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Metastatic Breast Cancer Collateral Damage Project (MBCCD): Scale development and preliminary results of the Survey of Health, Impact, Needs, and Experiences (SHINE)

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Abstract

Purpose—Until recently, people with metastatic breast cancer (MBC) had a very poor prognosis. New treatment approaches have prolonged the time that people with MBC live, but their quality of life has received less attention. Consequently, the needs and concerns across financial, vocational, psychological, social, and physical domains in MBC patients are poorly understood—particularly regarding the collateral damage or longer-term, life-altering impacts of MBC and its treatments. This study's aims were to characterize MBC-related collateral damage, identify groups most likely to experience collateral damage, and examine its associations with psychological health, illness management, and health behaviors.

Methods—Participants (*N* = 515) with MBC were recruited from Dr. Susan Love Research Foundation's Army of Women® and other advocacy organizations. Participants completed

questionnaires of MBC-related collateral damage, depressive symptoms, anxiety, self-efficacy for managing oncologic treatments and physical symptoms, sleep, and physical activity.

Results—Eight domains of MBC-related collateral damage, as well as MBC-related benefit finding, were reliably characterized. Concerns about mortality/uncertainty were most prominent. Participants also endorsed high levels of benefit finding. Participants younger than 50 years, with limited financial resources, or with children under 18 at home reported the most collateral damage. Collateral damage was associated significantly with compromised psychological health, lower illness management efficacy, and poorer health behaviors, beyond sociodemographic and medical characteristics.

Conclusions—Subgroups of MBC patients report long-term, life-altering consequences of MBC and its treatments, which relate to important health outcomes. Clinical implications and recommendations are discussed.

Keywords

Metastatic breast cancer; Quality of life; Survivorship; Supportive care; Psycho-oncology; Collateral damage

Introduction

In 2018, an estimated 268,670 women and men will be diagnosed with breast cancer and an estimated 41,400 will die [1], with the majority of deaths resulting from metastatic breast cancer (MBC). Survival rates for de novo MBC have increased substantially since the early 1990s [2], in part due to advances in medical treatment [3]. Therefore, the MBC population is growing, with 154,794 women estimated to be living with MBC [2]. Most research has focused on extending the lives of people with MBC, rather than maintaining or improving quality of life (QOL). However, with the increasing ability of treatments for MBC to prolong survival, it becomes critical to understand and address the needs and concerns of MBC patients with appropriate supportive care.

MBC patients report poor QOL [4, 5], as well as more pain and fatigue, and greater difficulty with physical, social, and emotional functioning, compared to those with early-stage disease [6]. However, the assessment devices used in the aforementioned studies were designed to apply to cancer patients generally and do not necessarily capture the disease-specific concerns of MBC patients. Qualitative data suggest that some specific, life-influencing aspects of MBC are not captured by traditional QOL assessments [7, 8]. Adverse symptoms and complications, termed *late effects*, can arise from breast cancer and its treatments long after diagnosis [9]. Research on late effects predominantly focuses on biomedical sequelae [10]; long-lasting changes in other aspects (e.g., psychological, social, vocational, financial, functional) of patients' lives—a concept we call *collateral damage* [11, 12] requires study. Characterizing MBC-specific collateral damage is important to better understand and improve the lives of people with MBC, as was the primary goal of the present study.

MBC patients typically undergo multiple and sequential treatments, resulting in psychological, illness management, and health behavior challenges. A number of MBC

patients report high levels of depressive symptoms [13, 14] and anxiety [15, 16]. One study demonstrated that 33% of MBC patients evidenced clinical levels of depression via diagnostic interviews [17]. In another study, 11% of MBC patients reported clinically elevated levels of depressive symptoms and anxiety 5 years after diagnosis [18]. Additionally, some MBC patients experience barriers to oncologic treatment adherence [19] and persistence [20], whereas others demonstrate high rates of adherence and persistence [21, 22]. Finally, with regard to health behaviors, the majority of MBC patients report marked sleep disturbances [23, 24] and less daily physical activity [25] than women without cancer, which is important given that sleep quality and physical activity predict mortality [26, 27]. Understanding how MBC-specific collateral damage is related to psychological health, illness management, and health behaviors is critically important to assist researchers in developing efficacious supportive care programs to enhance QOL for this underserved population.

In this study, we queried MBC-specific concerns, experiences, and collateral damage, and used patients' free-text responses to develop a Patient-Reported Outcome (PRO) questionnaire—the Survey of Health, Impact, Needs, and Experiences (SHINE). We examined demographic (i.e., age, children, marital status, education) and medical characteristics (i.e., metastatic site location, current medical treatment) as correlates of the SHINE subscales in an effort to identify groups most likely to experience MBC-specific collateral damage. Additionally, we examined associations between SHINE subscales and psychological health (i.e., depressive symptoms, anxiety), illness management (i.e., self-efficacy for symptom management, self-efficacy for managing treatments/medications), and health behaviors (i.e., physical activity, sleep).

Method

PRO measurement development

PRO measurement development includes the identification of conceptual themes, item generation, and psychometric analysis [28]. During all phases, the study team collaborated with an advocate task force of 11 women and men with MBC and 1 MBC caregiver, who provided their perspectives and shared in decision making with regard to the design of the study and interpretation of findings. We describe the first two PRO development phases in detail within the Electronic Supplementary Materials (Online Resource 1), including the collection of qualitative data to aid in establishing content validity [29]. Briefly, 353 adults with MBC completed a qualitative assessment, from which nine domains were identified: employment concerns, financial concerns, insurance problems, time reorganization, activity disruption, uncertainty, self-concept disruption, interpersonal consequences, and MBC-related benefit finding (see Online Resource 2 for descriptions). Identifying domains of responses guided the generation of 69 items. To maintain fidelity to the patients' verbatim statements from the qualitative assessment, 40 items were generated with Likert-scale response options that indicated degree of bother (herein referred to as Response Set A; 1 = Not at all, 2 = A little bit, 3 = Somewhat, 4 = Quite a bit, 5 = Very much), and 29 items were generated with response options that indicated level of agreement (herein referred to as

Response Set B; 1 = Strongly disagree, 2 = Disagree, 3 = Neither agree nor disagree, 4 = Agree, 5 = Strongly agree).

SHINE psychometric analysis

Potential SHINE items were administered online via the Dr. Susan Love Research Foundation's The Health of Women (HOW) Study® to the current analytic sample of MBC patients ($N = 515$). Participants were eligible if they had been diagnosed with MBC (any diagnosis duration, de novo diagnosis or progression), were > 18 years of age, and were able to read/answer questions in English. More than 30 advocacy organizations augmented participant recruitment (see Online Resource 3 for a list). Participants reported sociodemographic (i.e., age, parental status, marital status, financial status, years of education, race/ethnicity) and medical information (i.e., metastatic site location, current and past medical treatment).

Psychological health, illness management, and health behavior measures

Participants completed questionnaires on depressive symptoms, anxiety, self-efficacy for managing medications/treatments and physical symptoms, sleep disruption, and physical activity. Depressive symptoms (e.g., "I feel worthless"), anxiety (e.g., "My worries overwhelm me"), self-efficacy for managing medications and treatments (e.g., "I can manage my medication without help"), self-efficacy for symptom management (e.g., "I can manage my symptoms during my daily activities"), and sleep disruption (e.g., "I had a problem with my sleep") were assessed using 4-item subscales from the Patient-Reported Outcomes Measurement Information System measures [30], which have been used in oncology patient samples [31–33]. Participants rated items on a 5-point scale, and internal consistency was high ($a = 0.88$–0.91). Physical activity was assessed using a modified item from the California Teachers Study [34]. Participants reported the average number of hours per week they engaged in moderate physical activity (e.g., walking for exercise, jogging) within the past three months (rather than three years).

Analytic plan

Exploratory factor analyses (EFA) were conducted with robust estimation separately for each item response set to determine SHINE subscales. An EFA approach allows for subscales to emerge that were not hypothesized a priori and is recommended when determining a factor structure for a new measure [35]. Good model fit was chosen a priori as the combination of CFI > 0.95, SRMR < 0.08, and RMSEA < 0.06 [36, 37]. Advanced cancer patients experience barriers to research participation [38], including time demands [39]. The brevity of PROs is valued to facilitate ease of completion [40]. Accordingly, we sought to identify four-item subscales to minimize burden. When conceptually appropriate, we maintained the four highest-loading items for each factor if the items loaded strongly on a single factor (> 0.40) and not as strongly on others (< 0.40).

Cronbach's alpha coefficients estimated internal consistency reliability for each subscale, and subscale inter-correlations were examined. A within-subjects ANOVA evaluated differences between SHINE subscale scores. One-way ANOVAs and independent-samples *t* tests were conducted as appropriate to analyze differences in subscales as a function of age

(fewer than 50 years, 50–64, 65 and above), marital status (married, not married), financial status (having enough money to spend on special things vs. not having enough), race/ethnicity (non-Latina/o white, other race/ethnicity), education (less than 4-year college degree, 4-year college degree, more than 4-year college degree), parental status (no children, at least one child but none under 18 years of age living at home, at least one child under 18 living at home), metastatic site location (bone-only, single site [not bone], multiple sites), and current medical treatment (no treatment, endocrine therapy only, chemotherapy only, targeted therapy or immunotherapy only, endocrine therapy with immunotherapy or targeted therapy, other combination treatment without chemotherapy, other combination treatment with chemotherapy). Post hoc tests (i.e., Tukey's Honest Significant Difference Tests) evaluated pairwise differences for significant omnibus ANOVAs. To provide some adjustment for Type I error, pairwise differences were considered statistically significant at $p < .006$ (0.05/8 for 8 SHINE subscales).

Multivariable linear regression models evaluated whether SHINE subscales relate to psychological health, illness management, and health behaviors. SHINE subscales were entered as simultaneous predictors. Age, marital status, financial status, parental status, metastatic site location, and current medical treatment were entered as a priori covariates. Depressive symptoms, anxiety, self-efficacy for symptom management, self-efficacy for managing treatments/medications, physical activity, and sleep disruption were entered as dependent variables in separate analyses. Two-tailed significance tests were used, and $p < .05$ was considered statistically significant unless otherwise noted.

Results

Sample characteristics

Participants ($N = 515$) were women (99%) and men with MBC. On average, participants were 57 years old, well-educated, married/partnered, and did not have children at home (Table 1). The majority (91%) was non-Hispanic white, and most (82%) had not participated in clinical trials since their MBC diagnosis. There was considerable variability in metastatic site location and current medical treatment. The lack of racial/ethnic diversity in the sample precluded racial/ethnic comparisons.

Exploratory factor analyses

For Response Set A items, we expected six factors to emerge from the EFA, reflecting the following domains as generated in the qualitative phase: employment concerns, financial concerns, insurance problems, activity disruption, uncertainty, time reorganization. A five-factor solution met the a priori criteria for good fit (CFI = 0.96, SRMR = 0.02, RMSEA = 0.05). Four factors reflected hypothesized subscales (i.e., employment concerns, financial concerns, insurance problems, activity disruption). Feelings of uncertainty and concerns about mortality loaded onto a shared fifth factor. No factor reflecting time reorganization emerged from the EFA. Rather, time reorganization items loaded on either the activity disruption or mortality/uncertainty factor.

Three factors were expected to emerge from the Response Set B EFA: self-concept disruption, interpersonal collateral damage, benefit finding. A four-factor solution met the a priori criteria for good fit (CFI = 0.96, SRMR = 0.02, RMSEA=0.05). Two of the three emergent factors reflected hypothesized subscales (i.e., self-concept disruption, benefit finding[1]). Items hypothesized to load onto an interpersonal collateral damage subscale loaded onto two separate factors: interpersonal concerns, social isolation/withdrawal. Factor solutions for the SHINE measure are displayed in Table 2. In sum, a 36-item version of SHINE was created with nine subscales (see Online Resource 4 for the SHINE questionnaire and scoring instructions).

SHINE subscale characteristics

SHINE subscale internal consistency coefficients were adequate (αs > 0.71). Subscales were inter-correlated significantly (rs 0.12–0.67, ps < 0.01) with the exception of benefit finding with employment concerns (r = 0.08, p = 0.060). A within-subjects ANOVA among Response Set A SHINE subscales revealed that participants were most bothered by mortality/uncertainty concerns, followed by activity disruption, then by financial, employment, and insurance concerns, respectively ($F_{(4508)}$ = 111.38, p < 0.01). Additionally, participants endorsed strongest agreement with benefit finding, followed by interpersonal concerns, self-concept disruption, and social isolation/withdrawal ($F_{(4508)}$ = 101.53, p < 0.01). Pairwise differences between subscales within each response set were conducted; all subscales differed significantly from each other (ps < 0.004). Descriptive statistics for SHINE subscales and dependent variables are displayed in Table 3.

Relationships of SHINE subscales with sociodemographic and medical characteristics

Of demographic variables, only level of education was not related significantly to SHINE subscales (Fs < 2.90, ps > 0.056). The age groups differed significantly on all SHINE subscales (Fs > 7.65, ps < 0.002), with the exception of benefit finding (F = 0.65, p = 0.525). As displayed in Table 4, post hoc tests indicated that participants under 50 and those between 50 and 65 reported significantly more MBC-related collateral damage in almost every domain, compared to those over 65. Additionally, participants under age 50 reported higher concerns about mortality/uncertainty, financial concerns, and interpersonal concerns than those aged 50–65. With regard to financial status, participants who indicated not having enough money to spend on special things reported significantly more bother on all MBC-related collateral damage domains (ts > 3.55, ps < 0.001), except finding benefit ($t_{(487)}$ = 1.35, p = 0.177). Married participants differed significantly from unmarried participants on interpersonal concerns. Interpersonal concerns, but no other concerns, were significantly higher among married participants ($t_{(501)}$ = 3.51, p < 0.001). The three parental status groups differed significantly on five SHINE subscales (Fs > 7.65, ps < 0.002), but not on insurance problems, activity disruption, and benefit finding (Fs = 2.68, ps > 0.069). Participants with at least one child under 18 living at home reported significantly higher concerns about mortality/uncertainty, financial concerns, and employment concerns than those with at least one child (but none under 18 at home). Those with children of any age (in

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[1]One item included in the benefit finding subscale also loaded onto the self-concept disruption subscale at (− 0.44), which is weaker in magnitude than the other self-concept disruption item factor loadings. As such, this item was retained on the benefit finding subscale.

or out of the home) reported higher interpersonal concerns than those without children (Table 4). There were no significant pairwise differences at $p < 0.006$ between parental status groups on self-concept disruption.

With regard to medical variables, the three metastatic site location groups differed significantly on bother from employment concerns, mortality/uncertainty, activity disruption, and interpersonal concerns ($Fs > 3.23$, $ps < 0.040$), but not other SHINE subscales ($Fs < 2.72$, $ps > 0.067$). Participants with bone-only metastases and those with multiple site metastases reported significantly higher mortality/uncertainty and interpersonal concerns than those with single site (not bone) metastases (Table 4). There were no significant pairwise differences at $p < 0.006$ on employment concerns or activity disruption. The seven treatment groups differed significantly on all SHINE subscales ($Fs > 2.15$, $ps < 0.047$), except for social isolation and benefit finding ($F = 1.34$, $ps = 0.236$). Participants on no current treatment reported significantly fewer concerns about mortality/uncertainty and interpersonal concerns than those on combination therapy (with or without chemotherapy) or chemotherapy ($ps < 0.005$). Those on no current treatment also reported significantly lower interpersonal concerns than those on targeted therapy or immunotherapy ($p < 0.001$). Participants on endocrine therapy reported significantly lower interpersonal concerns than those on combination therapy (with or without chemotherapy) and less activity disruption than those on combination therapy (with chemotherapy) ($ps < 0.003$). No significant pairwise differences emerged with regard to employment concerns, financial concerns, insurance problems, social isolation/withdrawal, or self-concept disruption.

Relationships between SHINE subscales, psychological health, illness management, and health behaviors

Multivariable regression models indicated that SHINE subscales were associated significantly with depressive symptoms ($R^2 = 0.38$, $p < 0.001$), anxiety ($R^2 = 0.37$, $p < 0.001$), self-efficacy for medication/treatment management ($R^2 = 0.08$, $p < 0.001$), self-efficacy for physical symptom management ($R^2 = 0.32$, $p < 0.001$), sleep disruption ($R^2 = 0.10$, $p < 0.001$), and physical activity ($R^2 = 0.17$, $p < 0.001$), beyond covariates.

Higher depressive symptoms were associated significantly with higher concerns about mortality/uncertainty ($b = 0.56$, $SE = 0.20$, $p = 0.006$), higher self-concept disruption ($b = 0.97$, SE = 0.26, $p < 0.001$), more social isolation/withdrawal ($b = 1.32$, SE = 0.23, $p < 0.001$), and less benefit finding ($b = -0.49$, SE = 0.23, $p = 0.036$). Higher anxiety was associated significantly with more concerns about mortality/uncertainty ($b = 1.27$, $SE = 0.17$, $p < 0.001$), higher self-concept disruption ($b = 0.56$, $SE = 0.22$, $p = 0.012$), more social isolation/withdrawal ($b = 0.65$, $SE = 0.19$, $p = 0.001$), and more financial concerns ($b = 0.39$, SE=0.15, $p = 0.011$).

Higher self-efficacy for managing medications/treatments was associated significantly with less social isolation/withdrawal ($b = -0.36$, SE = 0.20, $p = 0.025$). By contrast, higher self-efficacy for managing physical symptoms was associated significantly with lower self-concept disruption ($b = -0.82$, SE = 0.27, $p = 0.003$), less activity disruption ($b = -1.34$, SE = 0.20, $p < 0.001$), more benefit finding ($b = 0.74$, SE = 0.25, $p = 0.003$), and higher concerns about mortality/uncertainty ($b = 0.61$, SE = 0.17, $p < 0.001$).

More sleep disruption was associated significantly with higher interpersonal concerns ($b = 0.66$, SE = 0.30, $p = 0.032$), and greater endorsement of moderate physical activity was significantly related to less activity disruption ($b = -0.56$, SE = 0.15, $p < 0.001$).

Discussion

Qualitative data ($N = 353$) suggested several domains in the experiences of people living with MBC, which quantitative analyses reliably characterized in 515 women and men with MBC. Nine distinct domains reflected in SHINE subscales were employment concerns, financial concerns, insurance problems, mortality/uncertainty, activity disruption, interpersonal concerns, social isolation/withdrawal, self-concept disruption, and benefit finding. MBC can be said to influence all aspects of patients' lives, including financial, vocational, psychological, interpersonal, and physical domains. Participants expressed prominent concerns regarding uncertainty and mortality, and finding benefit in the MBC experience was commonly reported.

Specific demographic and medical characteristics were associated with responses on eight SHINE subscales, but not on benefit finding. Participants younger than 50 years of age, with low financial resources, or with children under 18 years of age at home were most likely to report collateral damage. Specifically, participants younger than 50 reported greater collateral damage across all domains, consistent with research demonstrating that younger breast cancer survivors experience poorer QOL (for reviews, see [41, 42]). Participants with limited financial resources also reported significant collateral damage across all areas, extending previous research demonstrating that lower socioeconomic status and higher financial burden are correlates of poorer QOL and lower satisfaction with care in breast cancer survivors [43, 44]. The current finding that participants living with a child under 18 in the home reported significant collateral damage across most subscales is consistent with research that breast cancer survivors with children in the home report higher depressive symptoms and poorer QOL [45–47].

Marital status, metastatic site location, and current treatment differentiated responses only on particular SHINE subscales. Married participants reported greater interpersonal concerns than those who were unmarried, perhaps reflecting concern about intimate partners. Those with bone-only or multiple site metastases and who were receiving either chemotherapy or combination therapy reported greater concerns about mortality/uncertainty and interpersonal concerns. No previous study has demonstrated that MBC patients with bone-only metastases report poorer psychological or social functioning, and this finding was surprising. The advocate task force explained that bone metastases can cause high levels of pain and restrict daily activities (e.g., going up or down stairs, loading the dishwasher), which can subsequently limit one's ability to engage in social activities.

MBC-related collateral damage was associated significantly with psychological health, illness management, and health behaviors, beyond sociodemographic and clinical characteristics. Higher depressive symptoms and anxiety related to higher concerns about mortality/uncertainty, self-concept disruption, and social isolation/withdrawal. Additionally, higher depressive symptoms related to less benefit finding, and higher anxiety related to

more financial concerns. Depression and anxiety are prominent concerns for MBC patients [13–16].

Higher self-efficacy in managing medications/treatments was related to less social isolation/ withdrawal, extending previous research that social factors can be important for breast cancer-related treatment adherence [48]. Higher self-efficacy for managing symptoms was related to less activity disruption, lower self-concept disruption, more benefit finding, and higher concerns about mortality/uncertainty. Those with lower self-efficacy for managing symptoms may experience greater pain or fatigue, which can disrupt daily activities [49] and may influence patients' self-concept. Also, the salience of mortality for some MBC patients might prompt them to monitor and attend to symptoms closely.

Higher physical activity was associated with less activity disruption. Those who experienced activity disruption may not feel physically well enough to engage in moderately strenuous physical activity, or physical activity might increase energy or stamina to engage in valued activities. A third variable, such as physical symptom burden, may be influencing physical activity and activity disruption in this sample. Finally, sleep disruption was directly related to higher interpersonal concerns. Given that pre-sleep worry is associated with sleep disturbance [50, 51], future research should assess whether MBC patients with impaired sleep worry about loved ones while trying to get to sleep.

A limitation of this study is the lack of racial/ethnic diversity. The majority (91%) of participants were non-Hispanic white, which does not reflect the makeup of the MBC population. Caution is warranted in generalizing these findings to diverse groups. Also, the correlational and cross-sectional design precludes causal claims. For example, longitudinal, prospective research is needed to elucidate findings' directionality.

There are several notable strengths of this study. First, online recruitment and partnerships with advocacy organizations resulted in a large sample of MBC patients. Second, the qualitative assessment provided patient-driven domains of MBC-related collateral damage that were important to the patient population. Third, collaboration with the advocate task force resulted in a patient-centered study design and strengthened interpretation of the findings [12]. Finally, the SHINE measure is the first scale to assess MBC-related collateral damage with many items created from participants' own words. SHINE subscales are brief, which reduces burden, and they can be administered within the full 36-item measure or independently as 4-item subscales. Additional research is needed to validate the SHINE measure and examine its psychometric properties. Future studies should translate the SHINE measure into other languages (e.g., Spanish) and use targeted recruitment strategies to increase minority participation [52].

With regard to clinical implications, these findings can aid in identifying MBC patients who are at risk for experiencing collateral damage, including those of younger age, with children in the home, and at financial disadvantage. At risk MBC patients can then be introduced to a mental health specialist early in the cancer care trajectory to address psychosocial sequelae. This specialist should coordinate with the oncology team at all stages, including active treatment, and it may be important for the inter-professional team to address MBC-related

collateral damage directly with patients. Additionally, medical teams need to be educated on both short-term (i.e., side effects) and long-term (e.g., collateral damage, late effects) effects of MBC and its treatments. Taken together, these findings demonstrate that beyond sociodemographic and clinical characteristics, MBC-related collateral damage is important for psychological health, illness management, and health behaviors.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements

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Table 1

Sample characteristics and demographics ($N = 515$)

	n	*%*
Sex		
Female	510	99.0
Male	4	0.8
Transgender	1	0.2
Age		
< 50 years	134	26.0
50–64 years	220	42.7
> 65 years	128	24.9
Did not report	33	6.4
Education		
Less than 4-year college degree	132	25.6
4-year degree	160	31.1
More than 4-year degree	221	42.9
Did not report	2	0.4
Financial status		
Having enough money for special things	307	59.6
Not having enough money for special things	187	36.3
Did not report	21	4.1
Marital status		
Married/Living as married	369	71.4
Not married	141	27.4
Did not report	5	1.0
Children		
No children	125	24.3
At least 1 child (none under 18 living at home)	280	54.4
At least one child under 18 living at home	110	21.4
Metastatic site location		
Single site (not bone)	174	33.8
Single site (bone)	309	60.0
Multiple sites	32	6.2
Current oncologic treatment		
Endocrine therapy only	70	13.6
Chemotherapy only	62	12.0
Targeted therapy or immunotherapy only	51	9.9
Endocrine therapy with immune therapy or targeted therapy	46	8.9
Any other combination treatment with chemotherapy	87	16.9
Any other combination treatment without chemotherapy	154	29.9
No treatment	33	6.4
Did not report	12	2.3

Table 2

Factor solution for the SHINE measure

Item	Employment concerns	Financial concerns	Insurance problems	Mortality/uncertainty	Activity disruption
Response Set A					
1	**0.83**	−0.01	0.06	0.06	−0.08
2	**0.71**	0.01	0.02	−0.02	0.11
3	**0.65**	0.09	−0.05	<0.01	0.17
4	**0.62**	0.04	0.02	0.09	0.13
5	0.09	**0.83**	0.03	0.02	−0.04
6	−0.04	**0.74**	0.15	0.01	0.04
7	0.21	**0.70**	−0.04	0.09	<−0.01
8	0.24	**0.55**	0.03	−0.07	0.13
9	0.10	−0.03	**0.90**	−0.03	−0.01
10	0.07	−0.01	**0.86**	0.02	<0.01
11	−0.11	0.07	**0.69**	−0.01	0.10
12	−0.13	0.30	**0.66**	0.04	0.01
13	−0.05	0.05	−0.02	**0.88**	−0.02
14	<0.01	−0.04	<0.01	**0.86**	−0.06
15	0.10	0.02	−0.01	**0.70**	0.09
16	<0.01	−0.01	<−0.01	**0.54**	0.23
17	0.09	−0.02	0.02	0.05	**0.78**
18	−0.05	0.07	−0.01	0.14	**0.72**
19	0.08	0.05	−0.02	−0.02	**0.69**
20	<−0.01	−0.05	0.12	0.28	**0.48**

Item	Interpersonal concerns	Social isolation/withdrawal	Self-concept disruption	Benefit finding
Response Set B				
21	**0.81**	0.16	−0.03	−0.03
22	**0.80**	−0.01	−0.08	−0.02
23	**0.60**	−0.08	0.11	0.06
24	**0.53**	0.01	0.28	−0.07
25	<0.01	**0.73**	<0.01	0.01
26	0.19	**0.58**	0.11	−0.03
27	0.11	**0.46**	0.39	0.04
28	−0.01	**0.41**	0.38	−0.06
29	−0.01	0.19	**0.55**	−0.02
30	0.19	0.09	**0.50**	0.06
31	<−0.01	0.30	**0.49**	0.04
32	0.12	−0.08	**0.48**	−0.05
33	−0.04	0.02	−0.31	**0.66**
34	0.01	<0.01	−0.44	**0.50**
35	0.02	<0.01	−0.28	**0.56**
36	0.02	−0.45	0.09	**0.48**

The SHINE questionnaire (including all items) and scoring instructions are provided in Online Resource 4

Bold values indicate the items included in each respective SHINE subscale

Table 3

Descriptive statistics of SHINE subscales, psychological health, illness management, and health behaviors

	n	**Mean**	**Standard deviation**
PROMIS—depressive symptoms	450	8.36	3.73
PROMIS—anxiety	450	9.96	3.39
PROMIS—self-efficacy for managing medications/treatments	439	18.24	2.67
PROMIS—self-efficacy for managing physical symptoms	439	15.44	3.80
PROMIS—sleep disturbance	428	12.00	3.87
CTS—moderate physical activity (hours per week)	428	2.54	2.30
SHINE—employment concerns[a]	513	2.52	1.40
SHINE—financial concerns[a]	512	2.67	1.37
SHINE—insurance problems[a]	512	2.17	1.14
SHINE—mortality/uncertainty[a]	513	3.28	1.14
SHINE—activity disruption[a]	513	2.88	1.19
SHINE—interpersonal concerns[b]	508	3.61	0.88
SHINE—social isolation/withdrawal[b]	508	2.44	0.93
SHINE—self-concept disruption[b]	509	3.12	0.86
SHINE—benefit finding[b]	508	3.92	0.71

SHINE Survey of Health, Information, Needs, and Experiences, *PROMIS* Patient-Reported Outcome Measure Information System, *CTS* California Teachers Study

[a] Response options ranged from 1 (Not at all) to 5 (Very much)

[b] Response options ranged from 1 (Strongly disagree) to 5 (Strongly agree)

Table 4

Mean differences in SHINE subscale scores as a function of age, financial status, marital status, parental status, and metastatic site location

Pairwise comparison	Employment concerns	Financial concerns	Insurance problems	Uncertainty/mortality	Activity disruption	Interpersonal concerns	Social isolation/withdrawal	Self-concept disruption	Benefit finding
Age									
A–B	0.42	0.50*	0.25	0.45*	0.14	0.30*	0.13	0.16	0.01
A–C	1.38*	1.23*	0.74*	0.86*	0.59*	0.72*	0.54*	0.41*	−0.07
B–C	0.96*	0.72*	0.49*	0.40*	0.45*	0.43*	0.41*	0.25	−0.09
Financial status									
D–E	0.86*	1.72*	0.71*	0.55*	0.71*	0.29*	0.47*	0.37*	0.09
Marital status									
F–G	−0.14	−0.33	−0.01	0.10	−0.98	0.31*	−0.09	−0.04	−0.04
Parental status									
H–I	0.73*	0.65*	0.25	0.45*	−0.01	0.46*	0.28	0.25	−0.09
H–J	0.30	0.23	0.02	0.36	0.12	0.46*	0.18	0.21	0.05
I–J	−0.43	−0.42	−0.22	−0.08	−0.15	−0.01	−0.11	−0.04	0.14
Metastatic site									
K–L	0.33	0.32	0.20	0.42*	0.34	0.36*	0.12	0.22	−0.09
K–M	−0.03	0.11	0.02	0.03	0.10	0.02	<−0.01	0.06	<0.01
L–M	−0.36	−0.20	−0.18	−0.39*	−0.24	−0.34*	−0.12	−0.17	0.09

Differences between two groups were evaluated with paired-samples t tests, and differences between three groups were evaluated with Tukey's Honest Significant Difference Tests. To provide some adjustment for Type I error, pairwise differences were considered statistically significant at p < 0.006 (0.05/8 for 8 SHINE subscales)

A Less than 50 years of age, B 50–64 years of age, C 65 years of age and above, D Indicated not having enough money to spend on special things, E Indicated having enough money to spend on special things, F Currently married, G Not currently married, H At least one child under 18 years of age living at home, I At least one child (but none under 18 at home), J No children, K single site (bone), L single site (not bone), M multiple sites

*
p < 0.006