ORIGINAL ARTICLE

Development of a Concise QOL Questionnaire for Brain Tumor Patients

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ABSTRACT: ***Background:*** The purpose of this study was to develop and validate a self-administered questionnaire to measure the health-related quality of life (QOL) of patients with brain cancer. We wanted to assess both core and disease-specific concerns in a single, easy-to-use instrument, thus promoting concision and clinical utility. The questionnaire departs from its predecessors in that it was designed for- and validated among French speaking Canadians. ***Methods:*** A focus group of health professionals was used to develop items for the questionnaire, which was later validated with 105 patients suffering from brain cancer. The underlying structure of the questionnaire was investigated using principal component analysis and confirmed using a principal factor analysis. ***Results:*** The final version of the questionnaire contains 30 items. Seven multi-item scales, tapping into distinct dimensions of QOL, were uncovered (i.e., functional well-being, symptom severity/fear of death, social support/acceptance of disease, autonomy in personal care, digestive symptomatology, neurocognitive function, and pain). Assessment of reliability revealed elevated internal consistency for each of the seven scales (Cronbach coefficient alpha ≥.65), whereas known-groups validity (anchor-based approach) revealed that the different dimensions uniquely discriminated between patients with different functional levels (Karnofsky Performance Scores) and clinical status (exposure to neurosurgery, radiotherapy, and use of chemotherapy and anticonvulsants). ***Conclusion:*** Our QOL questionnaire, the Sherbrooke Neuro-Oncology Assessment Scale, or SNAS, taps into both core and disease-specific issues relevant to neuro-oncology patients. It has good validity and reliability, and clearly reflects the multidimensional nature of QOL. Depending on the research focus, it may be used in clinical trials to track the impact of disease and/or treatment on satisfaction, functional status, and general well-being.

RÉSUMÉ: Élaboration et validation d'un questionnaire sur la QDV pour les patients atteints de tumeurs cérébrales. ***Contexte :*** Le but de cette étude était d'élaborer et de valider un questionnaire autoadministré destiné à mesurer la qualité de vie reliée à la santé (QDV) de patients atteints de cancers du cerveau. Nous voulions évaluer les questions fondamentales et spécifiques de la maladie par un seul outil facile à utiliser, mettant l'emphase sur la concision et l'utilité clinique. Le questionnaire est différent de ses prédécesseurs du fait qu'il a été planifié pour et validé chez des Canadiens de langue française. ***Méthodes :*** Un groupe de discussion composé de professionnels de la santé a élaboré les éléments du questionnaire qui a par la suite été validé auprès de 105 patients atteints de cancers du cerveau. La structure sous-jacente a été évaluée au moyen de l'analyse en composantes principales et confirmée au moyen d'une analyse factorielle en facteurs communs. ***Résultats :*** La version finale du questionnaire contient 30 éléments. Sept échelles à plusieurs points, faisant appel à différentes dimensions de la QDV, ont été conçues (le bien-être fonctionnel, la sévérité des symptômes/la peur de la mort, le soutien social/l'acceptation de la maladie, l'autonomie pour les soins personnels, la symptomatologie digestive, la fonction neurocognitive et la douleur). L'évaluation de sa fiabilité a montré une concordance interne élevée pour chacune des sept échelles (coefficient alpha de Cronbach ≥ 0,65), alors que la validité de groupes connus (anchor-based approach) a montré que les différentes dimensions distinguaient clairement les patients qui avaient différents niveaux de fonctionnement (Échelle de Karnofsky) et statuts cliniques (qui avaient subi une chirurgie, de la radiothérapie, une chimiothérapie ou utilisaient des anticonvulsivants). ***Conclusion :*** Notre questionnaire sur la QDV, le Sherbrooke Neuro-Oncology Assessment Scale ou SNAS couvre tant les aspects fondamentaux que les aspects spécifiques de la maladie qui sont pertinents pour les patients en neuro-oncologie. Le questionnaire a une bonne validité et une bonne fiabilité et reflète clairement la nature multidimensionnelle de la QDV. Selon l'axe de la recherche, il peut être utilisé au cours d'essais cliniques pour suivre l'impact de la maladie et/ou du traitement sur la satisfaction, l'état fonctionnel et le bien-être des patients en général.

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Clinical studies in neuro-oncology typically express results using traditional outcome measures such as tumor size, toxicity effects, and of course, survival rates. Although paramount, these measures fail to fully capture the residual capacity, psychosocial health, and overall quality of life (QOL) of surviving patients. In recent years, a new emphasis has been placed on evaluating quality of life in patients, thus acknowledging the impact produced not only by the disease process, but also by different

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treatment modalities on overall well-being. As a result, cancer outcome studies now include multidimensional quality of life assessments to their list of prognostic variables[1]. A number of generic instruments currently exist which can help researchers and clinicians measure the impact of disease on physical, psychological and social well-being. Unfortunately generic instruments lack the ability to accurately assess the specific concerns raised by different patient populations, including neuro-oncology patients. One approach to this problem is to use both general QOL measures and disease-specific instruments[2]. This strategy provides a more accurate picture of the overall QOL profile of patients.

In neuro-oncology, evaluating QOL is paramount since the central nervous system is affected early in the disease process, and treatments are, unfortunately, often only palliative. Two frequently used (and often cited) QOL instruments are the European Organization for Research and Treatment of Cancer scale (EORTC[3]) and the Functional Assessment of Cancer Therapy scale (FACT[4]). Each instrument includes supplemental modules applicable to brain tumor patients (the BN20 module for the EORTC and the Br module for the FACT). In the United States, the most frequently used questionnaire is the FACT-Br, whereas the EORTC-BN20 is more frequently used in Europe and Canada[5]. As a rule, these instruments capture various aspects of QOL, including functional status, physical symptoms, social and emotional well being, global health, and cognitive function. The EORTC-BN20 and FACT-Br have been used in clinical studies with reasonable success. For example, using the EORTC-BN20, Taphoorn et al[6] found that the addition of temozolomide during and after radiotherapy for patients with newly diagnosed glioblastoma significantly improved survival without negatively affecting overall QOL. As a result, this protocol is now considered as the standard of care in the treatment of malignant astrocytic tumors.

Studies conducted with the FACT-Br reveal that neurocognitive function and QOL are closely related, but that cognitive decline occurs sooner, and predicts subsequent QOL scores in patients with brain metastases. This implies that the preservation of cognitive function may be an important short-term objective for the maintenance of elevated QOL[7]. Interestingly, a recent study conducted by Coyne et al[8] found that emotional well being (a subscale of the FACT) is not an independent predictor of survival in cancer patients. This finding does not dispute the utility of QOL research, but strongly warns against claims made to suggest that psychological states can change the organicity of malignant cancers, and impact the outcome.

Taken together, these studies demonstrate the importance of measuring QOL in clinical trials. Unfortunately, QOL is difficult to generalize since the concept is largely patient-driven and culturally biased. Ideally, different patient populations, in different cultural contexts, should be studied using QOL instruments that have been designed explicitly for them. In this pilot study we wanted to develop a QOL measure that would: (i) provide information germane to neuro-oncology patients, (ii) include items that we hypothesized as relevant, but not indexed by current questionnaires (e.g., problems with memory and impact of convulsions), and (iii) reflect the concerns expressed by patients in our particular cultural context (French Canada). We also wanted to assess general and specific dimensions of QOL in a single, easy-to-administer questionnaire. Concision was essential since we wanted an instrument that would comply with the realistic constraints placed on patients and hospital staff.

The aim of this study, therefore, was to develop and assess the psychometric properties of a new questionnaire (the Sherbrooke Neuro-Oncology Assessment Scale - or SNAS), specifically designed for patients with brain tumors. To do this we: (i) generated items using a focus group composed of health care professionals, (ii) explored the factor structure of our questionnaire by uncovering strong and stable dimensions of quality of life, (iii) assessed the internal consistency (Cronbach's coefficient alpha) of our factor-reduced questionnaire, and (iv) validated our instrument using an anchor-based validation approach. The validation process was completed by verifying if the factors identified in previous steps discriminated clearly between patients differing in clinical status, as defined by the scores obtained on the Karnofsky Performance Status scale (KPS) and by various additional clinical parameters (i.e., exposure to neurosurgery, radiotherapy, and use of chemotherapy and anticonvulsants). It is important to note that the KPS is one of the most commonly used functional measures in the neurosurgical literature[9]. It focuses on physical change and assesses ability to work, daily activities, self-care, and evidence of disease. By comparing our findings with those of the KPS, we can test our questionnaire's validity using an independent measure, or "anchor" that is considered a standard in the field (see Mackworth[10] for a similar approach). Although it might have been wise to also validate our results by comparing them to those of other QOL questionnaires (i.e., FACT-Br, and EORTC-BN20), we chose not to proceed with this option because we did not want to expose our patients to a protracted testing session. Past studies, in fact, confirm that completion rates are a particular problem during long testing sessions[11,12]. For this reason, only the KPS was used as an external (convergent) measure of QOL.

Methods

Between March and April 2007, 132 patients who were diagnosed with a malignant tumor of the central nervous system agreed to participate in our study. Patients were seen in the outpatient clinic of the neuro-oncology service of the Université de Sherbrooke's Hospital Center in Quebec, Canada. Patients filled out our quality of life questionnaire before consulting their physician. For some patients, the questionnaire was administered over the phone by a trained intern or research nurse. Twenty-seven patients chose not to participate or were unable to complete the questionnaire (owing to the presence of impaired cognitive capacities). Forty-six women and 59 men completed the questionnaire. Patient characteristics are presented in Table 1. All participants provided informed consent (in some cases the consent form was returned by mail). A KPS score was assigned by the consulting physician at the time the questionnaire was completed (or at the next visit for patients who completed the questionnaire by phone). Functional ability scores identified by the KPS vary by intervals of 10 and range from 0 (death) to 100 (no evidence of disease and full independence).When administered by health care professionals, the KPS has acceptable test-retest and inter-rater reliability and validity[13,14].

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Table 1: Demographic characteristics of brain tumor patients (N=105)

	N	Mean	Standard Deviation
Age (years)		47.4	14.5
Education (years)		12.7	3.5
Marital Status			
With spouse	74		
Single/divorced/widowed	31		
Work Status			
Working	15		
Not - due to illness	64		
Not – unrelated to illness	20		
Homemaker / student	6		
Pathological Diagnosis			
High grade gliomas*	56		
Low grade gliomas	17		
Metastatic tumors	20		
Other	12		
Hemispheric side of lesion			
Right	36		
Left	49		
Bilateral/other	20		
Surgery			
None**	9		
1	73		
>1	23		
Adjuvant therapy			
Radiation only	25		
Chemotherapy only	15		
Radiation + chemotherapy	48		
No radiation or chemotherapy	17		
Medication			
Anticonvulsants	74		
Corticosteroids	96		

* High grade gliomas include: glioblastoma multiform tumors, anaplastic astrocytomas, anaplastic oligodendrogliomas, and anaplastic oligoastrocytomas; ** Patients in the no-surgery group experience neither biopsy nor craniotomy. All nine patients in this group suffered from a primary neoplasm originating in the lung or breast, but which had metastasized to the brain. For these patients, optimal treatments could be undertaken without having to expose them to neurosurgery (including biopsy).

Item Generation

Items for the questionnaire were generated by a panel of health care specialists (neuro-oncologists, radiation oncologists, occupational therapists, social workers and nurses) who were all familiar with the life concerns usually raised by neuro-oncology patients. We chose to generate items using a panel of experts rather than through patient interviews because interactions between experts often reveal new themes and ideas not accessible during individual interviews[15]. The panel of experts generated an initial pool of over 70 items that were both general and specific to brain-cancer patients. This list was screened for conceptual redundancy and irrelevance. The final list contained 42 items. Items were rated on a 4-point Likert scale ranging from 1 (not at all) to 4 (very much). Most items asked whether patients were limited or dissatisfied in certain areas. However, some items asked about preserved abilities or positive feelings. Before scoring our questionnaire, items in the latter group were reverse scored. All items were written in French. It is important to mention that because some QOL concerns are ubiquitous, a number of items overlap with those found in other, currently available questionnaires (e.g., lack of energy, and loss of autonomy). We consider this overlap crucial since it denotes the strong face validity of our instrument. Most currently available QOL instruments, in fact, share a substantial degree of conceptual overlap and sometimes include only minor wording differences.

Data Analysis

Questionnaire items were coalesced into distinct, multi-trait scales using a principal component analysis. This analysis allowed us to measure the factorability of our questionnaire and estimate the number of factors to be extracted. Our final factor solution was confirmed using a principal factor extraction method. The internal consistency for all scales was assessed using Cronbach's coefficient α. Once strong and stable dimensions of QOL were identified, we validated our questionnaire using an anchor-based approach. This was done by conducting a series of independent t-tests using factor scale scores as dependent variables and clinical status as the independent variable (dichotomized from the various anchors). This approach is also called the known-groups method of comparison (see Aaronson et al[3], and Kan and Cusimano[16]) and allows researchers to differentiate subgroups of patients classified as a function of their clinical status. In the current study, mutually exclusive patient subgroups were determined based on KPS scores (below 80 or above 80), exposure to surgery, exposure to radiotherapy, use of chemotherapy, and use of anticonvulsant drugs.

RESULTS

Factor Analysis

Principal component extraction results revealed the presence of 13 factors with eigenvalues greater than one. However, analysis of the scree plot (eigenvalues plotted against factors) indicated the presence of only seven factors. Kaiser's measure of sampling adequacy (MSA) was sufficiently high to warrant factor analysis (MSA=0.7). In the next step, we conducted a principal factors analysis, using the following criteria to determine the adequacy of retained items: (i) saturation loadings ≥.30, and (ii) the absence of cross-loading ≥.35. After applying these criteria, 12 of the initial 42 items were excluded. To further optimize the stability and interpretability of the final factor solution, and because the factor correlation matrix contained a number of correlations greater than .32, we conducted a final principal factors analysis, exposing our seven factor solution to an oblique, promax rotation. Results for this analysis are presented in Table 2. Significant saturations vary between .31 to .96. Clustered items clearly reflect the seven factor structure of our questionnaire and indicate the presence of: (1) a functional well-being scale, (2) a symptom severity/fear of death scale, (3) a social support/acceptance of disease scale, (4) an autonomy in personal care scale, (5) a digestive symptomatology scale, (6) a neurocognitive function scale, and, (7) a pain scale. Together, the seven factors explain 52.2% of the total variance. Three of the factors are composed of only three items and one factor is composed of only two items. It is usually not recommended to have a small number of items per factor, however, since the correlation matrix (not shown) reveals that the items correlated strongly with one another (all rs>.65) and poorly with all others

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(all rs<.35), these factors are likely reliable, and were therefore retained. Table 2 also lists information on internal consistency (Coefficient α) and percentage of explained variance for each factor. Average factor scores (the average sum of each item included in a given factor) are presented in Table 2. Given the way the items were scored (i.e., reverse scoring of positive items), an increase in the factor score always indicates increased impairment and poorer QOL. Internal consistency was generally high, which justifies using the scales for subsequent group comparisons. The final version of the questionnaire is presented in Appendix A (items to be reverse scored are 5, 6, and 14-19). An adapted-to-English version is presented in Appendix B, and awaits official double-back translation and validation (to be conducted with an English speaking cohort).

Anchor-Based Validation

Depending on the clinical status variable used, important group differences in QOL were observed. Table 3 summarizes the results of the independent sample t-tests conducted with KPS, surgery, radiotherapy, chemotherapy, and anticonvulsant drug use as grouping variables. As shown in Table 3, patients with a KPS of 40-70 reported significantly poorer functional

Table 2: Saturation loadings, mean (raw score), standard deviation (SD), theoretical range [minimum-maximum], percentage of explained variance, and Cronbach coefficient α for each factor

	Factors						
Items	Functional well-being	Symptom severity/ fear of death	Social support/ acceptance of disease	Autonomy in personal care	Digestive symptomatology	Neurocognitive function	Pain
1	.58						
2	.31						
3	.77						
4	.63						
5	.66						
6	.56						
7		.40					
8		.71					
9		.38					
10		.43					
11		.50					
12		.47					
13		.96					
14			.80				
15			.53				
16			.55				
17			.71				
18			.39				
19			.46				
20				.48			
21				.90			
22				.82			
23					.67		
24					.86		
25					.37		
26						.73	
27						.62	
28						.59	
29							.85
30							.85
Mean	13.7	11.9	12.6	3.4	4.5	5.8	3.2
SD	4.3	3.8	3.5	1.2	1.7	2.3	1.7
[Min.-Max.]	[6-24]	[7-28]	[6-24]	[3-12]	[3-12]	[3-12]	[2-8]
Explained variance (%)	20.0	8.9	6.6	6.0	4.0	3.5	3.2
Alpha	.76	.75	.73	.80	.65	.71	.88

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Table 3: Differentiation of QOL scores as a function of clinical status

		Factors (mean ±SD)							
Clinical status variable	N	Factor 1 Functional well-being	Factor 2 Symptom severity/ fear of death	Factor 3 Social support/ acceptance of disease	Factor 4 Autonomy in personal care	Factor 5 Digestive symptomatology	Factor 6 Neurocognitive function	Factor 7 Pain	Total
Karnofsky Performance Scale (KPS)									
KPS 40-70	44	15.6 ± 3.4	12.1 ± 3.8	13.2 ± 3.4	3.7 ± 1.7	4.6 ± 1.7	6.2 ± 2.4	3.5 ± 1.9	63.1 ± 11.9
KPS 80-100	61	12.3 ± 4.3	11.7 ± 3.9	12.1 ± 3.6	3.1 ± 0.4	4.5 ± 1.7	5.5 ± 2.1	3.0 ± 1.6	58.1 ± 8.9
P value		**.0001**	.58	.16	**.007**	.86	.16	.14	**.02**
Neurosurgery									
No	9	15.5 ± 3.9	10.8 ± 3.6	12.0 ± 2.2	3.0 ± 0.0	4.1 ± 0.9	6.0 ± 1.7	2.2 ± 0.4	60.9 ± 9.0
Yes	96	13.5 ± 4.3	12.0 ± 3.9	12.6 ± 3.7	3.4 ± 1.2	4.6 ± 1.8	5.8 ± 2.3	3.3 ± 1.8	60.0 ± 10.5
P value		.22	.37	.65	**.001**	.44	.77	**.0001**	.84
Radiotherapy									
No	46	12.5 ± 4.5	11.8 ± 4.1	12.6 ± 3.6	3.3 ± 1.2	4.2 ± 1.6	5.2 ± 2.0	3.0 ± 1.7	57.4 ± 9.5
Yes	59	14.6 ± 4.0	12.0 ± 3.7	12.5 ± 3.6	3.4 ± 1.1	4.8 ± 1.8	6.3 ± 2.4	3.4 ± 1.8	62.2 ± 10.6
P value		**.01**	.91	.87	.49	**.04**	**.02**	.21	**.03**
Chemotherapy									
No	42	12.8 ± 5.0	12.6 ± 4.4	12.3 ± 3.5	3.4 ± 1.3	3.9 ± 1.3	5.7 ± 2.4	3.0 ± 1.5	59.5 ± 10.8
Yes	63	14.2 ± 3.7	11.4 ± 3.4	12.8 ± 3.6	3.4 ± 1.0	4.9 ± 1.8	5.9 ± 2.2	3.3 ± 1.9	60.5 ± 10.2
P value		.15	.14	.50	.92	**.004**	.71	.33	.65
Anticonvulsants									
No	31	13.9 ± 4.0	10.6 ± 3.1	12.4 ± 3.4	3.2 ± 0.6	4.4 ± 1.0	5.9 ± 2.3	2.8 ± 1.5	58.3 ± 8.9
Yes	74	13.5 ± 4.3	12.4 ± 4.0	12.6 ± 3.7	3.4 ± 1.3	4.6 ± 1.9	5.7 ± 2.2	3.4 ± 1.8	60.5 ± 10.9
P value		.70	**.03**	.75	.14	.38	.69	.11	.36

P values printed in bold indicate significant differences between groups

well being, autonomy in personal care and overall QOL than patients with a KPS score of 80-100. Patients who underwent neurosurgery experienced significantly more pain and greater loss in autonomy than did patients without neurosurgery. Likewise patients who received radiotherapy experienced poorer functional well being, increased digestive symptoms, poorer neurocognitive functioning and reduced overall QOL compared to patients not exposed to radiotherapy. Patients who received chemotherapy experienced increased digestive symptoms compared to patients who did not receive chemotherapy. Finally, patients who required anticonvulsants to control their seizures experienced more serious disease-related symptoms/greater fear of death than did patients who did not need anticonvulsants because of underlying seizures. It is important to point out that group membership served only as a proxy for our patients' overall clinical and functional status. Although, we cannot be sure whether group differences in QOL are attributable to disease severity or treatment effects, differences between groups were in the expected direction, reflecting poorer QOL in patients with more impaired clinical status (or increased treatment side-effect/toxicity).

Discussion

The purpose of the present study was to develop and validate a new QOL questionnaire tailored specifically for brain cancer patients. Although a number of generic and disease-specific instruments exist, clinicians (and researchers) do not currently have access to a single instrument that would allow them to quickly measure the most prevalent set of concerns raised by this population. We developed the SNAS, in part, to address this drawback. The final version of the SNAS includes 30 items and takes approximately ten minutes to complete. The questionnaire has a stable seven factor structure which captures specific dimensions of QOL, namely: 1) functional well-being, 2) symptom severity/fear of death, 3) social support/acceptance of disease, 4) autonomy in personal care, 5) digestive symptomatology, 6) neurocognitive function, and 7) pain. These factors are highly consistent (all Cronbach alphas ≥.65), and together, reflect the known multidimensional nature of QOL[3,4,17-19].

An anchor-based approach was used to further assess the psychometric properties of our instrument. Consistent results were obtained revealing that the SNAS was differentially responsive to criterion groups and, therefore, had acceptable

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validity. A key finding was that functional and autonomy measures of QOL (Factors 1 and 4) successfully identified patients who differed in terms of their KPS scores. Since these measures are explicitly assessed by the KPS, we can be sure that the SNAS is sensitive to functional well-being and autonomy in personal care. Furthermore, the SNAS was responsive to the side effects (e.g., toxicity) of treatment. For example, having undergone neurosurgery negatively impacted QOL by decreasing levels of autonomy and increasing pain (Factors 4 and 7). On the other hand, exposure to radiotherapy negatively affected functional, digestive and neurocognitive functions (Factors 1, 5, and 6). Chemotherapy treatments generally increased nausea and vomiting (Factor 5), whereas the use of anticonvulsants to treat the presence of seizures was associated with disease severity and fear of death (Factor 2). In terms of QOL, these findings indicate that different treatments are associated with different side-effect profiles. These unique profiles are surprisingly consistent with the distinct set of complications brought about by specific treatment modalities (see Schiff and O'Neill[20]), further confirming the sensitivity of our instrument.

It is important to point out that our questionnaire was administered relatively early in the disease process of patients. As a result, the immediate side-effects of treatment likely had a greater influence on QOL than the positive mid- to long-term effects of treatment on pathology. This interpretation is entirely consistent with our observations and suggests that a longitudinal approach is needed to better appreciate the benefits of treatment on QOL. A longitudinal design would also allow us to measure our questionnaire's sensitivity to change. Responsiveness to change is an important component of any psychometrically sound instrument and will be explored in our follow-up investigations.

An interesting finding was that clinical status had no effect on social support/acceptance of disease (Factor 3). This suggests that the extent of psychosocial help and the ability to live with a life-threatening disease is not related to overt clinical variables. Instead, the extent of social support obtained by loved ones and, in particular, the capacity to accept terminal-illness may be explained by intangible factors, such as emotional adjustment. In agreement with this hypothesis, a recent paper by Ray et al[21] found that patients with advanced cancer who are peacefully aware of their condition have lower rates of psychological distress. A follow-up study by the same group also found that spirituality promoted equanimity in the face of terminal-illness[22]. As suggested by the authors, this is reminiscent of Erikson's[23] work on mortality and end-of-life issues, where the approach to death is met with either ego integrity or despair depending on personality and psychological well-being. Social support/acceptance of disease, therefore, is an important component of QOL despite the fact that it does not distinguish patients who differ on functional or clinical status.

Together, these results lend considerable support to the clinical validity of the SNAS. Nevertheless, one should be aware of the limitations of the current research. One possible limitation is the relatively small number of patients (N=105) included in this pilot study. A sample size of approximately 100 subjects is considered a minimum when conducting multivariate analyses (i.e., factor analysis). More subjects would certainly promote greater reliability and reduce the risk of interpreting empirically overfitted results. Despite this limitation, a number of research teams have published excellent validation studies using comparable sample sizes[2,24,25]. It is important to remember that large patient samples (i.e, 500 or more) are difficult to obtain in neuro-oncology research, owing, in large part to the low incidence of brain cancer (< 0.001%)[20]. The likelihood of recruiting a large number of patients also decreases when research trials do not have a multicentric focus.

Our small sample also prevented us from conducting separate analyses as a function of disease state or histological subtype. Histological subtypes are particularly important to consider when studying prognostic or survival factors, and may also reveal interesting information germane to QOL. For example Osoba et al[26] found that patients with recurrent anaplastic astrocytomas and patients with glioblastoma multiform tumors generally report similar levels of QOL. However, the presence of pain and visual problems is reported more frequently in glioblastoma multiform patients. Such symptoms are often amenable to treatment, emphasizing the importance of conducting a comprehensive evaluation of QOL and paying attention to histology. Along the same line, it may also be important to dissociate brain metastases from primary tumors. Although neurological symptoms, fatigue, and treatment side-effects may be similar between patients with primary and metastatic tumors, systemic-symptoms, and the presence of multiple foyers may be more problematic for patients with brain metastases. Increased disease burden may also explain why patients with advanced metastatic cancers typically respond with QOL scores that are similar to those obtained by patients with high-grade gliomas (see Osoba et al[26]). Future research is necessary to validate the inclusion of patients with metastatic lesions in brain-cancer studies.

Despite the limitations noted above, the SNAS is the first QOL questionnaire specifically developed to assess both general and disease-specific concerns in a single easy-to-administer version. Having a single instrument avoids having to use a modular approach to assessment. This benefits patients since they do not have to complete a large number of questions spread over two or more instruments. A short but valid self-report questionnaire such as ours provides an obvious clinical advantage. In fact, long testing sessions are increasingly being recognized as a challenge for terminally-ill patients, especially when concentration and fatigue are a presenting problem. The importance of brevity during testing has even pushed the EORTC quality of life group to develop a new shorter version of their widely-used core QOL questionnaire (i.e., their original QLQ-C30). The EORTC's new, shorter instrument, the QLQ-C15, is an extremely promising tool and its conception demonstrates that even a short questionnaire (i.e., 15 questions) can adequately measures global quality of life issues[19]. The QLQ-C15, however, is not sensitive to disease-specific concerns (nor was it intended to be) and must be supplemented by items or modules measuring missing issues. The SNAS, on the other hand, was intended to be both brief and sensitive to the principal QOL concerns expressed by brain cancer patients.

To our knowledge, the SNAS is also the first QOL questionnaire originally designed in French. It is not the translated version of an original English instrument, and so, does

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not suffer from semantic ambiguity, a rare but possible consequence of the translation process. As far we know, it is also the first QOL questionnaire to have been validated among French Canadians. As such it provides valid Canadian content, applicable to our unique cultural context.

In summary, the SNAS is a short, multidimensional QOL questionnaire with strong psychometric properties. It provides a comprehensive evaluation of functional status and of its influence on various dimensions of QOL. Until therapies that markedly improve the disease process can be found, QOL measures will continue to be a critical component of health care in neuro-oncology. In this manner, the SNAS provides a tumor-specific instrument that is substantially different from currently available questionnaires. The underlying format of the SNAS (i.e., a single instrument that measures both core and disease specific issues) should allow health care professionals to obtain a rapid yet precise picture of the QOL profile experienced by neuro-oncology patients.

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See Appendix A and B on following pages

Appendix A Original French version of the Sherbrooke Neuro-oncology Assessment Scale (SNAS)

QUESTIONNAIRE DE QUALITÉ DE VIE CHEZ LE PATIENT ATTEINT DE NÉOPLASIE CÉRÉBRALE

Nom: _____

Date: _____

Les questions suivantes traitent de la qualité de vie des patients atteints de la même maladie que vous. Lisez chaque énoncé, puis encerclez le chiffre approprié, à la droite de l'énoncé. Il n'y a pas de bonnes ou de mauvaises réponses.

		Aucunement	Un peu	Beaucoup	Énormément
1.	Depuis le début de votre maladie, avez-vous eu un manque d'énergie au point de vous allonger ou de vous asseoir pour de longues périodes durant la journée?	1	2	3	4
2.	Avez-vous de la difficulté à dormir?	1	2	3	4
3.	Avez-vous de la difficulté à exécuter une tâche qui nécessite un effort physique tel que porter un sac d'épicerie lourd ou une valise?	1	2	3	4
4.	Votre maladie vous empêche-t-elle de fonctionner normalement lors de vos loisirs ou de votre travail?	1	2	3	4
5.	Avez-vous l'impression d'être autonome?	1	2	3	4
6.	Êtes-vous capable de conduire votre véhicule?	1	2	3	4
7.	Avez-vous eu des convulsions?	1	2	3	4
8.	Avez-vous peur d'avoir des convulsions?	1	2	3	4
9.	Est-ce que la peur de convulser vous empêche de faire certaines activités, tel qu'aller à l'épicerie ou au restaurant?	1	2	3	4
10.	Est-ce que les effets secondaires de votre traitement vous incommodent?	1	2	3	4
11.	Avez-vous ressenti de la tristesse?	1	2	3	4
12.	Avez-vous perdu espoir dans la lutte contre votre maladie?	1	2	3	4
13.	Est-ce que la mort vous inquiète?	1	2	3	4
14.	Avez-vous du soutien de la part de votre famille? (la famille inclue parents, frères et soeurs)	1	2	3	4
15.	Avez-vous du soutien de vos amis?	1	2	3	4
16.	Votre famille accepte-elle votre maladie?	1	2	3	4
17.	Avez-vous la possibilité de discuter de votre maladie avec votre famille?	1	2	3	4
18.	Avez-vous appris à vivre avec votre condition de santé?	1	2	3	4
19.	Êtes-vous capable d'apprécier la vie dans le contexte de votre maladie?	1	2	3	4
20.	Avez-vous besoin d'aide pour vous alimenter?	1	2	3	4
21.	Avez-vous besoin d'aide pour vous laver?	1	2	3	4
22.	Avez-vous besoin d'aide pour utiliser la toilette?	1	2	3	4
23.	Avez-vous présenté des maux de cœur?	1	2	3	4
24.	Avez-vous présenté des vomissements?	1	2	3	4
25.	Avez-vous présenté de la constipation?	1	2	3	4
26.	Avez-vous de la difficulté à vous concentrer?	1	2	3	4
27.	Avez-vous de la difficulté avec votre mémoire?	1	2	3	4
28.	Avez-vous présenté une baisse de la vue?	1	2	3	4
29.	En excluant la douleur causée par l'opération, avez-vous ressenti de la douleur depuis le début de votre maladie?	1	2	3	4
30.	La douleur limite-telle vos activités?	1	2	3	4

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Appendix B Adapted-to-English version of the Sherbrooke Neuro-oncology Assessment Scale (SNAS)

SHERBROOKE NEURO-ONCOLOGY ASSESSMENT SCALE (SNAS)

Name: _____

Date: _____

Listed below are a number of questions concerning quality of life issues that affect patients with the same illness as yours. Read each question and circle the number that best applies to you. There are no right or wrong answers.

		Not at all	A little	Quite a bit	Very much
1.	Since the start of your illness have you felt a lack of energy, forcing you to lie-down or sit for prolonged periods of time?	1	2	3	4
2.	Do you have a hard time sleeping?	1	2	3	4
3.	Do you have a hard time doing strenuous activities, such as carrying grocery bags or lifting a suitcase?	1	2	3	4
4.	Does your illness limit your recreational or professional activities?	1	2	3	4
5.	Do you feel you live autonomously?	1	2	3	4
6.	Can you still drive a car?	1	2	3	4
7.	Have you experienced convulsions?	1	2	3	4
8.	Do you fear having convulsions?	1	2	3	4
9.	Does the fear of having a convulsion prevent you from carrying out certain activities, such as grocery shopping or going to the restaurant?	1	2	3	4
10.	Do the side-effects of your treatment bother you?	1	2	3	4
11.	Have you felt sad?	1	2	3	4
12.	Have you lost hope in the fight against your illness?	1	2	3	4
13.	Do you worry about death?	1	2	3	4
14.	Do you have support from family? (family includes parents brothers and sisters)	1	2	3	4
15.	Do you have support from friends?	1	2	3	4
16.	Does your family accept your illness?	1	2	3	4
17.	Have you had the chance to talk about your illness with your family?	1	2	3	4
18.	Have you learned to live with your illness?	1	2	3	4
19.	Can you enjoy life in spite of your medical condition?	1	2	3	4
20.	Do you need help with eating?	1	2	3	4
21.	Do you need help with washing?	1	2	3	4
22.	Do you need help when using the toilet?	1	2	3	4
23.	Have you experienced nausea?	1	2	3	4
24.	Have you experienced vomiting?	1	2	3	4
25.	Have you experienced constipation?	1	2	3	4
26.	Do you have trouble concentrating?	1	2	3	4
27.	Have you experienced trouble with your memory?	1	2	3	4
28.	Have you experienced trouble with your eyesight?	1	2	3	4
29.	Excluding the pain caused by neurosurgery, have you experienced any pain since the start of your illness?	1	2	3	4
30.	Does pain limit your activities?	1	2	3	4

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