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Assessing multidimensional worry in cancer survivors

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Introduction

Anxiety in cancer survivors has been characterized in numerous ways. One way is posttraumatic stress disorder (PTSD) symptoms [1]. This approach usefully captures intrusive thoughts, avoidance, and hyperarousal – focusing on cancer as a past trauma creating current symptoms. Another characterization of anxiety focuses on the fear of recurrence (FOR) [2]. FOR appears common in survivors, potentially lasting for many years post-treatment. Still, others have characterized anxiety with multidimensional scales, such as for prostate cancer [3] and breast cancer [4].

Worry differs from these in that it is future oriented; therefore, it is unlike PTSD symptoms, which are past-focused. Worry shares with FOR that both are cognitive behaviors aimed at reducing anxious arousal. FOR is a contextually specific and important worry, but survivors may also worry about other issues. At least two worry scales have been developed for women with breast cancer. The 8-item Cancer Worries Scale includes worries about recurrence, future surgery, and family [5], yielding a one factor solution. The 15-item Brief Cancer-Related Worry Inventory includes worries about cancer getting worse, effects of current treatment, work, and economics [6], yielding a three factor solution for (i) future prospects; (ii) physical and somatic problems; and (iii) social and interpersonal problems.

Building on important work with breast cancer survivors, we aimed to develop a multidimensional measure of worry, which (i) creates items based on the words of survivors; (ii) describes a range of concerns; and (iii) is brief, and therefore, practical in clinical and research applications.

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Conflict of interest

The authors have no conflict of interest relating to this study or this manuscript.

Part 1: Item creation

The first phase of scale development involved item generation. We recruited 48 (42 men and 6 women) Veterans Health Administration (VHA) cancer survivors (age mean (M) = 65.46, standard deviation (SD) = 10.04) who had treatment for genitourinary (n = 14), digestive (n = 14), lung (n = 10), blood (n = 6), and other (n = 4) cancers for individual interviews; further selecting 14 of these who reported worry and were interested/available to participate in focus groups. From these data sources, 51 worry statements were identified, which were then condensed to 26 items through team consensus on the basis of redundant content.

Part 2: Scale refinement and validation

Methods

Participants—The 170 VHA cancer survivors (167 men and 3 women) age 22–88 years (M = 64.66, SD = 9.40) completed individual interviews as part of a larger study of oral-digestive cancer survivors, defined here as having cancer, regardless of cure, remission, or active state. Participants were Caucasian (n = 138; 81%), African American (n = 25; 15%), or other (n = 8); 9% (n = 15) were Hispanic. Most (n = 141; 83%) were high school graduates.

Participants were diagnosed with head and neck (n = 68; 40%), esophageal/gastric (n = 18; 11%), or colorectal cancer (n = 84; 49%) 6 months previously of American Joint Committee on Cancer Stage I (24%), II (28%), III (22%), or IV (26%), and had received surgery (n = 122), chemotherapy (n = 102), and/or radiation (n = 69). About half (55%) had finished treatment. Individuals in hospice care or with dementia or psychosis were excluded.

Procedures—Interviews were conducted in person, with questions read aloud. The study was approved by the Institutional Review Boards of the Boston and Houston VA Medical Centers.

Measures—A 15-item scale was created by eliminating 11 items that were (i) specific to oral-digestive cancers, for example, worry about swallowing, so the scale would apply to diverse cancers; (ii) rarely endorsed; (iii) redundant on the basis of high correlation; and (iv) had high component loadings in exploratory principal components analysis.

The 17-item Posttraumatic Check List-Civilian version [7] was used to assess cancer-related PTSD symptoms. The 9-item Patient Health Questionnaire (PHQ) [8] was used to measure depressive symptoms. The 29-item Patient-Reported Outcomes Measurement Information System [9] (PROMIS) depression and anxiety subscales were also used.

Analyses—Item and scale properties were examined through descriptive statistics, reliability with *Cronbach's* alpha, and validity with *Pearson's* correlation between worry and other symptom scales, using SPSS Version 21 (IBM Corporation Armonk, New York, USA). Confirmatory factor analyses were performed with maximum likelihood estimation and root mean square error of approximation (RMSEA) for model fit in MPLUS Version 6

(Muthén & Muthén Los Angeles, California, USA). We only considered p values <0.01 significant.

Results

Item and total scale characteristics

Item M , SD , and frequency data appear in Table 1. Highly endorsed items reflected a wide range of worries: cancer coming back, my family's financial security, burdening family, and something in my body that no longer works. These items were endorsed by almost half the sample as 'sometimes to always'; however, SD indicate some items were more relevant to some individuals, for example, 'making the most of the time I have left'. Concerns about healthcare were the least frequently endorsed.

Combining items to create a total scale score, the observed scale range was 0–58, out of a potential scale range of 0–60. Twenty individuals (11.8%) rated all items 0 (never). The scale mean was 16.75 ($SD = 14.15$), with positive skew (0.73). Cronbach's alpha was 0.92. Cancer worry was negatively correlated with age ($r = 0.34$, $p < 0.001$), but did not vary by race or education, nor with cancer stage, type, treatment types, or whether the individual was still in treatment.

Scale factor structure

A five factor confirmatory factor analyses solution (Table 1) had adequate fit ($RMSEA = 0.05$), significantly better than a one factor solution, ($\chi^2(10, N = 170) = 161.30$, $p < 0.001$; one factor $RMSEA = 0.11$). Factor intercorrelations ranged from 0.65–0.88 ($p < 0.001$).

Items within each factor were summed to create total subscale scores based on these factors. The recovery subscale had the highest mean endorsement at 4.15 (± 3.78), which was significantly different from existential issues ($M = 3.45 + 3.61$; $t = 2.79$, $p < 0.01$) and healthcare ($M = 1.91 + 2.63$; $t = 9.71$, $p < 0.01$).

Scale validity

The total worry scale was correlated with PTSD symptoms ($r = 0.79$; $p < 0.001$) and anxiety on the PROMIS ($r = 0.72$; $p < 0.001$), and to a lesser extent with depression on the PHQ ($r = 0.53$; $p < 0.001$) and PROMIS ($r = 0.67$; $p < 0.001$) (Table 2).

Discussion

Following a qualitative item development based on patients' statements and analyses to guide item selection, we developed a 15-item scale for worry in cancer survivors. Our study was limited by our sample, which predominantly men who receive care in the VHA for oral-digestive cancers. In this way, it complements the breast cancer literature, but needs to be replicated in larger longitudinal samples with diversity in types of cancers, treatment type and time, and demographic characteristics and validated in comparison to numerous outcomes including GAD scales.

In this sample, the scale demonstrated high internal consistency reliability and criterion validity. Worry occurred across five domains: fear of recurrence, healthcare, family, existential issues, and recovery. Worries about recovery from treatment, for example, ‘something in my body that no longer works,’ were most frequently endorsed. These concerns again highlight the need for cancer survivor care that targets rehabilitation from persisting effects of the treatment [10]. Consistent with the literature, fear of recurrence was also a significant concern. Worry about the impact of cancer on family was present, ranging from the emotional to financial burden of cancer on family, as well as, caretaking. In addition, worries such as ‘making the most of the time I have left’ suggest that for some, cancer is a profoundly existential experience. It is noteworthy that worry did not vary by cancer type, treatment type or time, or stage, suggesting these worries are not restricted to being in treatment or facing death.

Our scale is similar to the 15 item measured by Hirai *et al* [6], except theirs had only one item about healthcare, which loaded onto their social factor, and one item about life/death, which loaded onto their FOR factor. However, the consistency of our scale, developed with mostly male oral-digestive cancer patients in the USA with theirs developed with female breast cancer patients in Japan, provides some additional support for the validity of multidimensional worry assessment. Such measures may be useful for targeting interventions and improving quality of life after cancer treatment.

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Key points

- We present a 15 item multidimensional worry scale developed in a sample of veterans diagnosed with oral-digestive cancers.
- Factor analyses confirmed 5 domains of worry which were: fear of recurrence, healthcare, family, existential, and recovery.
- Worry was present in half the sample, unrelated to cancer stage, types, or treatments.
- Assessment of a wide range of worries is important to identify those in distress and to guide interventions after treatment.
- Confirmation in other samples with diverse cancers and demographics is needed.

Table 1

Item characteristics

Item	Descriptive statistics			Standardized factor loadings				
	M	SD	% ^a	Fear of recurrence	Health care	Family	Existential	Recovery
1. My cancer coming back	1.40	1.37	44	0.79				
2. Another type of cancer	1.05	1.34	32	0.89				
3. Future diagnostic tests	1.14	1.28	39	0.73				
4. Whether I have the best care/right care	0.51	.95	17		0.76			
5. Errors that hospitals or doctors made or might make	0.72	1.07	24		0.70			
6. Having dignity as I'm dying	0.68	1.14	22		0.76			
7. Who will take care of my children/family	0.71	1.23	24			0.67		
8. My family's financial security	1.56	1.65	47			0.74		
9. Burdening my family	1.38	1.39	46			0.86		
10. Getting done what I want to do before I die	1.23	1.44	42				0.78	
11. Making the most of the time I have left	1.21	1.47	40				0.81	
12. Am I doing everything I should to beat it	1.02	1.34	31				0.70	
13. When will I return to normal	1.46	1.539	42					0.82
14. Something in my body that no longer works	1.51	1.520	47					0.69
15. When can I go back to work/or my usual activities	1.18	1.481	37					0.69

M, mean and SD, standard deviation.

^aReflects percent endorsed sometimes to always.All factor loadings were statistically significant at $p < 0.001$.

Table 2

Scale intercorrelations

	Anxiety		Depression	
	PCL	PROMIS	PHQ	PROMIS
Total Scale	0.79	0.72	0.53	0.67
Fear of recurrence	0.70	0.63	0.67	0.61
Care	0.61	0.59	0.57	0.56
Family	0.64	0.60	0.57	0.51
Existential	0.64	0.52	0.58	0.50
Recovery	0.66	0.64	0.67	0.59

PCL, posttraumatic check list; PROMIS, patient-reported outcomes measurement information System; and PHQ, patient health questionnaire.

All correlations were statistically significant at $p < 0.001$.