

Moving from clinician-defined to patient-reported outcome measures for survivors of high-grade glioma

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Patient Related Outcome Measures

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Background: Persons with high-grade glioma face both neurological and cancer-related symptoms from the tumor itself and its treatment affecting their daily lives. Survival alone is not an adequate outcome, the quality of the survivorship experience needs to be regarded with equal importance. Patient-reported outcome (PRO) measures can be used to evaluate treatment effects and symptom management interventions.

Purpose: The aim of this review was to identify the use, challenges, and potential of PRO measures in survivors of high-grade glioma.

Methods: A narrative expert opinion review was performed on the subject. In addition to our own experiences we searched PubMed, Cumulative Index to Nursing and Allied Health Literature, the Cochrane Library, and PsycINFO for brain tumor-specific PRO measures used in the population of adult patients with high-grade glioma, both original articles and reviews were included.

Results: There are several PRO measures that have been validated for patients with primary brain tumors including high-grade glioma. PRO measures are used both in clinical trials to evaluate the effect of treatment on health-related quality of life, and in daily clinical practice for holistic needs assessment and symptom management. Common PRO measures used for patients with high-grade glioma are European Organization for Research and Treatment of Cancer general instrument for patients with cancer together with brain tumor module, Functional Assessment of Cancer Therapy-Brain, and MD Anderson Symptom Inventory for Brain Tumor. Neurologic and cognitive disorders often occur in patients with high-grade glioma, which affects patients' ability to self-report over time, making it more challenging in this population. PRO as a primary outcome seems underutilized.

Conclusion: For clinical research, PRO measures need to be used together with other clinical outcome measures rather than replacing traditional outcome measures. Moving to more use of PRO measures in survivorship care has potential to improve patient-caregiver-healthcare team communication, symptom management, and quality of care. Implementing PROs in survivorship care should also involve caregivers and a response based on the results.

Keywords: high-grade glioma, brain tumor, patient-reported outcome measures, symptom management

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Introduction

Gliomas are the most common primary brain tumor in adults. They are classified into different subgroups and graded according to WHO tumor grade (ranging from I-IV) where higher grade means more malignant tumor.¹ High-grade gliomas, WHO grade

III–IV, (ie, anaplastic astrocytoma, anaplastic oligodendroglioma, and glioblastoma) are considered incurable and there are limited numbers of long-term survivors. Acute or subacute neurologic symptoms such as headaches, seizures, neurocognitive dysfunction, and motor deficit, often lead to diagnosis and impact patients from the time of diagnosis.² Treatment of high-grade glioma is multimodal, incorporating surgery, radiotherapy, and/or chemotherapy.^{3–7} Although treatment aims to prolong life, these modalities may have implications in terms of both short- and long-term symptoms and health-related quality of life (HRQoL).⁸

Traditional outcome measures used for patients with cancer are tumor size and response to treatment, overall survival, and prolonging patients' lives with stable disease, so-called progression-free survival. Today, most clinical trials also include patient-centered outcomes, or clinical outcome assessment (COA) tools, to evaluate the effect of treatments on patient function and impact on HRQoL. According to The US Food and Drug Administration (FDA), there are four different types of COA measures; patient-reported outcomes (PROs), clinician-reported outcomes (ClinROs), observer-reported outcomes (ObsROs), and performance outcomes (PerfOs), Table 1. PROs are defined as any aspect of a patient's health condition reported directly by the patient

without interpretation of the patient's response by a physician or anyone else. PROs can provide insight into subjective concepts only known to the patient, like HRQoL and experience living with the disease.^{9,10} ClinRO assessments are conducted and reported by health care professionals, for example, assessment of neurological function. ObsRO measures report about the patient's health condition from someone other than the patient or the health care professionals, usually a family member. Observer or proxy reports can be used when a patient cannot self-report, for example, due to cognitive or linguistic problems. PerfO measures are usually administered by a health care professional and performed by the patient, for example, a neurocognitive test.⁹

Data available from qualitative studies about the experience of patients with high-grade glioma indicate a high symptom burden with complex and dynamic supportive care needs also affecting family members, friends, and caregivers sharing the survivorship experience with the patient.^{11–15} Survivorship care and survivorship care plans are needed and are being implemented in neuro-oncology.^{16,17} According to the National Coalition for Cancer Survivorship and the NCI Office of Cancer "An individual considered a cancer survivor from the time of diagnosis, and throughout the balance of his or her life."

Table 1 Different patient-centered outcome measures

Patient-centered outcome measures		
Clinical outcome assessment	Definition	Example
PRO measures	Patient-reported outcome, patient's self-report of symptoms, function or health-related quality of life	Health-related quality of life: EORTC-QLQ-C30 and BN20, FACT-Br Symptom assessment: MDASI-BT
PerfO measures	Performance outcome, testing of patient's function by a professional	Neurocognitive function: for example The Montreal Cognitive Assessment (MMSA) Function/Activity limitations, BADL: ex. Barthel index (BI)
ClinRO measures	Clinician-reported outcomes, assessments were a clinician applies professional expertise to judge and interpret their observations of a patient's health or function	Performance status: ECOG/WHO performance status, KPS scale, Neurologic assessment: NANO scale
ObsRO measures	Observer-reported outcomes	Observations reported by someone else who knows the patient, usually a family member, for example, observations about patients' behavior or function in daily life

Abbreviations: EORTC QLQ-C30, European Organization for Research and Treatment of Cancer general instrument for patients with cancer; EORTC BN20, European Organization for Research and Treatment of Cancer brain tumor module; FACT-Br, Functional Assessment of Cancer Therapy-Brain; IADL, Instrumental activities in daily life; MDASI-BT, MD Anderson Symptom Inventory for Brain Tumor; NANO, Neurologic Assessment in Neuro-Oncology.

Important components identified in survivorship care are surveillance of new or recurrent cancers, coordination of care, and support for consequences of cancer and treatment.¹⁸ Symptom management is one of the key components and includes identifying, preventing or treating the symptoms of the disease, side effects caused by treatment, and psychological, social or spiritual problems related to the disease or the treatment.¹⁹ Symptom management strategies can incorporate preventive interventions, patient and family self-management methods, and prescribed interventions to treat symptoms.²⁰

In this review, we aimed to describe the current use of PROs in survivors and survivorship care of high-grade glioma. We highlighted the potential and challenges of PRO in this group of patients.

Methods

For this narrative expert review we searched the e-resources PubMed, the Cochrane Library, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and PsycINFO for PROs used for adult patients with high-grade glioma. Inclusion criteria were original articles and reviews in English language reporting use of PROs in clinical trials or clinical practice in adult patients with high-grade glioma. The search strategy consisted of a combination of terms for (High-grade gliomas) OR (Glioma) OR (Brain neoplasms) OR (Brain tumors) AND (Patient Reported Outcome Measures) OR (Patient Outcome Assessment) OR (Self-Assessment). Additional articles were identified through previous topical reviews. PRO measures not specific for primary brain tumors, PROs for one-dimensional specific symptoms or studies that included both patient and caregiver assessments were excluded.

Results

There are several PRO measures specifically validated for patients with brain tumors including high-grade glioma, as seen in Table 2. PROs are used both in clinical trials to evaluate the effect of treatment on HRQoL and in daily clinical care for needs assessment and symptom management.

PRO measures in clinical trials for patients with high-grade glioma

PROs, usually HRQoL, are used in clinical trials to assess the impact of new therapeutic strategies on the patient. HRQoL can also be an important second primary endpoint in trials where the treatment has no effect on overall survival, but

improvement in HRQoL is observed.²¹ HRQoL is defined as a multidimensional concept, covering physical, psychological, and social dimensions as well as symptoms induced by the disease and its treatment.²² This is especially important in high-grade glioma patients, where improving survival has been shown to be extraordinarily difficult and maintenance or improvement of neurologic function and HRQoL are as important as prolonged survival.^{9,23,24} PRO measures used in clinical trials for patients with high-grade glioma are HRQoL and symptom burden.²⁵ In a systematic review by Dirven et al, 2014, they looked at the level of PRO measures reported and the methodological quality of the PRO reporting in randomized controlled trials (RCTs) of primary malignant brain tumors. In 13 out of 14 of the RCTs identified (2004–2012) the Functional Assessment of Cancer Therapy-Brain (FACT-Br)^{26–29} or the European Organization for Research and Treatment of Cancer general instrument for patients with cancer (EORTC QLQ-C30)^{30–38} was used to measure HRQoL.³⁹ Several challenges using PRO measures in clinical trials have been reported, including concerns regarding the methodological quality of the reporting of PRO measures. PRO measures that should be used in clinical decisions need to be collected, analyzed, and interpreted correctly. Using the International Society for Quality of Life Research checklist for reporting PRO measures,^{40,41} only two of the RCTs provided high-quality PRO evidence.^{6,36,39} Since then, the use and reporting of PROs in clinical trials have been discussed and are now more frequently reported in a separate paper and according to guidelines or checklists.^{42,43} Other limitations to be aware of using PRO measures in neuro-oncology have been described and include missing data, patient's ability to self-report, selection bias, timing of the assessment, and response shift.^{44,45} Common reasons of missing data are often administration failure, high symptom burden or progression of disease. Electronic data capture may facilitate data collection and reduce missing data due to administration failure. Patients with high-grade glioma often also suffer from neurologic and cognitive disorders which also affect patients' ability to self-report, resulting in unreliable or missing data. Studies that have explored the use of caregivers as proxy when patients are not able to self-report have mixed results.^{9,45,46} For patients with high-grade glioma and proxy ratings, there are studies which used EORTC QLQ-C30,^{47,48} Fact-Br,^{49–51} and MD Anderson Symptom Inventory for Brain Tumor (MDASI-BT)^{52,53} showing fair-to-good congruence between patients and their proxies, but in clinical trials, reporting of PROs usually ends when patients are not able to self-report.

Table 2 Patient-reported outcomes used in neuro-oncology

Tool	Number of items	Purpose	Domains	Reference
Health-related quality of life				
EORTC QLQ-C30	30	Health-related quality of life, generic instrument for patients with cancer	Five functional scales (physical, role, emotional, cognitive and social functioning), three symptom scales (fatigue, pain, and nausea/vomiting), six single items (dyspnea, insomnia, appetite loss, constipation, diarrhea, and financial impact) and a two-item scale for global health and overall quality of life. Recall period: last week	91
EORTC-QLQ-BN20	20	Brain cancer module	BN20 four multi-item scales (future uncertainty, visual disorder, motor dysfunction, and communication deficit) and seven single-item symptom scales (headaches, seizures, drowsiness, hair loss, itchy skin, leg weakness, and bladder control) Recall period: last week	92
FACT-G	27	Health-related quality of life, generic instrument for patients with cancer	Five domains (functional, physical, social, family, and emotional well-being)	93,94
FACT-Br	23	Brain cancer module	23 items brain tumor-specific symptoms	95
Symptom assessment tools				
MDASI-BT	22 6	Cancer- and brain tumor specific symptoms. Symptom severity and interference in daily life	22 items in six domains (general, gastrointestinal, constitutional, neurologic deficit, cognitive, and affective) Interference in daily life, (activity and mood) Recall period: 24 hours	67,93,94,96
NFBrSI-24	24	Symptom assessment/ Symptom index for patients with advanced brain tumors	24 items, where 21 out of 24 items are included in FACT-Br three subscales (disease-related symptoms, treatment side effects and function/well-being) Recall period: 7 days	71
Holistic and supportive care needs assessment				
Brain PCI	48 10 4	Holistic needs assessment	Section 1. 48 items for practical, family, emotional, spiritual and physical issues Section 2. 10 items, referral requests Section 3. 4 fields for writing questions Recall period: prior to visits	72
SCNS34-BS	34 16	Supportive care needs	34 items (psychologic, health system and information, physical and daily living, patient care and support, sexuality) 16 brain tumor-specific items Recall period: last months	97,98

Abbreviations: EORTC QLQ-C30, European Organization for Research and Treatment of Cancer general instrument for patients with cancer; EORTC BN20, European Organization for Research and Treatment of Cancer brain tumor module; FACT-G, Functional Assessment of Cancer Therapy-General; FACT-Br, Functional Assessment of Cancer Therapy-Brain; MDASI-BT, MD Anderson Symptom Inventory for Brain Tumor; NFBrSI-24, National Comprehensive Cancer Network & Functional Assessment of Cancer Therapy Brain Symptom Index; PCI, Patient Concern Inventory; SCNS34-BS, Supportive Care Needs Survey 34 plus brain subscale.

PRO measures in clinical practice

There is a growing interest in using PROs to improve individual patient care, both from health care professionals and patients themselves. There are hospitals implementing electronic PROs into routine oncology practice for symptom

assessment and management.⁵⁴ PRO measures have been advocated as an effective way to improve patient-provider communication, symptom control, self-management, and increase patient satisfaction.⁵⁵ In two randomized trials in patients with other types of cancers (not brain tumors),

patients receiving chemotherapy were randomly assigned to either electronic patient-reported symptom monitoring (and a routine to respond to patients' results when needed) or usual/traditional care.^{56,57} The group of patients assigned to electronic patient-reported symptom monitoring had better HRQoL⁵⁶ and in one trial even increased survival compared to the group with usual care.⁵⁷ However, to our knowledge, published work of this set-up in patients with high-grade glioma is lacking. Challenges of integrating PROs in clinical practice are many, among them engaging health care professionals to implement PROs into existing clinical workflows⁵⁸ and selecting PRO measures that are meaningful to the patients and have adequate psychometric properties.⁵⁹ When implementing PROs in clinical practice, it is also important to aid both patients and health care professionals, to visualize results so they can be easily interpreted and so that they can act on the results.⁶⁰⁻⁶² For patients with high-grade glioma, we found specific tools for symptom assessment and holistic needs assessment (HNA) being used in clinical practice, as seen in [Table 2](#).

Symptom assessment and management is an important part of survivorship care. Patients with high-grade glioma experience both cancer-related symptoms like fatigue and future uncertainty, and progressive neurologic symptoms caused by the tumor itself and treatment.^{2,8} Therefore, generic PRO measures cannot always be used in this population to detect symptoms or needs. In the Conceptual framework for survivorship care for neuro-oncology described by Leeper and Milbury, they present potential PROs to use in neuro-oncology survivorship care; HRQoL, fatigue, mood, functional status, cognitive status, seizure control, headache, and pain.¹⁶

HRQoL instruments such as EORTC QLQ-C30 are also used in clinical practice^{63,64} and the EORTC QLQ has developed a manual for the use of EORTC instruments in clinical practice.⁶⁵ King et al, 2016, examined the use and impact of HRQoL assessment tools in clinical cancer care settings, but did not find any studies exclusively in brain cancer patients.⁶⁶ In addition to those PRO instruments used to measure HRQoL, there are other instruments for measuring symptoms and symptom burden in patients with brain tumors, the MDASI-BT^{25,67} and the National Comprehensive Cancer Network & Functional Assessment of Cancer Therapy Brain Symptom Index (NFBrSI-24), as seen in [Table 2](#). The MDASI-BT was developed to cover both cancer-related and neurologic symptoms in patients with primary brain tumors and is used in both clinical practice and trials to identify symptoms, symptom severity, impact on patients' life, and to

evaluate symptom management interventions.^{2,25,67-70} The NFBrSI-24 is a more recently developed tool to assess symptoms in patients with advanced brain tumors.⁷¹

The aim with HNA is to provide a more holistic view of the complex needs of patients and to enhance communication between the patient, caregivers, and health care providers. There are a number of clinical tools to support HNA in cancer care, for example, the National Comprehensive Cancer Network (NCCN) Distress Thermometer. HNA tools are often designed as a checklist and are easy for the patient to complete before consultations. This process can help patients (and caregivers) to describe their situation and to remember to ask questions. It can also help health care professionals to focus on the patient's agenda.^{72,73} The NCCN Distress Thermometer has been used successfully to detect distress in patients with primary brain tumors including high-grade glioma.^{74,75} But generic cancer HNA tools may need to be adapted to also capture the different neurological symptoms and concerns occurring in patients with high-grade glioma.⁷² A recent systematic review evaluated existing brain-specific PRO measures used in adult brain tumor patients in clinical settings to investigate the potential of these for HNA. They found four clinical tools: the Brain Patient Concern Inventory (Brain PCI),⁷² the MDASI-BT,^{67,76} the NFBrSI-24,⁷¹ and the Supportive Care Needs Survey 34 plus brain subscale (SCNS34-BS), as seen in [Table 2](#). The Brain PCI and SCNS34-BS were designed for clinical use and HNA prior to visits but needed psychometric testing, whereas the MDASI-BT and NFBrSI-24 are psychometric-tested symptom assessment tools but would need further development to be used for HNA.⁷⁷

Discussion

The aim of this review was to identify the current use of PRO measures in survivors of high-grade glioma, and to reflect on potential and challenges of different outcome measures. We observed that there is a movement toward more use of PROs in cancer patients including patients with high-grade glioma. However, for patients with high-grade glioma, there is a relative lack of data concerning long-term PROs, use of PROs in clinical practice, interventions to improve PROs, and even patient satisfaction where PROs are used. There is a risk for "questionnaire fatigue" if PROs are increasingly used and not acted upon.

Traditional outcomes in patients with high-grade glioma are surprisingly complex and have their shortcomings. For example, radiological response assessment has shown both pseudo-progression and pseudo-response

depending on treatment.^{78,79} For this reason, different outcomes are needed in combination to get a reasonable picture of the disease status of a patient. To improve the response assessment in neuro-oncology, the “Response Assessment in Neuro-Oncology” (“RANO”) working group has established criteria that can be used for brain tumors.⁸⁰ There is a movement toward clinical trials where different COAs are used together to evaluate net clinical effect, with both subjective and objective measures. For example, in RTOG 0525, a combination of neurocognitive tests, HRQoL (EORTC QLQ-C30 and BN20), and symptoms (MDASI-BT) was used.⁸¹ Recently, a ClinRO assessment tool for neurologic function among neuro-oncology patients was developed, The Neurologic Assessment in Neuro-Oncology (NANO) scale. The NANO scale was designed to be combined with radiographic assessments and other COAs like PRO measures and neurocognitive tests, to provide an overall assessment of outcome for neuro-oncology patients in clinical trials and in daily practice.⁸²

Commonly used PRO measures for patients with high-grade glioma are EORTC QLQ-C30,^{47,48} Fact-Br,^{49–51} and MDASI-BT.^{52,53} The “Response Assessment in Neuro-Oncology-Patient-Reported Outcome” (“RANO-PRO”) working group provides guidance on the use of PRO and will develop existing and new PRO measures for adult patients with brain tumors, where needed.⁹ The RANO-PRO group and the EORTC quality of life group are developing a self- or observer-reported instrument to measure instrumental activities in daily life (IADL), in brain tumor patients. The EORTC IADL for patients with brain tumors will include complex activities in a patient's daily life like preparing food, ability to handle finances, shopping, and housekeeping.^{83,84} There is also ongoing work to update the EORTC brain cancer module BN20. The brain cancer module was developed more than 20 years ago and since then treatments have changed and patients may now experience symptoms not captured by the current questionnaire (<https://qol.eortc.org/questionnaire/bn20-update/>).

Where clinical trials are designed to follow patients' HRQoL until progression or recurrence, there is a risk that long-term side effects from treatment might be missed. There are PRO measures which capture specific issues in cancer survivors, but not used in patients with high-grade glioma that we know of. The EORTC quality of life group is developing a PRO instrument to capture HRQoL issues relevant to disease-free survivors of cancer, EORTC QLQ cancer survivorship questionnaire. They describe a “cancer

survivor” as any person who has been diagnosed with cancer who has completed treatment with curative intent (with the exception of maintenance treatment) and is disease-free (no evidence of active cancer). This definition may not suit patients with high-grade glioma but low-grade glioma patients were included in the study.⁸⁵

To improve measurement precision and relevance to patients, PRO measures should ideally be adapted to the individual patient while retaining direct comparability of scores across patients. This is achievable using item banks and computerized adaptive tests (CATs). The EORTC quality of life group has developed a CAT item bank for the functional domains and symptoms of the EORTC QLQ-C30. The EORTC CAT Core will be a more precise and flexible measurement system than the EORTC QLQ-C30.⁸⁶ Another item bank is the National Institutes of Health Patient Reported Outcomes Measurement Information System (PROMIS). PROMIS was developed for the general population with multiple chronic health conditions and has been used to measure common cancer symptoms in routine oncology outpatient care.⁸⁷ A recent study used the item banks PROMIS and The Quality of Life in Neurological Disorders (Neuro-QoL) to evaluate low- and high-grade glioma patients' perspective on functional domain affecting HRQoL.⁸⁸

However, there are limitations to the use of PRO measures that should be acknowledged. Due to consequences of neurologic and cognitive disorders often occurring in patients with high-grade glioma the transition to “PROs only” in patients with high-grade glioma may be problematic. In addition, since the more traditional outcome measures are extraordinarily important in interventional studies, the field of high-grade glioma is not ready for a move from clinician-reported outcome measures to PRO measures. The situation would perhaps be different if longevity was the rule due to effective treatment. We acknowledge that trained health care professionals can sometimes identify symptoms not known to either the patient themselves or caregivers, but under-reporting of symptoms by clinicians may be a more common scenario.⁸⁹ On the other hand, in observational studies and in daily clinical practice, PROs and observer or proxy reports from caregiver are crucial. We also need to know more about how to involve close caregivers as proxies or observers. Studies using proxy reports often look at caregiver and patient congruence for HRQoL ratings, but we know there might be a point where patients' and caregivers' consensus decreases. One way is therefore to obtain proxy ratings alongside a patient's own self-report until the

patient can no longer report him- or herself and then consider using patient by proxy ratings.⁹⁰ Caregivers need instructions on how they can help the patient respond or how they can respond as a proxy or an observer. Maybe we need a PRO proxy version with additional information for caregivers. Another way is to use more observer or objective measures for caregivers, like the IADL.

There are clear benefits of moving toward more active use of PRO measures in clinical practice. We think PRO measures better capture symptoms related to quality of survival as experienced by patients, and assessment may facilitate communication between parties. In addition, active involvement of patients and caregivers is likely to facilitate learning, empowerment, and self-management in addition to communication. This is important on individual level, but also, aggregated research data are important to better guide direction for future symptom management and research. Even though item banks and CATs may choose questions more relevant to the patient, what helps the patient is presumably not the measurement itself but how we understand and respond to the patients' results. If we want to create better health outcomes it is important that we understand the meaning of the symptoms for the individual. The most common symptom might not always be the most severe. Complexity of the cause of symptoms and distress in patients with high-grade glioma also make it difficult to evaluate supportive and treatment effects. One obstacle is the lack of evidence to support many symptom-based interventions, making it challenging for health care professionals to provide recommendations.²⁰ Still, to see a PRO measure as primary outcome in clinical trials in patients with high-grade gliomas is exceedingly rare.

New technical solutions enable remote data collection, sharing data in real-time, notifications to health care team when needed, and integrating the results into the electronic health record. With the new technical solutions, the use of PROs may be a structured way to both measure, document, and communicate to improve the patient's health outcome and survivorship care. Today PRO measures, through a questionnaire, are often completed before an appointment with health care providers. More flexibility in the use of PRO measures might encourage patients to also report in-between visits, for example, patients or caregivers can document symptoms like side effects from treatment or seizures when it actually happens. However, to achieve clinical integration, first we need to find ways to share or visualize the results from PRO measures in a way patients, caregivers, and health care professionals can understand and respond to the results when needed.

Conclusion

Outcome measures are complex in patients with high-grade glioma. Efforts are being made with more refined and more holistic use of different COAs, including PRO measures in neuro-oncology. For clinical research, PRO measures need to be used together with other clinical outcome measures rather than replacing traditional outcome measures. Moving to more use of PRO measures in survivorship care has potential to improve patient-caregiver-health care team communication, symptom management, and quality of care. Implementing PROs in survivorship care should also involve caregivers and a routine to act on the results. We need to learn more about collecting and visualizing results and responding to PROs.

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Disclosure

The authors report no conflicts of interest in this work.

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