience.[28] The most commonly reported need unique to caring for a person with brain tumor was for information on adjusting to cognitive changes in the patient.[28] This highlights the importance of developing screening pathways to assess the unmet needs of carers of people with HGG, in addition to patients, linked to appropriate evidence-based support (e.g.[30]). To this end, we are currently developing a brief screening version of the Supportive Care Needs Survey-Partners and Caregivers (SCNS-P&C)[31] feasible for routine screening of caregivers' unmet needs for implementation in clinical practice.[32]

While this analysis provides important insights into the suitability of the SCNS-ST9 measure for screening the unmet needs of people with HGG, the results are limited to the Australian English-speaking population. There is a need to explore the suitability of these screening items for other culturally and linguistically diverse (CALD) groups. The BRAINs research team are currently working with others to perform psychometric and content analysis of the Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP)[33] to develop a brief version of this measure suitable for use as a screening tool in clinical practice. This will inform the best approach to screening for supportive care needs specific to Aboriginal and Torres Strait Islander people with primary brain tumor. However, there is also a need to investigate the relevance of the SCNS-ST9 in other CALD groups. While some of this work can be conducted in Australia, international initiatives and collaboration may be more efficient to explore the need for diverse cultural and language adaptations.

Other limitations to this study include the analysis being limited to two time points. Future research is needed to explore the clinical utility of unmet need screening measures at different phases in the disease trajectory, including among those in longer-term survivorship. In addition, participants were excluded if they were unable to complete questionnaires due to language, literacy or functional (eg, aphasia or poor performance status) reasons. Due to this selection bias, the present findings are unlikely to generalize to these individuals and further efforts are required to determine how best to screen for the supportive care needs of those with language (eg, aphasia) and physical impairments. Finally, although participants were able to receive assistance from their carer to complete measures, the number of participants who received assistance while completing the SCNS measures was not recorded in the original cohort study. Given a previous study examining the feasibility of using the SCNS-ST9 with glioma patients found that assisted completion helped to minimize completion errors,[20] future research examining screening tools for unmet needs in this population should systematically collect whether measures were completed independently or with assistance, and what type of assistance was required.

In conclusion, this study demonstrated the sensitivity and clinical utility of using a brief tool (SCNS-ST9) to screen

for the unmet needs of people with HGG. Implementation of this screening tool in clinical practice may help facilitate identification of patients with some level of unmet need, ensuring they are triaged for more comprehensive clinical assessment and enabling timely referral for support. Use of this screening tool, supported by clinical pathways, has the potential to improve equitable access to support services for people living with HGG and those with primary brain tumor more broadly, including those living in rural and remote regions and from CALD backgrounds, potentially contributing to reduced disease burden and better quality of life for these patients.

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[1]The time of data collection (July 2008–December 2012) was prior to the adoption of WHO 2021 classification for CNS tumors. At the time of data collection, patients diagnosed with high grade glioma (Grade III–IV) were included.

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