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Psychometric evaluation of the Caregiver Needs Screen in neuro-oncology family caregivers

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Abstract

Background and Purpose: The informal care demands of primary malignant brain tumor (PMBT) patients include unique issues associated with neurological and cognitive symptoms. Existing caregiver needs questionnaires do not include these disease-specific symptoms, which are particularly distressing. Therefore, we have developed the neuro-oncology Caregiver Needs Screen (CNS) and evaluated its psychometric properties.

Methods: The 32-item instrument was developed based on PMBT caregiver interviews (N=109) and expert review. The CNS was tested along measures of depression, anxiety, burden and mastery in 122 PMBT caregivers. Principal components analysis was used to examine item properties and internal structure. Internal consistency reliability and construct validity were assessed.

Results: Six subscales were identified with internal consistency ranging between α=.653 and α=.857. Convergent validity was verified by moderate/high correlations between measures of caregiver wellbeing and CNS scale scores.

Conclusions: Findings provide preliminary evidence of reliability and validity for the CNS. This instrument can be useful when assessing caregivers’ needs for supportive care.

Keywords: caregiver needs; screening instrument; psychometric evaluation; neuro-oncology; brain tumor.

Introduction

In adults, primary malignant brain tumors (PMBTs) are a rare form of cancer, with an age-adjusted incidence rate of 8.7 per 100,000 (Ostrom et al., 2015). With limited effective treatment options available, PMBTs are often rapidly progressive and prognosis remains poor (Omuro & DeAngelis, 2013). Moreover, patients suffer from various disease- and treatment-specific symptoms that impair their physical, emotional and neuropsychological functioning (Mukand, Blackinton, Crincoli, Lee, & Santos, 2001; Taphoorn & Klein, 2004). It is widely acknowledged that these symptoms set this patient group apart from the general cancer patient population and can increase the burden placed on the family caregiver (McConigley, Halkett, Lobb, & Nowak, 2010; Schubart, Kinzie, & Farace, 2008; Sherwood et al., 2008). Indeed, over half of family caregivers in neuro-oncology experience significant levels of psychological distress (Choi et al., 2012; Trad et al., 2015), and providing informal care can have negative consequences for caregivers' physical health (Schulz & Sherwood, 2008; Sherwood et al., 2016).

Maintaining caregiver wellbeing is vital not only to prevent the onset of health issues in family caregivers and to protect society's access to the largest group of health care providers who operate at no financial cost, but also because evidence is emerging that caregiver wellbeing is associated with patient health and functioning. In cancer in general, poor caregiver mental health is associated with poor perceived quality of care (Litzelman, Kent, Mollica, & Rowland, 2016). Moreover, higher caregiver demand burden was found to be related to poorer survival in advanced cancer patients (Dionne - Odom et al., 2016). In neuro-oncology in particular, caregivers' feelings of being in control of the care situation (i.e. their level of caregiver mastery) has been associated with glioblastoma patient survival (Boele et al., 2017).

Background and Purpose

Neuro-oncology caregivers' level of unmet needs is associated with psychological distress (Halkett et al., 2018). An important first step in the development of any programme to improve family caregivers' wellbeing is to identify the needs and issues that are present. Questionnaires to identify caregiver needs have been developed for cancer populations in general (Campbell et al., 2014; Girgis, Lambert, & Lecathelinais, 2011; Kim, Kashy, Spillers, & Evans, 2010), but none of these include the disease-specific difficulties that arise when taking care of a patient with a brain tumor. Questionnaires focused on brain tumor patients' symptoms (Armstrong et al., 2006; Taphoorn et al., 2010; Weitzner et al., 1995) on the other hand, are not intended for use by caregivers. These symptoms in particular have been identified as increasing caregiver distress (Sherwood et al., 2004), so it is vital that these are included in caregiver measures. Based on qualitative analysis of 109 caregiver interviews to assure adequate representation of the disease specific issues caregivers may experience, we have therefore developed a neuro-oncology Caregiver Needs Screen. This is a measure of distress related to specific unmet needs in the caregiver environment, and as such can be used to provide information on areas in which further assessment or intervention is required. In this article, the development and psychometric testing of this instrument are described.

Methods

Instrument development

The Caregiver Needs Screen was developed in two phases: 1) item generation and reduction; 2) reliability and validity testing, see Figure 1.

Phase one. In addition to quantitative behavioral and biological data, in-depth semi-structured interviews with 109 family caregivers of patients with a PMBT were performed as part of a longitudinal, descriptive study on the mind-body interactions in neuro-oncology caregivers (NIH R01 CA118711). One qualitative interview per caregiver was performed between baseline and 12 months post-initial diagnosis. These interviews were designed to capture the caregiving experience across the disease trajectory and to determine areas of need for future interventions. Participants had to be the primary nonprofessional, non-paid caregiver as identified by the patient (>21 years old; diagnosed with a PMBT as verified by pathology); > 21 years of age; able to read and speak English; and not currently taking care of anyone else other than children under 21. After providing written informed consent, individual interviews lasting approximately 64 minutes were performed either in person or over the telephone. Open-ended questions, such as '*What are the hardest things to deal with in caring for X (care recipient's name)*' were used. All interviews were transcribed verbatim by a research assistant, and every 10th interview was validated by the PI. Conventional content analysis (Hsieh & Shannon, 2005) revealed 39 general areas of concern for family caregivers. An item pool was generated based on these themes, where necessary breaking down themes into subthemes or collapsing items that overlapped based on expert opinion. A 0-10 scale for distress resulting from specific needs was chosen as it provides information on the extent to which further assessment or intervention is needed. Low levels of distress resulting from a need suggest that either the need is not urgent, or that the caregiver has the necessary resources to mitigate the distress on their own. High levels of distress should trigger further assessment. The final item pool (34 items) was reviewed by experts in caregiving, neurosurgery, neuro-oncology, and methodology. A further 5 items were added/collapsed after this, resulting in a questionnaire titled the Caregiver Needs Screen containing 32 items each representing a commonly occurring issue for caregivers.

Phase two. As part of another study a large sample of family caregivers was recruited (see below). Among other measures, caregivers were asked to complete the Caregiver Needs Screen in order to evaluate the reliability and validity of the instrument (see below).

Participants and procedure

Data presented here were collected as part of a randomized clinical trial that was aimed at evaluating the effectiveness of an internet-based, nurse guided supportive intervention program for family caregivers in neuro-oncology (NIH R01 NR013170). To evaluate the psychometric properties of the tool, only baseline data were used, which were collected before randomization to a treatment condition took place. Inclusion criteria were similar to those described above for study R01 CA118711. After obtaining consent for study participation, participating caregivers completed online questionnaires presented in a fixed order as part of the baseline assessment.

Outcome Measures

The Caregiver Needs Screen (CNS; see Supplementary materials) was presented online along other measures of caregiver emotional wellbeing:

Depressive symptoms. The 10-item shortened version of the Center for Epidemiological Studies – Depression scale (CES-D) was used to measure caregivers' depressive symptoms (Andresen, Malmgren, Carter, & Patrick, 1994; Radloff, 1977). Caregivers rate their experience of depressive symptoms in the past week on a 4-point scale, ranging from 0 ('rarely or none of the time (<1 day)') to 3 ('all of the time (5-7 days)') with higher scores representing higher levels of depression.

Anxiety. The shortened 3-item version of the Profile of Mood States – Anxiety (POMS-A) questionnaire was used to assess anxiety (Usala & Hertzog, 1989). Anxious feelings (being on edge, nervous, or tense) were rated on a 5-point scale, higher scores indicate more anxiety.

Caregiver Burden. The Caregiver Reaction Assessment (Given et al., 1992) was used to indicate the experienced level of caregiver burden regarding the impact of providing care on 1) caregivers' self-esteem; 2) caregivers' feelings of abandonment; and 3) disruptions in caregivers' schedules. Higher scores indicate a greater level of burden, except for the self-esteem subscale where higher scores represents better self-esteem.

Caregiver Mastery. The 8-item Mastery Scale (Pearlin & Schooler, 1978) was used to assess caregivers' perception of control over the care situation. Item scores range from 1 (‘strongly disagree’) to 4 (‘strongly agree’), with higher total scores indicating higher levels of perceived control.

Statistical Analysis

Data analyses were performed using SAS (SAS, Inc., Cary, NC) and Statistical Packages for the Social Sciences (SPSS, v.24) software. Descriptive statistics were used to describe the study sample in terms of demographic and clinical characteristics. Item distributions were examined using graphical methods such as histograms and boxplots.

Next, principal component analysis (PCA) was performed to examine the underlying internal structure of the CNS. The recommended sample size to conduct a PCA is 100 or more (MacCallum, Widaman, Zhang, & Hong, 1999); therefore, the sample size of 122 was sufficient for the analysis. The polychoric correlation was selected to construct the item-correlation matrix as it is recommended for non-normally distributed ordinal data (Baglin, 2014; Olsson, 1979). The PCA extraction method was selected because it allows the researcher to examine the total variance explained as a measure of model fit and is recommended for item reduction (Costello & Osborne, 2005). Both orthogonal (Varimax) and oblique (Promax) rotations were performed, however, only the Promax solutions are reported as this method considers the correlation among components (Darton, 1980). In addition to the total variance explained, the scree plot, eigenvalues, and component loadings were assessed to verify the factor structure of the CNS. Items with component loadings > .4 were retained to form factors, and items with loadings >.4 on more than one factor were flagged as cross-loaders. Content experts were then consulted to consider the factors and to make suggestions for the final factor structure.

Once the factor structure was examined by the content experts, Cronbach’s alpha coefficients were calculated as an indicator of internal consistency, with optimal values lying between .7 and .9 (Bernstein & Nunnally, 1994). If items cross-loaded on multiple scales, analyses were repeated both with and without the item in question, and allocated to the scale which showed the best fit (largest increase in Cronbach's alpha). Subscale scores were formed by summing across items of each factor. The frequency of the lowest and highest scores for each subscale were calculated as an indicator of floor and ceiling effects (>15% of participants having the minimum or maximum score, respectively). When floor and ceiling effects occur, discrimination among those scoring low or high, respectively, becomes impossible, rendering detection of changes over time more difficult. Means and standard deviations were generated and histograms were created to illustrate subscale score distributions.

As a measure of construct validity, Pearson correlation coefficients were generated to determine relationships between the subscales of the Caregiver Needs Screen and other measures of caregiver wellbeing (depression; anxiety, caregiver burden; mastery). For highly related constructs, moderate to strong associations (r~ +/- 0.40 to 0.80) between these determinants and the factors of the CNS were expected (Nunnally JC, 1994).

Results

Participants

A total of 182 were invited to participate in the study, of which 122 agreed to participate and completed informed consent procedures. The main reasons for non-participation were feeling overwhelmed and lack of a caregiver. In total, data from 122 caregivers were included in the analysis. The average age of participants was 52.9 years (SD=11.61), and the majority of the caregivers were women (63.1%). Most (73%) were in a spousal relationship with the patient and most were college graduates (60%). Three quarters (75%) of caregivers were employed full time. Patients' diagnoses included glioblastoma (56%), astrocytoma grade I-III (19%), and other primary malignant (25%).

Factor structure

Initially, an eight-factor structure was produced using PCA. Once the research team consulted with content experts, a six-factor structure was suggested based on clinical and conceptual judgment. Thus, the PCA was rerun forcing a six-factor structure. The research team and content experts met again to review the results of the six-factor structure. Seven of the 32 items were moved from the factor on which they had the highest loading to a factor that made more conceptual sense.

Thirty-one items of the 32-item CNS were found to represent six underlying constructs, with factors labeled as: 1) neurological symptoms; 2) oncologic symptoms; 3) personal communication (friends, family); 4) communicating with health care providers; 5) resources; and 6) caregiver health. The scree plot supported these factors with eigenvalues greater than one. The 6-factor structure explained 75.8% of the variance. The matrix of factor loadings is displayed in Table 1.

Two items did not load on any factor at the threshold of > .4: item 13 ('your loved one's nutrition') and item 29 ('skin changes'). These items were dropped from the scale, resulting in a 30 item, 6 factor CNS scale.

Reliability (internal consistency)

One item (12: 'changes in your loved one's disease status') initially loaded on factor 1 (neurologic symptoms) but cross-loaded on factor 4 (communicating with health care providers). Based on content, the item could fit in either scale; therefore, item 12 was included in a reliability analysis of factor 1 (neurological symptoms) and factor 4. Adding item 12 to factor 4 did not increase alpha considerably (α =.83 (without) to .86 (with); therefore the item was left in factor 1. Internal consistencies are displayed in Table 2.

Floor and ceiling effects

One floor effect for the subscale 'personal communication' was found; 26.1% of participants had a minimum score. With percentages of minimum and maximum scores ranging from 0.8%

to 9.2% in other subscales, no other floor or ceiling effects were detected. The scale score distributions are displayed in Figure 2.

Convergent validity

We found moderate to strong correlations between the different subscales of the CNS and the CES-D ranging from r =.43 for ‘personal communication’ to r =.67 for ‘neurologic symptoms’, and the POMS-A ranging from r =.41 for ‘communicating with health care providers’ to r =.63 for ‘caregiver health’. These results indicate scores on the CNS subscales were related to increased feelings of depression and anxiety in caregivers.

The subscale ‘neurologic symptoms’ furthermore showed correlations of moderate strength with caregiver burden (schedule disruptions; r =.47) and mastery (r =-.47). When caregivers rated their distress related to patients’ neurologic symptoms higher, they also experienced more burden due to schedule disruptions and a worse feeling of being in control of the care situation (mastery). The subscale ‘caregiver health’ was negatively associated with mastery (r =-.42), indicating that worse caregiver health is related to worse feelings of mastery. Various weaker correlations have been found for other subscales and measures of caregiver burden and mastery, see Table 3.

Discussion

The purpose of this study was to develop a screening instrument to measure neuro-oncology caregivers’ needs, and to provide preliminary evidence of its psychometric properties. We established that the resulting 30-item Caregiver Needs Screen has acceptable internal consistency reliability and evidence of convergent validity. The constructs measured by the CNS subscales were related to depression and anxiety scores in particular, with moderate to strong correlations across all subscales. This confirmed our expectations, as the CNS assesses the level of distress caregivers experience as a result of a range of issues; a concept that is highly related to both depression and anxiety (Mitchell, 2007; Ridner, 2004). Indeed, the three concepts are often used interchangeably in the literature e.g., (Choi et al., 2012; Donker, Griffiths, Cuijpers, & Christensen, 2009; Pilkonis et al., 2011). The CNS provides a novel assessment of the link between providing care, and the development of depression and anxiety. This is especially relevant in light of a recent publication showing a consistently high correlation between unmet needs and psychological distress in caregivers of high-grade glioma patients over a six month period (Halkett et al., 2018). Specific needs-related acute distress that remains unresolved, can lead to more chronic mood disorders such as anxiety and depression.

The correlations with measures of caregiver burden and mastery were generally weaker, which also follows expectations as these constructs are related, but conceptually different. Moderate correlations were found between the subscales ‘neurologic symptoms’ and ‘caregiver health’ and mastery, as well as between ‘neurologic symptoms’ and caregiver burden due to schedule disruptions. These associations are not surprising, as neurologic symptoms, including seizures and changes in patients’ thinking and behavior, can be particularly difficult for caregivers to cope with (Madsen & Poulsen, 2011; Sherwood et al., 2006). This could lead to an increased burden and a decreased sense of mastery. In a similar sample of family caregivers we previously found that PMBT patients’ problem behaviors were related to lower levels of caregiver mastery, which in turn was associated with increased depressive symptoms in caregivers (Sherwood et al., 2007). This underscores the complex interactions between these related, but distinct, indicators of caregiver emotional health – and emphasizes the satisfactory convergent validity of the CNS.

Although we were unable to assess test-retest reliability using only the baseline assessment from our randomized controlled trial, we were able to check for floor and ceiling effects and found these to be absent for all scales except ‘personal communication’, where a floor effect was found. Detecting a decrease in distress due to issues related with personal communication, could therefore be difficult. However, for all other subscales our results suggest that the CNS is capable of detecting changes over time – an essential feature of any needs assessment tool.

Despite the promising results of this preliminary psychometric evaluation of the CNS, this study also has its limitations. The majority of our participants were women (63%). Although this represents the general family caregiver population (Family Caregiver Alliance, 2012; Pinquart & Sörensen, 2006), with women reporting more caregiving hours and more caregiving tasks (Pinquart & Sörensen, 2006), a more equal gender distribution might have led to slightly different findings. Although we tested the CNS in a large sample of caregivers of patients with PMBT, further investigation of its psychometric properties in samples which include caregivers of patients with non-malignant or secondary brain tumours is advised. Moreover, the ‘personal communication’ scale is not performing as well as the other scales. Because caregivers highlighted needs related to personal communication with very high frequency, this scale was nevertheless retained. Finally, as mentioned above, we could not assess all aspects of validity and reliability. Instrument validation is often considered to be an ongoing process and future studies that include this measure could provide further more confirmatory information on the psychometric properties of the CNS.

Relevance to nursing practice and research

To summarize, the current investigation provided evidence for the reliability and validity of the CNS as a 30-item measure of neuro-oncology caregiver distress resulting from unmet needs. Intended as a screening questionnaire, it is brief and can be completed in 5-7 minutes. During focus groups after using the tool in an intervention trial, we received no complaints regarding its length, however there is further potential to develop a short-form for use in busy clinical routine. Identifying needs and issues is a vital part of any attempt to improve family caregivers’ wellbeing. Existing caregiver needs questionnaires developed for cancer populations do not include the neurological and cognitive issues that are associated with taking care of a PMBT patient. The CNS is the first needs screening instrument to have been developed for this population and can prove valuable in a research setting, as well as in clinical practice when aiming to improve family caregivers’ wellbeing. Protecting family caregivers’ wellbeing can prevent emotional and physical health issues in caregivers, and has the potential to prove beneficial for patient health as well.

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Figure 1. Flowchart of the questionnaire development and validation process.

Table 1. Pattern of factor loadings.

Item	C1	C2	C3	C4	C5	C6	CMM
Changes in relationship	.714						.874
Changes in disease status	.523						.725
Changes in thinking	.900						.856
Emotions	.818						.844
Difficulty speaking	.800						.765
Muscle weakness	.753						.829
Changes in vision	.561						.679
Safety issues	.740						.732
Numbness/tingling	.436						.641
Headaches/pain	.006*						.857
Seizures	.281*						.614
Financial issues		.825					.786
Employment concerns		.887					.780
Obtaining resources		.837					.677
Spiritual issues		.722					.678
Communicating/family			.645				.821
Talking with children			.853				.826
Nausea and vomiting				.754			.930
Changes in appearance				.859			.710
Shortness of breath				.756			.830
Blood clots/bleeding				.042*			.512
Sleep problems				.051*			.856

Fatigue				.057*			.900
Changes in appetite				.023*			.849
Bowel problems				.711			.621
Communicate providers					.893		.725
Manage medications					.669		.657
Treatment options					.719		.768
Caregiver emotion health						.437	.790
Caregiver physical health						.467	.470
%Variance Explained (Total= 75.8)	18.4	6.2	7.6	11.6	26.5	5.5	

*Item moved from original factor loading due to content expert input

CMM= Communalities

Note: ‘Skin changes’ and ‘Your loved one’s nutrition’ did not load on any factor

Table 2. Internal consistencies of proposed CNS subscales (N=122).

Factor	No. of items	Cronbach's alpha
1. Neurologic symptoms	11	.857
2. Oncologic symptoms	8	.771
3. Personal communication	2	.653
4. Communicating with health care providers[a]	3	.826
5. Resources	4	.812
6. Caregiver health	2	.750

[a]without item 12

Figure 2. Scale score distributions with normal curves.

Top to bottom, left to right: Neurologic Symptoms (M=33.86, sd=25.20, N=117); Oncologic Symptoms (M=15.47, sd=13.27, N=116); Personal Communication (M=4.25, sd=4.62, N=119); Communicating with Health Care Providers (M=8.28, sd=7.83, N=117); Resources (M=11.48, sd=9.89, N=118); Caregiver Health (M=7.47, sd=5.20, N=120).

Table 3. Correlations between subscales of the Caregiver Needs Screen and other measures of caregiver wellbeing.

Factor	CES-D	POMS-A	Burden: self-esteem	Burden: abandonment	Burden: schedule disruptions	Mastery
1: Neurologic symptoms	.670***	.609***	-.306**	.266**	.465***	-.472***
2: Oncologic symptoms	.540***	.455***	-.171	.161	.329	-.241**
3: Personal communication	.428***	.409***	-.145	.296**	.153	-.252**
4: Communicating with health care providers	.502***	.407***	-.188*	.227*	.256**	-.290**
5: Resources	.569***	.506***	-.216*	.297**	.252**	-.346***
6: Caregiver health	.636***	.628***	-.337***	.272**	.286**	-.421***

*=p<.05; **=p<.01; ***=p<.001.

Abbreviations: CES-D: Center for Epidemiological Studies – Depression scale; POMS-A: Profile of Mood States – Anxiety

Supplementary material: The Caregiver Needs Screen.

Caregiver Needs Screen

Listed below are a number of issues that caregivers may face as they help care for a loved one with a brain tumor. Thinking about the issues you faced during the past 2 weeks, please select the number that best describes how distressed you have been about that issue where **0 = not at all distressed and 10 = as distressed as you can imagine.** If you did not experience that issue, please select 0.

The following questions refer to issues related to taking care of your own needs.

In the **past 2 weeks**, how distressed have you been about….

1. Maintaining Your Emotional Health as a Caregiver	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
2. Maintaining Your Physical Health as a Caregiver	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

0 = “not at all distressed” **and** **10 = “as distressed as I can imagine”**

The following questions refer to issues related to communication.

In the **past 2 weeks**, how distressed have you been about ….

3. Communicating with Health Care Providers	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
4. Communicating with Family and Friends	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
5. Talking with Children or Grandchildren	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

0 = “not at all distressed” and 10 = “as distressed as I can imagine”

The following questions refer to issues related to obtaining needed information and services.

In the **past 2 weeks**, how distressed have you been about ….

6. Managing your loved one’s medications and side effects	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
7. Your loved one’s treatment options	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
8. Financial, Legal, and Advanced Planning Issues	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
9. Employment Benefits, Work Related Concerns, or Insurance Issues	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

10. Finding and Obtaining Community Services and Resources	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

0 = “not at all distressed”   and   10 = “as distressed as I can imagine”

The following questions refer to general issues you may face as a caregiver.

In the **past 2 weeks**, how distressed have you been about ….

11. Changes in the Relationship with your Loved One	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
12. Changes in your loved one’s disease status	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
13. Your loved one’s nutrition	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
14. Spiritual Issues	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

0 = “not at all distressed”   and   10 = “as distressed as I can imagine”

The following questions refer to <u>issues your loved one</u> may experience as a result of cancer or treatment.

In the **past 2 weeks**, how distressed have you been about **your loved one's….**

15. Sleep Problems	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
16. Fatigue	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
17. Emotions	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
18. Changes in Thinking, Behavior, Personality	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
19. Difficulty Speaking	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
20. Muscle Weakness	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
21. Headaches or Other Types of Pain	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
22. Changes in Sensation: Loss of Feeling or Numbness and Tingling	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
23. Seizures	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
24. Changes in Vision	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
25. Safety Issues	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
26. Changes in Appetite	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
27. Bowel Problems: Constipation, diarrhea, and incontinence/toileting	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

issues											
28. Nausea and Vomiting	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
29. Skin Changes	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
30. Blood Clots or abnormal bleeding	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
31. Changes in Appearance	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
32. Shortness of Breath	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

0 = “not at all distressed”   and   10 = “as distressed as I can imagine”