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Holistic Needs Assessment in Brain Cancer Patients: A Systematic Review of Available Tools

Introduction

A diagnosis of brain cancer affects nearly 10 000 adults per year in the United Kingdom and has a devastating impact on individuals and their significant others (Cancer Research UK, 2015b). Gliomas are the most common type of primary intra-cerebral cancer and constitute approximately 75% of cases (Taphoorn et al., 2010). Of these > 60% are high grade Glioblastoma Multiforme (GBM) that has a median survival of 12 months (Hayat, 2011). Although 40-50% of brain cancers occur in the > 60 year age range, compared to most other cancers, the incidence is more widely distributed across all ages groups. There is a significant impact on younger adults due to poor survival rate and the age at which brain cancer occurs (Cancer Research UK, 2015a). Therefore, brain cancer is the most common cause of death from solid cancers in the 16-24 year old age range and the second most common cancer death in adults in the 25-49 years old age range in the UK (Cancer Research UK, 2015c).

Brain cancer differs significantly from other cancers due to the unique neurocognitive symptoms and higher symptom burden (Ford, Catt, Chalmers, & Fallowfield, 2012). Upon diagnosis, patients must deal with the implications of a life limiting illness whilst coping with the symptoms, which can be severe and progressive (Cavers et al., 2012). Approximately 50% of patients present with headaches, and other common symptoms include confusion, hemiparesis, gait imbalance, language difficulties personality changes, mood disturbance (e.g. anxiety, fatigue, depression), decreases in mental capacity, and problems with concentration (Butowski & Chang, 2007; Catt, Chalmers, & Fallowfield, 2008; Janda et al., 2008; Omuro & DeAngelis, 2013). Seizures are common with rates of up to 60–75% for individuals diagnosed with low-grade gliomas and 25–60% with high-grade gliomas. This may impact employment, social interactions and independence (Englot, Chang, & Vecht, 2016). Patients have self-reported behavioural changes such as disinhibition

(19%), anger (27%), inappropriate behaviour (27%) or apathy (41%) (Simpson et al., 2015). This presents significant challenges for the patients and their carers.

Treatment options in brain cancer can cause multiple local and general side effects. Patients undergoing brain radiotherapy will typically have a number of side effects including hair loss, nausea and fatigue. They also frequently suffer cognitive symptoms related to the area of the brain being treated due to injury and swelling (Grant, 2004). Similarly, the common side effects of chemotherapy include haematological toxicity, fatigue, nausea and vomiting, rash and impaired liver function (Omuro & DeAngelis, 2013). Other treatments such as steroids, used to reduce brain swelling, can result in myopathy, hyperglycaemia, personality change, weight gain and insomnia (Dietrich, Rao, Pastorino, & Kesari, 2011). There are also numerous common side effects from antiepileptic drugs such as fatigue, nausea, dizziness or visual disturbances and these may be more pronounced and common in patients with brain tumours (Perucca, 2013). Identifying the problems that impact patients and their families is an important first step in providing supportive care.

Numerous studies and reviews have demonstrated high levels of unmet needs in cancer patients. These include lack of support in managing anxiety, depression and fatigue or lack of information (Barg et al., 2007; Harrison, Young, Price, Butow, & Solomon, 2009; Hwang et al., 2004; Janda et al., 2008; McDowell, Occhipinti, Ferguson, Dunn, & Chambers, 2010; Pigott, Pollard, Thomson, & Aranda, 2009; Puts, Papoutsis, Springall, & Tourangeau, 2012; Sanders, Bantum, Owen, Thornton, & Stanton, 2010). However patients often do not communicate psychological concerns to their clinicians (Wen & Gustafson, 2004) and there is evidence that health care professionals may not detect emotional distress (Mitchell, Hussain, Grainger, & Symonds, 2011). The lack of detection of needs for all cancers is problematic, but possibly more significant in patients with brain cancers, as they have one of the highest rates of depression (Hartung et al., 2017) and this in combination with their significant and unique needs, necessitate targeted mechanisms to deliver appropriate supportive care.

Holistic needs assessment (HNA) has been widely used to identify concerns and unmet needs in many cancers (National Cancer Action Team, 2012). HNA typically

includes a review of physical, psychological or emotional, spiritual, social, practical and other domains of needs to provide a systemic assessment which can aid in planning appropriate supportive care or referrals (Richardson, Medina, Brown, & Sitzia, 2007). There are numerous tools that are commonly used for HNA across all cancer types such as, the Sheffield Profile for Assessment and Referral to Care (SPARC) (Ahmed, Ahmedzai, Collins, & Noble, 2014), National Comprehensive Cancer Network (NCCN) Distress thermometer and concerns checklist (National Comprehensive Cancer Network, 2013) or the Macmillan electronic HNA (Ipsos Mori, 2013). However, it has been suggested these are not suitable for brain cancers due to the unique needs of these patients, as they lack specificity and sensitivity in assessing needs such as neurocognitive symptoms, which are often most significant problems (Armstrong, Cohen, Eriksen, & Cleeland, 2005; Dirven et al., 2018; Janda, Eakin, Bailey, Walker, & Troy, 2006; Rooney et al., 2014). Cognitive impairments may present additional challenges for this population to complete patient reported outcome measures (PROMs). Therefore, it is important that the development of tools includes individuals with brain cancers to assess user comprehension and acceptability (e.g. length and format).

The aim of the review is to systematically identify and evaluate the psychometric properties and clinical utility of tools that assess needs, problems or concerns in brain cancer patients. We sought to identify tools that were developed and tested specifically on a brain cancer population which could be used to support HNA. We defined HNA tools as those that identified an unmet need that prevented optimal wellbeing. The tools needed to look at a minimum of two of the domains of need in the categories of physical, psychological or emotional, spiritual, practical or social needs. The search was focused on tools designed to assess need in clinical care as opposed to outcome measurements purely for clinical research. This did include those classified as 'symptom' assessment measures as these have been suggested and used as a strategy to support problem identification (Canadian Partnership Against Cancer, 2012; Watanabe, Nekolaichuk, & Beaumont, 2012).

Methods

A systematic literature search was undertaken in February 2018. The following electronic databases were searched: MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and PsycINFO. This was to identify the literature which reported the development, psychometric testing or clinical utility testing of tools that were developed as a PROM and undertake need or symptom assessments in brain cancer. The search strategy aimed at including all relevant literature; but was limited to the most common databases, studies on humans and studies on adults.

The following search terms were included:

(Needs Assessment) OR (Symptom Assessment) OR (Self-Assessment) OR (Patient Outcome Assessment) OR (inventory or tool* or measure* or instrument*) AND (Brain Neoplasms). Dependant on the database, Subject Headings which encompassed relevant concepts were used or some terms were limited to abstract and title to improve the sensitivity and specificity. The search strategy was devised by a healthcare librarian and one of the authors (JA). The search strategy for MEDLINE is presented in the online supporting information (Appendix S1). Citations from relevant research articles or systematic reviews of cancer HNA tools were reviewed for potential relevant research studies. The corresponding authors of the relevant tools were contacted to request additional information.

Study Selection

Each paper was assessed for relevance by JA using the following inclusion and exclusion criteria. Inclusion criteria included primary research published in English which reported the development, psychometric testing or clinical utility testing of PROMs for the assessment of adult (age ≥ 18) brain cancer patients' needs or generic cancer needs assessment tools developed specifically on a brain cancer or brain tumour population. Studies that included benign brain tumours as well as brain cancers were included due to the similar symptom profile. Articles needed to be published as full text article as recommended by the COSMIN protocol for systematic reviews of measurement properties (Terwee, de Vet, Prinsen, & Mokkink, 2011). However, we excluded studies which only included patients who have brain metastasis due to the differing symptom profile which would be present due to their underlying primary cancer diagnosis. Tools were selected that identified unmet

needs, concerns or problems. All literature that contributed to the development of 'brain specific' content of a needs assessment tool, was included in the review. The tools had to have been developed for completion by patients. There were no date limits to ensure all development studies were included. Exclusion criteria were any other PROMs which do not measure needs (for example health related quality of life (QOL) or satisfaction) or those that only looked at only one aspect of need (for example information needs).

Data extraction and quality appraisal strategy

Data from the selected studies was extracted using standardised forms. The tool characteristics are presented in Table 1 and the data which represented the psychometric properties of the tools is summarised in Table 2. This information was then used to support the evaluation of each of the tools psychometric properties and use as an HNA tool.

To evaluate the psychometric properties of each identified tool, the 'Consensus-based Standards for the selection of health Measurement INstruments' or COSMIN checklist was used (Mokkink et al., 2006; Mokkink et al., 2010). This checklist was developed through a Delphi study of 57 international experts to help select an instrument for use, to review studies, to design or report the measurement properties of a new tool (Mokkink et al., 2010). This checklist provides evaluation criteria for psychometric properties (Mokkink et al., 2010) which are then given a rating of excellent, good, fair, poor or not assessed by taking the lowest rating of any of the items that make up each attribute (Terwee et al., 2012). Interpretability and generalizability are not rated but a list of considerations is provided as no scoring criteria was developed for these properties (Terwee et al., 2012). A description of the psychometric properties is provided (Box 1).

Three studies have proposed evaluation criteria for HNA tools, which were used in systematic reviews and research (Bonevski et al., 2000; Richardson et al., 2007; Wen & Gustafson, 2004). To undertake the appraisal of the tools for use as a HNA, these were used to formulate the criteria used in this review. These publications all included the need for good psychometric properties focused on validity and

reliability, a consideration of user acceptability for patients and those administering and interpreting the results. All authors in their proposed criteria mentioned tools should capture the holistic dimensions of need - although the exact criteria varied. Ratings based on these criteria were determined as detailed in Box 2.

Results

The search was undertaken from 01 February 2018 to 27 February 2018 and this process is illustrated in Figure 1. The total number of articles identified using the search criteria was 5901 and 526 duplicates were removed leaving 5375 articles to screen. After reviewing titles and abstracts there were 142 remaining articles screened by full text and 8 were included in the review. Reference lists were reviewed to search for any additional relevant citations and none were found. Corresponding authors of tools were contacted and this process provided one other relevant paper.

In total, nine articles were identified describing four tools, which have the potential to assess needs, problems or concerns in brain cancer patients and a summary of their characteristics is presented in Table 1. These were the Supportive Care Needs Survey 34 plus brain subscale (SCNS34-BS); MD Anderson Symptom Inventory – Brain Tumor Module (MDASI-BT); Brain Patient Concern Inventory (PCI); and the National Comprehensive Cancer Network/Functional Assessment of Cancer Therapy-Brain Symptom Index (NFbrSI-24) and the studies which developed these tools are detailed in the following section.

Summary of tools and the developmental studies

Brain Patient Concern Inventory

There was only one study which reported the development of the Brain PCI (Rooney et al., 2014). This study described the process for questionnaire design, however, the number of healthcare professionals or geographical location was not specified for those involved in developing content. In the assessment of user acceptability, 45 patients were recruited from a cancer centre in Scotland. In addition, 21 feedback forms were obtained from healthcare professionals in this centre but it was unclear how many participants were involved (Rooney et al., 2014).

MD Anderson Symptom Inventory – Brain Tumor Module

There were four studies that reported the development of the MDASI-BT for clinical and research purposes. The first study undertook item generation and content validity (Armstrong et al., 2005), the second focused on reliability and validity testing (Armstrong et al., 2006), and two studies looked at the test-retest reliability (Armstrong, Vera-Bolanos, Acquaye, Gilbert, & Mendoza, 2014; Armstrong et al., 2012). All participants for all studies were recruited from a large cancer centre in Texas, with the exception of the inclusion of experts recruited to develop content validity with 50% recruited out with the institution (Armstrong et al., 2005).

National Comprehensive Cancer Network/Functional Assessment of Cancer Therapy-Brain Symptom Index

There was one study that reported the development of the NFbrSI-24 (Lai et al., 2014). However they utilised survey results from a previous study of 69 healthcare professionals from throughout the United States (Cella et al., 2003) in the development of content validity. The main developmental study recruited 50 patients with advanced primary brain tumours from six National Comprehensive Cancer Network institutions along with ten physician experts (Lai et al., 2014).

Supportive Care Needs Survey – 34 plus brain subscale

There were two studies that reported the development of the SCNS34-BS (Janda et al., 2008, 2006) designed to look at supportive care needs. The first study focused on content validity and involved 18 patients and carers in item generation (Janda et al., 2006). The second study's main aim was to look at supportive care needs, however the relationship with anxiety and depression was examined and this aspect provides an assessment of construct validity (Janda et al., 2008). The studies were completed with a supportive care service in a region of Australia. In the following section, relevant psychometric properties of these four tools will be evaluated.

Evaluation of Psychometric properties

The developmental studies and their psychometric properties are outlined in Table 2 and the quality scoring based on COSMIN criteria (Terwee et al., 2012) is detailed in Table 3.

Validity

Content validity was developed in all tools with some advised approaches such as the use of literature, reference to other tools and the input of experts as well as end users (de Vet, Terwee, Mokkink, & Knol, 2011; Reeve et al., 2013; Scholtes, Terwee, & Poolman, 2011). Item generation was completed with the end users for the SCNS34-BS (Janda et al., 2006), MDASI – BT (Armstrong et al., 2005) and the NFbrSI-24 (Lai et al., 2014) however, this important aspect was missing from the Brain PCI (Rooney et al., 2014). The next step of content validity should undertake a more extensive evaluation to assess comprehensiveness and comprehensibility. This was evident in the MDASI – BT (Armstrong et al., 2006) and the NFbrSI-24 (Lai et al., 2014) with both tools utilising qualitative and quantitative methods. The MDASI – BT which has met the criteria for a ‘good’ rating rather than ‘excellent’, as there were less than 10 participants from the end users (patients) and the NFbrSI-24 was rated as ‘excellent’.

Another aspect of validity is construct validity, or hypothesis testing, which is frequently undertaken with QOL, performance status, anxiety and depression, or distress (Richardson et al., 2007). The three studies that analysed this aspect were rated from ‘poor’ to ‘good’. The SCNS34-BS examined the relationship between supportive care needs and distress utilizing the Hospital Depression and Anxiety Scale (HADS) (Zigmond & Snaith, 1983). Multivariate logistic regression analysis was performed rather than recommended test of a correlation co-efficient resulting in the ‘poor’ rating. However, it should be acknowledged this was not the stated purpose of the study and this did demonstrate a relationship between these constructs. The NFbrSI-24 (Lai et al., 2014) was rated ‘good’ rather than ‘excellent’ as the sample size was < 100 and the MDASI-BT was rated ‘good’ rather than ‘excellent’ due to only recruiting from one centre (Armstrong et al., 2006).

No studies undertook measures of structural validity, however as HNA is a likely to be a formative model, as need is comprised of many unrelated factors, this property is not relevant (Terwee et al., 2012). There were no studies examining cross-cultural validity.

Reliability

The SCNS34-BS (Janda et al., 2008, 2006) and the Brain PCI (Rooney et al., 2014), did not undertake any testing of reliability in the reviewed studies. The MDASI-BT looked at internal consistency for each sub-scale (Armstrong et al., 2006) and demonstrated 'excellent' internal consistency within the recommended range (Mokkink et al., 2012). The NFBrSI-24 demonstrated acceptable internal consistency for the full symptom index however the treatment side effect subscale fell slightly below recommended limits ($\alpha = 0.65$), which corresponds to a 'fair' rating for this property (Mokkink et al., 2012).

The inter-rater reliability and test-retest reliability for the MDASI-BT was first reported in Armstrong et al., (2012). As this review is focused on the use of tools as a PROM the inter-rater reliability is not relevant. The test-retest variable was measured on a subgroup of 21 patients using Spearman correlations between the two time points and the analyses supported test-retest reliability but it was an inadequate sample size for this psychometric property (Mokkink et al., 2012). However, a subsequent study of 92 individuals undertook test-retest measurements at 24 hours and 7 days (Armstrong et al., 2014). This demonstrated good congruence between both time intervals and based on the 7-day recall and a sample size of 92, a rating of 'good' was made for this criteria. Although there is not a specific time interval advised in the COSMIN rating scale some authors advocate an interval of about two weeks (de Vet et al., 2011). The time interval must be balanced between ensuring respondents do not remember their answers and the stability of the patient's condition. Measurement error was not specified for any tool.

Interpretability

The COSMIN criterion does not provide ratings for this property, however, the MDASI-BT demonstrated a significant correlation with inpatient and outpatient status and both the MDASI-BT and NFBrSI-24 demonstrated a significant correlation between symptoms and performance status. This provides the ability to assign meaning to the changes through commonly understood clinical connotations. Responsiveness was not reported in any of the reviewed studies.

Generalizability

A further limitation of each of the tools assessed is that they have all been developed and tested only in one country, which may impact their generalizability to other regions. Even though all were developed in English, meanings can have cultural and language variations, therefore cross-cultural validity should be assessed. The MDASI-BT and Brain PCI have been developed for our target group, including all stages of primary brain cancer patients. In their development, the NFbrSI-24 focused on only advanced brain tumours and the SCNS34-BS included a significant proportion of benign tumours.

The MDASI-BT and the NFbrSI-24 demonstrated good psychometric properties while both the Brain PCI and SCNS34-BS are lacking evidence of reliability and validity. Of these the MDASI-BT, as developed for all brain cancer patients, would be most suitable, however additional development would be needed to encompass the holistic aspects of need.

Evaluation of tools for use as a Holistic Needs Assessment tool

We summarised the details of the evaluation of the four tools identified, in relation to their quality and usefulness as a HNA tool (Table 4). The first criterion was to comprehensively represent the common domains of need. The original SCNS-34 was designed using a theoretical framework developed with five constructs of need (Bonevski et al., 2000). Although this was not specifically examined for the additional brain tumour subscale, in combination with SCNS-34, there is representation of the common domains of need (Janda et al., 2008). Similarly, the MDASI-BT structure and design was underpinned by a theoretical framework of individual characteristics of patient burden and symptoms (Armstrong et al., 2006). This tool was designed to assess emotional and physical symptoms with aims of evaluating treatments and planning interventions to alleviate symptoms, therefore the focus is on physical and psychological problems and other domains of need are not covered. The Brain PCI appeared to cover the majority of the relevant domains of need, but the process for comprehensively representing these was not discussed (Rooney et al., 2014). The NFbrSI-24, similar to the MDASI- BT, was developed as a symptom questionnaire rather than a HNA tool therefore the focus was on physical and emotional symptoms.

The SCNS34-BS did not report any details of the user acceptability or how usable this might be in a clinical situation. The NFbrSI-24 and MDASI-BT did not formally assess acceptability, although completion time of the MDASI-BT was noted to take approximately 10 minutes. The Brain PCI did examine user and assessor acceptability and found that despite the presence of cognitive difficulties in many participants, 91% of patients found this questionnaire 'easy' or 'very easy' to complete. The Brain PCI was rated positively from clinicians with 19/21 feedback forms rating the tool as useful, however 14/21 stated that increased consultation time, although this was not formally assessed (Rooney et al., 2014).

In the context of the evaluation criteria for an HNA tool, the Brain PCI appears most suitable due the assessment of most of the domains of need and the assessment of the usability from the perspective of the patient and clinician.

Discussion

This is the first review of assessment tools developed for brain cancer patients that may be used to assess unmet needs or concerns. This review found four tools which could be considered for HNA, however none had strong psychometric properties, and the two that were developed for HNA had only minimal psychometric testing. Some of the studies that developed these tools were conducted prior to publication of the COSMIN criteria so other specifications may have guided their methodology, however these criteria now present a reliable and valid process to evaluate tools supporting the choice of this criteria. The lack of psychometric testing is not unique to brain cancer and is reflected in other reviews of HNA for generic cancer (Richardson et al., 2007) or other specific cancers such as lung cancer (Maguire et al., 2013). As previously discussed, most authors support the need for psychometric testing of HNA, however the authors who developed the Brain PCI (Rooney et al., 2014) shared the alternative viewpoint presented by Garssen & de Kok, (2008). They assert that the priority for research on HNA tools should not be the development of the psychometric properties but a focus on the feasibility of usage of screening tools in clinical practice and the effects of decisions made by the health care providers, ultimately focused on the outcomes for patients.

While it might be questioned whether tools that are developed as ‘symptom questionnaires’ such as the MDASI-BT or the NFbrSI-24 were appropriate to consider, they were included for a number of reasons. There were a lack of PROMs which facilitated the patient’s identification of concern in brain cancer. In addition, the use of a validated symptom scale in combination with targeted problem checklist focused on the other domains of need is an approach that has been adopted for generic cancer needs assessment in Canada (Canadian Partnership Against Cancer, 2012; Watanabe et al., 2012).

User acceptability for both the patient and clinician is a key component when developing questionnaires or assessment tools for clinical use. The ideal instrument should assess the perceived burden, usefulness and meaning in relation to improving the existing strategies for detection of unmet need. User acceptability and burden, is important for all PROMs, but as previously highlighted, in brain cancer this is particularly important as completion can be impacted by the neurocognitive impairments. In clinical trials for brain cancer patients, QOL form completion can be poor, with either no form completed or missing items (Dirven et al., 2014; Walker et al., 2003). A recent study in Germany with patients diagnosed with glioma highlighted that even with support in clinics up to 10% of participants erroneously completed the SCNS-34 and this rises to 20% without support (Renovanz et al., 2016). They highlighted structure and comprehension as contributing factors but also noted that if patients were distressed more errors occurred. There is also data that suggests that if clinicians find the questionnaires cognitively demanding, burdensome or not clinically relevant, their support of implementation and response to any PROM could be sub-optimal (Gilbert, Sebag-Montefiore, Davidson, & Velikova, 2015). There clearly needs to be a balance between ensuring the relevant problems of a neuro-oncology population are assessed, while minimising burden.

The findings suggest two potential options that could be considered for HNA in Brain cancer. The Brain PCI, out with its psychometric properties, demonstrated moderate to strong characteristics in relation to HNA quality criteria and with additional psychometric testing may offer one approach. Alternatively, the MDASI – BT demonstrated the strongest psychometric properties and could provide the basis for

an alternative approach. This tool could be combined with a more holistic assessment, similar to the approach the Canadian Partnership Against Cancer (2012) that uses the Edmonton Symptom Assessment System together with the Canadian Problem Checklist. However, based on the results of this review, that although progress has been made, no tool provides a comprehensive approach in identifying needs without further development.

Recommendations for further research

Recently, an international multidisciplinary working group has been set up to evaluate and provide guidance on the use of patient reported outcomes in neuro-oncology (Dirven et al., 2018). This may provide valuable information on the use of HNA or provide direction on what other PROMs could generate high quality evidence to help evaluate the impact of HNA processes in future research.

In addition, to the areas already discussed, there are many other aspects of HNA in brain cancer which would benefit from research. The use of electronic HNA are increasingly used and may provide a basis for improving compliance and providing this information to a variety of health care providers. Electronic PROMs are acceptable to patients and have the potential to provide a variety of modes (e.g. internet based, hand held devices) and could be personalised based on patient preferences or capabilities (Gilbert et al., 2015). However, the IT systems to collect this data in a meaningful, accessible, and secure ways need to be developed and tested.

There is also a need to look at studies comparing different pathways for HNA and the impact of this process. For example, where is it completed, at what point in the treatment trajectory and which health or social care provider receives and reviews it. Most importantly, research should focus on the impact of HNA in improving outcomes such as reducing distress or increasing wellbeing.

Strengths and Limitations

This was a rigorously conducted review of tools that may support HNA in brain cancer. This review has some limitations. The diversity and quality of methodological approaches was challenging when comparing tools. There were also differences in

the aims of tools and although they all aimed to measure some aspects of needs or problems, some may have not been designed specifically to undertake a holistic assessment. Despite this limitation, their inclusion was useful, as if an existing tool was to be adapted – these could be considered.

Conclusion

Providing supportive care and meeting the needs of patients with brain cancer who in many cases have a poor prognosis, is challenging. HNA has been identified as an important strategy to facilitate this process. This review has provided a comprehensive overview of the content and measurement properties of four tools that could be used for HNA in brain cancer. Similar to other reviews of holistic needs assessment tools in cancer, this review identified a variety of tools for assessing needs, however there is currently a lack of evidence to support what might be the best tool or even consensus on how to evaluate this in a clinical setting (Higginson, Hart, Koffman, Selman, & Harding, 2007; Richardson et al., 2007; Wen & Gustafson, 2004). It is clear, due to the lack of a clearly suitable tool in this area, that the evidence base to develop this area of supportive care is limited. Ideally a fit-for-purpose, psychometrically robust, and context-specific tool should be developed specifically for brain cancer patients, to be used in everyday practice to allow for meaningful communication to identify supportive care needs. The lack of a tool, which adequately meets these requirements, supports the need to further explore how HNA can be performed in brain cancer patients to optimize this intervention.

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Box 1 – Definitions of Psychometric properties for PROMs

Psychometric property	Definition	Considerations
Validity	The degree to which an HR-PRO instrument measures the construct(s) it purports to measure	
<i>Content validity:</i>	Content validity seeks to assess if the component parts and tool measures what it is intended to	Initial development through the literature, expert opinion and patient input Refinement of item selection and phrasing through end users
<i>Hypothesis testing or (Construct validity):</i>	The degree to which the scores of the PROM are consistent with hypotheses (for instance with regard to internal relationships, relationships to scores of other instruments, or differences between relevant groups) based on the assumption that the tool validly measures the construct to be measured.	Any measurement tools used, as a comparator, should have adequate measurement qualities. Two criteria should be met; 1) that hypotheses should be stated in the methods including magnitude and 2) 75% of the results are in accordance with these hypotheses which should be reported as a correlation
<i>Structural validity</i>	The degree to which the scores of an PROM instrument are an adequate reflection of the dimensionality of the construct to be measured	This is appropriate for use when a measurement tool is based on reflective model - not for those based around a formative model. HNA is likely to be considered formative due to independent contributing factors.
<i>Cross-cultural validity</i>	The degree to which the performance of the items on a validity translated or culturally adapted PROM instrument are an adequate reflection of the performance of the items of the original version of the PROM instrument	
Reliability	Refers to the stability of responses over time or between respondents (reproducibility) and the consistency of the items in the tool. Reliability contains two measurement properties: Internal consistency and test-retest reliability	

<i>Internal consistency:</i>	The extent to which items in a questionnaire scale are correlated, thus measuring the same concept.	The most common method used is Cronbach's alpha and it should be calculated for each dimension separately.
<i>Reliability: Test-retest reliability:</i>	The degree to which repeated measurements in stable persons provide similar answers.	Correlation values between administrations of 0.70 are considered acceptable. Two weeks is often considered an acceptable time gap
<i>Measurement error:</i>	Refers to changes in the scores of the tool that are not attributed to a true change in the construct to be measured.	This will require two measurements usually about 2 weeks apart (to prevent recall) and the construct to be measured should remain stable.
<i>Responsiveness: (also called sensitivity)</i>	Refers to the ability of a tool to detect changes over time, which correlates with the construct being assessed.	
<i>Interpretability</i>	Refers to the ability to attach meaning (for example commonly understood concepts) to the tools results or changes in the tools results. This looks at the degree to which one can assign qualitative meaning to quantitative scores.	An important concept within this is the ability to detect the MIC which is the lowest level at which a patient feels a change is important to them. Interpretation of this is gives a clinically important level for clinicians assessing the effects of treatments or need for intervention (de Vet et al., 2011).

HR-PRO = Health-related patient reported outcome, PROM = patient reported outcome measurement, HNA = holistic needs assessment, MIC = minimal important change

Derived from the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) checklist (Mokkink et al., 2012; Mokkink et al., 2010)

Box 2 – Criteria for Tools for Holistic Needs Assessment

Needs assessment characteristic	Definition	Recommendations if applicable	Rating
Planned use of tool	Tools can be primarily designed for research or clinical use. The approach to needs assessment in most cases will be with a specific tool for this purpose	A holistic needs assessment tool should be designed with the purpose of assessment of patient needs for clinical purposes and developed and tested for the intended population (Richardson, Medina, Brown, & Sitzia, 2007). – however some strategies such as Canadian Partnership Against Cancer (2009) have advocated symptom assessment with an amended problems checklist as a reasonable approach	Weak – primary purpose not needs assessment and/or not developed for clinical use Strong – primary purpose is brain tumour patient needs assessment in clinical practice
Identification of the dimensions of need	The literature clearly identified a number of domains to be considered which included physical, psychological, social, emotional, financial, sexual, functional and spiritual domains in HNA (Cleeland et al., 2000; Johnsen, Petersen, Pedersen, & Groenvold, 2011; Schofield, Gough, Lotfi-Jam, & Aranda, 2012; Waller, Girgis, Currow, & Lecathelinais, 2008).	HNA tools should assess the multidimensional impact of cancer. Within this criterion, reference to a theoretical or conceptual framework can help to identify factors, which are important to assess.	Weak – no theoretical framework, not covering the majority domains of needs Moderate – covering majority of domains of needs but no theoretical framework Strong – theoretical framework and covering the majority domains of needs
Psychometric properties	Demonstrate strong psychometric properties	The COSMIN criteria were chosen to assess the psychometric properties as described in the previous section.	Weak – Little evidence of psychometric properties Moderate – some limited evidence of psychometric properties Strong – good evidence of psychometric properties
4 Be user-friendly	A number of elements should be considered such as the time to complete, ease of completion, comprehension, and perceived usefulness as a tool to communicate needs.	It is generally agreed that reading level for patient reported health outcome measures should not exceed 12 years of age (Streiner & Norman, 2008). In patients with primary brain tumours, cognitive impairment is very common with 54% demonstrating some form of cognitive impairment often related to language, memory and attention (Zucchella, Bartolo, Di Lorenzo, Villani, & Pace, 2013). Lai, Jensen, et al., (2014)	Weak - no user assessment Moderate – some subjective assessment from users Strong – subjective assessment from users and objective assessments (for example encompassing assessment of reading level, acceptably form completion requirements and recall time frame)
5: Be assessor friendly	The time, energy and resources for those receiving and responding on questionnaires needs to be	Vodermaier, Linden, & Siu, (2009) highlight that a short questionnaire of 5-20 items may have a moderate chance of use in busy clinics compared	Weak - no assessment Moderate – some subjective assessment

considered (Maguire et al., 2013). This criterion relates to the ease of interpretation and usefulness to clinicians to support HNA. It should also consider variables that may affect health care resources such as does it add time to the overall consultation

to longer formats, and there may be resources associated with scoring longer questionnaires if required.

from clinicians or objective assessment
Strong – subjective assessment from users and objective assessments (for example encompassing usefulness, ease of interpretation and resource implications)

, HNA = holistic needs assessment, COSMIN = CONsensus-based Standards for the selection of health Measurement INstruments

Figure 1 – Systematic Search

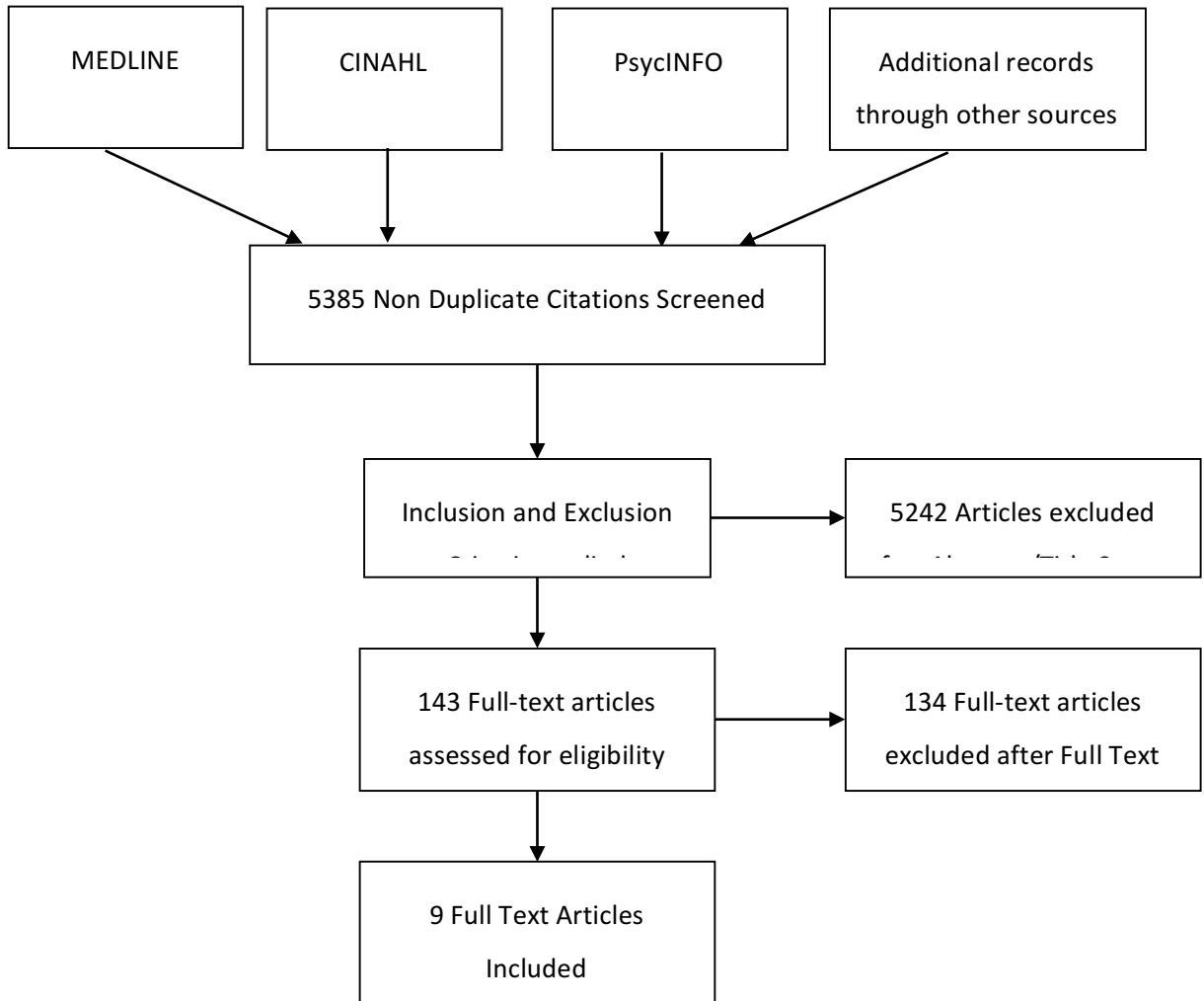


Table 1 – Summary of tool properties

Tool	Purpose	Domains	N of items	Response options	Recall period	Scoring	Time to administer
Brain PCI	HNA CU	Practical, family, emotional, spiritual and physical – with options to request referral and space to ask questions.	58 plus 4 free text questions	Tick box to ‘issues that have been a concern’	‘recently’	Tick box only	60% of patient report <15 minutes
MDASI-BT	SYM CU & R	Six affective, cognitive, focal neurologic deficits, constitutional, generalized symptom, and a gastrointestinal related factor.	29	Scaling – A 11 point Likert scale in relation to the presence and severity of each symptom in the, with 0 being “not present” and 10 being “as bad as you can imagine” 11 point Likert scale in relation to level of interference.	Last 24 hours	Individual symptoms scored none, mild (1-4), moderate (≥ 5) and severe (≥ 7) and average for overall rating of symptom burden	Less than 10 minutes
NFbrSI-24	SYM CU & R	Three subscales; disease related symptoms (physical and emotional), treatment side effects and functional/wellbeing.	24	Scaling - A five-point intensity scale based on ‘how it applies to you’ from ‘not at all’ to ‘very much’	Last 7 days	Individual symptoms/concerns are scored with higher scores reflecting less symptoms and concerns (negatively worded items are	NR

reversed). Each domain has a score as well as overall questionnaire.

SCNS34-BS	HNA CU	<p>Format - Brain specific 'add on' questionnaire to SCNS34.</p> <p>Five domains SCNS34 (Psychological, Health system and information, physical and daily living, patient care and support, sexuality); care needs.</p> <p>The brain subscale has no grouping of domains</p>	50	Scaling - Five categorical responses, ranging from high need to no need.	Last month	Patients grouped according no or low needs and those with moderate or high needs.	NR
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Brain PCI – Brain Patient Concern Inventory, MDASI – BT – MD Anderson Symptom Inventory and Brain Tumor Module, NFBrsI-24 - 24-item National Comprehensive Cancer Network/Functional Assessment of Cancer Therapy-Brain Symptom Index, SCNS34-BS – Supportive Care Needs Survey (Short Form) with Brain Subscale
HNA = holistic needs assessment, SYM = symptom assessment, CU = clinical use, R = research or clinical trial use
NR = not reported

		location	N* (subgroups if applicable)	Sex (%)	Age in years range (%) Or mean = x		validity
Brain PCI	(Rooney et al., 2013)	UK One cancer centre	53	M (55), F (47)	18-34 (11), 35-59 (62), >60 (21)	<ul style="list-style-type: none"> • Other tools • Expert opinion 	NR
MDASI – BT	(Armstrong et al., 2005)	USA (multi location)	20 (16 = HCP 4 = PBT or C)	NR	NR	<ul style="list-style-type: none"> • Theoretical framework • literature review • Expert opinion • CVI > 0.80) 	NR
MDASI – BT	(Armstrong et al., 2006)	USA One cancer centre	201	M (57), F (43)	18-45 (52) 45-84 (48)	NR	Principal component analysis endorsed the six underlying constructs
MDASI – BT	(Armstrong et al., 2012)	USA One US cancer centre	230 (115 PBT and C dyads) (Test-retest subgroup N = 21 PBT)	PBT = M (63), F (37) C = M (27), F (73)	x = 48.2	NR	NR
MDASI- BT	(Armstrong et al., 2014)	USA One US cancer centre	100 92 completing three time-points	M (62), F (38)	19-77 x = 48	NR	NR

24	et al., 2014)	Six cancer centres/hospitals	plus 10 HCP (for Content validity ONLY)	NR			<ul style="list-style-type: none"> refine items from 20 to 24 Expert opinion (domains) 	FACT General, physical, social, emotional, and brain tumour specific concerns ($p = 0.59, 0.57, 0.40, 0.35, \text{ and } 0.50$, respectively; $P_s < 0.05$)
SCNS34-BS	(Janda et al., 2006)	Australia	36 (N = 18 C, 18 PBT)	M (30.5), F (69.5)	NR*		<ul style="list-style-type: none"> Literature review Expert input Focus groups Interviews 	NR
SCNS34-BS **	(Janda et al., 2008)	Australia	75	M (46), F (54)	< 50 (53.5) >50 (46.5)	NR		<p>Patient adjusted odds ratio with patients categorised as high need (95% CI)</p> <p>Depression > 11 = OR 2.11 (CI - 1.10-4.03)</p> <p>Anxiety > 11 = OR 2.89 (CI- 1.29-6.45)</p>

Brain PCI – Brain Patient Concern Inventory, MDASI – BT – MD Anderson Symptom Inventory and Brain Tumor Module, NFBrsI-24 - 24-item National Comprehensive Cancer Network/Functional Assessment of C Subscale

NR = details not reported in article

M= male, F = female

PBT = primary brain tumour patient C = Carer HCP = health care professional

X = mean

CVI = content validity index

DV = divergent validity, CV = convergent validity

FACT - Functional Assessment of Cancer Therapy

KPS – Karnofsky Performance status, ECOG-PS = Eastern Co-operative Oncology Group Performance Status

REM = relate-enjoy-mood, WAW= walk-activity-work

* All primary brain cancer patients unless otherwise specified

**Study also reported results of 70 carers separately

Evaluated measurement properties	Content Validity	Hypothesis testing	Internal consistency	Reliability test retest
Brain PCI	Poor	NA	NA	NA
MDASI – BT	Good	Good	Excellent	Good
NFbrSI-24	Excellent	Good	Fair	NA
SCNS34 – BS	Fair	Poor	NA	NA

Brain PCI – Brain Patient Concern Inventory, MDASI – BT – MD Anderson Symptom Inventory and Brain Tumor Module, NFBrSI-24 - 24-item National Comprehensive Cancer Network/Functional Assessment of C Index, SCNS34-BS – Supportive Care Needs Survey (Short Form) with Brain Subscale, NA = not assessed

				properties	results)
Brain PCI	(Rooney et al., 2013)	Strong - has been developed for needs assessment with only brain cancer patients	Moderate - recognised domains covered, facility to add questions around needs. No theoretical or conceptual framework.	Weak	Moderate - feedback from patients sought on comprehensiveness and ease of completion
MDASI- BT	(Armstrong et al., 2005) (Armstrong et al., 2006) (Armstrong et al., 2012) (Armstrong, et al., 2014)	Weak - has been developed for primary brain cancer patients but focus on symptoms	Weak - Has only focused on psychosocial and physical symptoms. Scaling of intensity and interference. Conceptual framework used	Strong	Weak - time frame for completion 10 minutes but no user subjective feedback
NFbrSI-24	(Cella et al., 2003) (Lai, Jensen, et al., 2014)	Weak - has been developed for primary brain cancer patients but focus on symptoms and concerns – but has excluded items of concern not related to disease or treatment such as financial concerns	Weak - Has only focused on general wellbeing, psychosocial and physical symptoms or concerns. Scaling of intensity	Strong	Weak - no reported data
SCNS-34 BS	(Janda et al., 2006) (Janda et al., 2008)	Strong - is designed for needs assessment in a brain tumour population	Moderate - recognised domains covered and scaling of level of need. No theoretical or conceptual basis	weak	Weak - no reported data

Supplementary Material (Appendix S1) - Medline Search Query

	Query	Results
S 1	(MH "Brain Neoplasms+")	137,481
S 2	(MH "Needs Assessment") OR (MH "Symptom Assessment") OR (MH "Self-Assessment")	40,841
S 3	(MH "Patient Outcome Assessment+")	4,802
S 4	TI (inventory or tool* or measure* or instrument*) OR AB (inventory or tool* or measure* or instrument*)	3,384,453
S 5	S2 OR S3 OR S4	3,417,451
S 6	S1 AND S5	11,337
S 7	S1 AND S5 Limiters - Human; Age Related: All Adult: 19+ years Search modes - Boolean/Phrase	4,926