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Evaluation of the Symptom Representation Questionnaire (SRQ) for Assessing Cancer-Related Symptoms

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Abstract

Multi-dimensional, multi-symptom approaches to cancer symptom assessment and management have been emphasized across health disciplines. However, each dimension that is assessed significantly increases patient/subject burden. Efficient, reliable, and valid assessment of the critical dimensions of patients' most salient symptoms is important in clinical and research settings. The Symptom Representation Questionnaire (SRQ), derived from information processing theory, assesses critical cognitive and emotional factors that are known to influence coping and outcomes. The SRQ was developed and evaluated in a three-phase process: 1) item selection, modification, and review by theoretical and clinical experts; 2) pilot evaluation of feasibility and psychometric properties; and 3) large sample psychometric evaluation. In phase three, members (n=713) of the National Ovarian Cancer Coalition participated via mailed surveys. Internal consistency was good for all subscales (α= 0.63 – 0.88). The internal structure of the SRQ was theoretically consistent except that emotional representation, identity, and consequence items all loaded onto a single factor. Between-group comparisons supported construct validity: representations differed between long-term survivors and women with active disease. Finally, there were significant correlations between SRQ subscales and Symptom Interference and Life Satisfaction. The SRQ appears to be a psychometrically sound instrument for assessing representations of cancer-related symptoms. This instrument could play an essential role in advancing knowledge of the relationships among representations of symptoms, symptom management processes, and symptom related outcomes. It could also be used in intervention research when changes in symptom representations are hypothesized to mediate changes in outcomes as a result of psycho-educational interventions.

Keywords

Symptom assessment; illness representations; symptom management; ovarian cancer; cancer

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NOTE TO AU: AS YOU READ THROUGH THE PROOFS, PLEASE MAKE SURE THAT WHEN YOU USE MDASI YOU MEAN THE SYMPTOM INVENTORY IN TOTO; IF YOU ARE TALKING ABOUT THE MDASI INTERFERENCE SUBSCALE, PLS MAKE SURE THAT IS CLEAR.

Introduction

Individuals with cancer are known to experience multiple, concurrent symptoms that can be related to the illness, the various treatments, or both. The importance of a multi-dimensional, multi-symptom approach to symptom assessment and management has recently been emphasized across health care disciplines (1–5). However, which dimensions are most critical to assess remains unclear (6). This is a very important question for multiple symptom assessment because each dimension that is assessed dramatically increases patient or subject burden. Efficient, reliable, and valid assessment of critical dimensions of a patient's most salient cancer-related symptoms is important for both clinical and research settings. The purpose of this paper is to describe the Symptom Representation Questionnaire (SRQ) (Appendix), a survey derived from a well-supported information processing theory that identifies critical cognitive and emotional factors that influence health-related coping and outcomes (7,8). The SRQ is designed to assess the severity of 22 cancer-related symptoms followed by an assessment of five additional important dimensions of a person's three most bothersome symptoms.

Background

A wide variety of cancer symptom assessment instruments exist [for an excellent review, see (6)]. There are two limitations to the existing set of instruments. First, most instruments are *either* multi-dimensional (focusing on the multi-dimensional nature of a single symptom) *or* multi-symptom (with a limited dimensional assessment of multiple symptoms) (6). For those that do assess multiple dimensions of multiple symptoms (>5), the majority focus on the presence of symptoms in combination with measures of symptom severity and/or distress (9–16). Two instruments add an assessment of frequency or duration (17,18) while two others add an assessment of interference with function or life activities to the assessment of presence and severity (2,19). Finally, one tool weights the importance of symptoms independently from measures of intensity and distress (20).

The second limitation of existing tools is that most multi-dimensional symptom assessment tools are not well-grounded in relevant theory. Leventhal's Common-Sense Model (CSM), provides a useful framework for selecting dimensions of the symptom experience that are critical to assess because of their influence on symptom management processes and outcomes (7,8). The CSM, as an information processing model, asserts that individuals use both internal and external information to construct meaning for an event and the emotion that accompanies it. The set of constructed meanings and emotions are referred to as "representations". These representations are highly individualized and may not fit with medical models of illness. However, it is these representations that guide how individuals cope with their health problems (7,8). A wealth of literature exists supporting the theory that individual's cognitive and emotional representations about their health problems guide how they cope with those problems (21–25). In addition, representations have also been shown to predict important health-related outcomes (21,24,26–29).

The Illness Perception Questionnaire (IPQ) (30,31), a structured measure of illness representations, has facilitated much of this work. Currently, there are versions for use in over 10 disease states and in more than 10 languages, but no analogous versions exist for the assessment of multiple illness-related symptoms. While there are versions of the recently revised IPQ (IPQ-R) for acute and chronic pain, these versions view pain as an injury (acute pain) or an illness (chronic pain) rather than a symptom of other health problems. Therefore, a valid and reliable instrument is needed to assess representations of symptoms. Such an instrument could play an essential role in advancing knowledge of the relationships among

representations of symptoms, symptom management processes, and symptom related outcomes.

In summary, most current instruments that are designed to assess multiple dimensions of multiple symptoms are: 1) limited to assessments of severity, frequency, and distress, and 2) atheoretical – selection of the dimensions for assessment are not based on theoretical conceptualization of the critical cognitive and emotional assessments that individuals make as they experience a symptom. In an effort to address these limitations, the SRQ was developed based on the Common-Sense Model of Self-Regulation, and derived from the IPQ. The SRQ is designed to provide a multidimensional assessment of multiple cancer-related symptoms and overcomes limitations of previous measures by basing dimensions of assessment on a well-supported self-regulation theory that explains the inter-connected relationship between cognitive and emotional beliefs (representations) and coping with a health threat. In this way, the SRQ has potential for both clinical and research applicability. In clinical settings, the SRQ may provide important information regarding the emotional distress associated with symptoms, the perceived consequences of a symptom, and the extent to which an individual believes that s/he is able to control the symptom. These data are vital to help clinicians intervene to decrease symptom distress and to track the efficacy of treatment on symptom-related outcomes. In research, the arena in which the SRQ will likely make its greatest contribution, the SRQ may provide an important means to decompose the effects of interventions on symptom-related outcomes, particularly as it has been proposed that changes in symptom representations mediate the effects of cognitive behavioral interventions on symptom-related outcomes. These types of interventions, termed “Representational Interventions” have shown promise in several randomized controlled trials (32–35). This paper describes the development and psychometric evaluation of the SRQ through a three-phase process: Phase 1: Modification of the IPQ and evaluation of evidence for validity based on instrument content; Phase 2: Pilot testing for feasibility and initial psychometric evaluation; and Phase 3: Final psychometric evaluation in a large sample of women with ovarian cancer.

Methods

Phase 1: Item Selection/Modification from the IPQ

The IPQ was the source for items used in the SRQ. The original IPQ contains 38 items addressing the five dimensions of illness cognitive representations as described by Leventhal and colleagues: identity, cause, timeline, consequences, cure/control (7,8). Identity refers to the label(s) associated with the symptoms of a health problem; cause refers to a person’s beliefs about the origin of the health problem; timeline relates to ideas about whether the problem is acute, chronic, or cyclic in nature; consequences are ideas about the short- and long-term outcomes of the problem; and cure/control refers to beliefs about the extent to which one can cure or control a health problem.

Over the past 10 years, the IPQ and the IPQ-R have been used extensively in health psychology research and have documented excellent internal consistency and test re-test reliability (30, 31). In addition, theoretically supported relationships between subscales of the IPQ and other measures of perceived disability, perceived health, health-related distress, and beliefs about recovery from current health problems have provided support for construct validity of the IPQ (27,36,37).

Several modifications to the IPQ were made to create the SRQ. First, each item from the IPQ was changed from addressing “my illness” to “this symptom.” Next, the basic format of the IPQ was modified to accommodate assessment of three patient-selected symptoms instead of a single illness.

Once the initial changes were made, the content of the instrument was reviewed for evidence of validity by experts in theoretical framework (*n*=6) and experts in clinical oncology (*n*=6). The instrument was also reviewed by experts in survey design (*n*=5). In addition to format changes, the following modifications were made to each of the six sections of the instrument based on recommendations of the expert panel.

Identity—In the IPQ, illness identity is operationalized as the number of symptoms experienced. The IPQ contains a list of 12 symptoms that the patient is asked to rate according to frequency on a four-point scale ("all of the time," "frequently," "occasionally," "never"). The symptom list was modified for the SRQ based on recommendations from the developers of the original IPQ that the core symptom list be amended to reflect the symptoms common to the type of illness being studied. The SRQ symptom list was originally generated from the M. D. Anderson Symptom Inventory (MDASI) that includes 13 symptoms common to individuals receiving treatment for cancer (2). This list was then reviewed by four gynecologic oncologists, two oncology certified nurses with expertise in gynecologic oncology, and two doctorally-prepared experts in symptom assessment. These experts were asked to identify either a) symptoms currently on the list that were not commonly seen in women with gynecologic cancers, or b) symptoms that were commonly seen in women with gynecologic cancers that were not currently on the list. After review and discussion of all suggestions, the group came to a consensus on 26 symptoms (12 of the original MDASI symptoms plus 14 symptoms relevant to gynecologic cancer) to be used in Study #2. Following Study #2, two symptoms (bleeding and mouth sores) were deleted due to low prevalence rates (<3%), one symptom (weakness) was deleted due to overlap (r >0.80) with fatigue, and constipation and diarrhea were combined as "bowel disturbances" based on recommendations from a significant number (>5%) of women, resulting in a 22 symptom scale.

On the SRQ, instead of rating the frequency of each symptom, patients rate the severity of each symptom on an 11-point scale, from 0 (did not have it) to 10 (as bad as I can imagine). Identity on the SRQ is then operationalized as the severity of the particular symptom being assessed. The 0–10 numerical rating scale is the most widely used scale for assessing symptom severity and has well-established psychometric properties in pain, fatigue, and multi-symptom assessment (2,38,39).

Cause—In the IPQ, cause is assessed using 10 items describing common perceptions of causes of illness (germ or virus, diet, pollution, heredity, stress, etc.). Individuals are asked to identify the extent to which they agree that each factor caused their illness. Again, the developers of the IPQ recommended that these questions be modified by other investigators to reflect specific illness or symptom experiences. For the SRQ, cause is assessed with two questions **(AU: SHOULD "TWO QUESTIONS" BE "TWO STATEMENTS"?)**: "Cancer is causing my symptom" and "Treatment for cancer is causing my symptom." Patients are asked to identify, on a five-point scale identical to the IPQ, the extent to which they agree (strongly agree to strongly disagree) with each item. Subscale scores are created using mean scores across items. The following four subscales, timeline, consequences, cure/control, and emotional representations, use the same response options.

Timeline—Two of the three timeline items were retained from the IPQ to assess subjects' beliefs about how long their symptom(s) will last. A third item, which originally was included in the IPQ cure/control scale (my illness /symptom will improve in time) but has since been shown to address the timeline dimension (30), was also included in this scale.

Consequences—All seven items from the IPQ were retained in the initial testing of the SRQ. These items address the extent to which the symptom has an effect on various aspects of the subject's life.

Cure/Control—Three of the six items from the IPQ were retained for the SRQ in order to assess subjects' beliefs about the extent to which they could cure or control their symptom(s). One of the other items is now included in the timeline scale (see above). One item, addressing the possibility of recovery from the illness, was deemed not relevant to specific symptoms. Finally, one redundant item (there is very little to be done to improve my illness) was dropped to keep length at a minimum.

Emotional Representation—Four items from the Symptom Representation Interview Questionnaire (40) were selected to address an individual's emotional representation of their symptoms. These items address the extent to which the symptom causes emotional distress. The items were drawn from Cameron et al.'s interview questionnaire because the original IPQ did not contain items designed to address emotional representations (40). The IPQ-R now contains similar items (30).

Once item selection and modification was complete, a pilot evaluation of the SRQ was undertaken.

Phase 2: Feasibility and Preliminary Psychometric Evaluation

Purpose—The goals of this phase were to 1) evaluate the feasibility of using the SRQ to assess multiple symptoms; 2) evaluate the evidence for validity of using mean subscale scores across a variety of different symptoms; 3) evaluate evidence for construct validity of the instrument and its subscales, and 4) finalize item selection to reach a goal of three items per subscale in order to reduce subject burden. Because literature regarding the impact of cancer-related symptoms suggests that symptoms rarely occur in isolation (3), the authors felt it was necessary to conduct a multi-dimensional assessment of multiple symptoms. However, there were concerns that both time-related subject burden and the risk of cognitive overload with an assessment of cognitive representations of a large number of symptoms would be high if too many symptoms were included in the multi-dimensional assessment. Based on early pilot trials, feedback from women with gynecologic cancers, and input from expert clinicians, a total of three symptoms were selected as a reasonable balance between multi-symptom, multi-dimensional assessment and subject burden. Similarly, for the number of items per subscale, the goal was to maximize reliability and validity and minimize response burden. For most subscales, three items were found to be sufficient, however for the "consequences" subscale, more items were required because of the wide range of consequences experienced by cancer patients.

Sample and Procedure—Subjects were recruited from an outpatient gynecologic cancer clinic during a six-month period following Institutional Board approval. Women receiving chemotherapy for gynecologic cancers, and able to read and write in English were invited to participate on the day they were to receive chemotherapy. Sixty-nine women were approached; 54 (79%) agreed to participate. Informed consent was obtained and women were instructed to complete the survey twice, 7 and 10 days after their chemotherapy treatment. They were given two sets of questionnaires and pre-paid postage return envelopes for each questionnaire. The principal investigator called participants at home on day 7 and day 10 to remind them to complete the questionnaires.

Measures

Feasibility: An investigator developed questionnaire was used to evaluate a) clarity of questionnaire instructions; b) length of time to complete the questionnaires; c) item clarity; d) ease of completing the questionnaire; and e) any difficulties associated with completing the questionnaires.

SQR: Symptom representations were assessed using the SRQ. Participants completed the symptom identity (severity) checklist and then were asked to identify the three symptoms they "noticed most in the last week." Participants completed the five subscales measuring cognitive representations (identity, cause, timeline, consequences, cure/control) and the single emotional representation subscale for **each** symptom. Higher subscale scores reflect “more” of each dimension.

MDASI Interference Subscale: This subscale assesses the extent to which symptoms have interfered with life activities during the past week and was used as a measure of convergent construct validity (2). Specific items of the MDASI include ratings of interference with general activity, mood, work, relations with other people, walking, and enjoyment of life. Participants respond on an 11-point scale from 0 (did not interfere) to 10 (interfered completely). A mean score of the six items is calculated. This scale has been shown to be reliable (alpha = 0.91 to 0.94) and sensitive to differences in both ECOG performance status and treatment status of cancer patients (2).

Data Analysis Plan—A series of reliability analyses were performed to evaluate the validity of creating mean subscale scores across different symptoms for each individual. The first set were calculated for a single symptom, fatigue ($n = 27$). This represents the most homogeneous set of responses on the SRQ. Next, reliabilities were calculated for the symptom “noticed most” by each individual. Therefore, while only one set of SRQ symptom reports were used for each individual, different individuals reported on different symptoms. Finally, reliabilities across all SRQ symptom reports for all individuals were calculated.

Two approaches were used to evaluate the stability of the SRQ. The first approach consisted of evaluating the extent to which individuals identified the same symptoms as “noticed most in the past week” on two different occasions over a three-day time period. The second approach, a test re-test reliability approach, was to calculate time 1 to time 2 correlations for each subscale of the SRQ.

The Standards for Educational and Psychological Testing (41)were followed in the process of establishing construct validity for the SRQ. According to the American Educational Research Association, validation is the process of developing a sound argument for how to interpret scores on a test and the relevance of the test to its proposed use. Because of the very wide range of types of tests, the types of evidence that best support the validity of a proposed test also vary widely. Therefore, it is recommended that validation be clarified by developing a “set of propositions that support the proposed interpretation for the particular purpose of testing” (41, p. 9). In line with these recommendations, we proposed that evidence for the validity of the SRQ should be based on the following propositions: 1) the content and internal structure of the SRQ should be consistent with the underlying theoretical framework – The Common-Sense Model of Illness Representations (evaluated in Phase II and III); 2) test scores should be replicable and consistent across a short (e.g., 2 weeks) time frame (evaluated in Phase II); 3) responses to the SRQ should be sensitive enough to detect differences among women at different phases of the cancer trajectory (evaluated in Phase III); and 4) based on the CSM, higher scores on emotional representations, identity, and consequences, and lower scores on perceived controllability should be associated with higher scores on the MDASI Interference Subscale (Phase II and III), and overall life satisfaction (Phase III).

Because there is no “gold standard” that can be used when evaluating validity of symptom assessment instruments, instruments were selected that would allow comparison of similar constructs, that were short enough to minimize response burden, and that had strong established validity and reliability. Validity and reliability are established for the MDASI in the cancer population, making it a good tool for comparison. Life satisfaction is a more global measure

of quality of life, with established reliability and validity, but it is an instrument that does not have the response burden associated with many other quality-of-life measures.

Results

Sample Characteristics: The mean age of participants was 57.47 years (SD = 11.26); mean years of education was 13.86 (SD = 2.85). The majority were Caucasian (93.9%), married (64.8%), with a median household income in the $50–70,000 range. The majority had a diagnosis of ovarian cancer (70.4%); 11.6% had been diagnosed with cervical cancer; the remaining 16% included women with endometrial, vaginal, or uterine cancer. The mean time since diagnosis was 14.48 months (SD = 17.40).

Feasibility: Of the 54 women recruited to the study, 49 women (90.7%) completed the first set of questionnaires, and 43 (79.6%) completed both sets. Feeling too ill to complete the survey was the most common reason for withdrawing from the study (*n*=3). The mean completion time for the entire survey packet was 26 minutes (SD = 15.54). In their systematic review of symptom assessment instruments, Kirkova et al. (6) found that the median time to completion was a 10 to 15 minutes (range, 1 to 20 minutes). However, it should be noted that the survey packet also included several open-ended questions about symptom-related coping strategies in addition to the SRQ. Over 90% of the women agreed that the instructions and specific questions were clear and that the questionnaire was easy to complete. Only 11% of women felt that the survey was annoying to complete. In response to questions about the relevance of the SRQ, 85% said the questions made sense to them, and 71% agreed that the questions reflected how they thought about their symptoms.

Validity of Using Mean Scores Across Different Symptoms: ***Internal consistency:*** Table 1 summarizes the series of internal consistency analyses conducted for fatigue only (*n*=27), most noticed symptom report, and items from all three symptom reports. With the exception of the timeline subscale for fatigue only ($\alpha = 0.37$), all subscales showed adequate internal consistency (range 0.71 – 0.92). Internal consistency reliabilities were best for subscales created using items from all three symptom reports.

Stability: Of the 43 women who completed surveys at both T1 and T2, 3 women stated that they did not have symptoms that they noticed enough to comment on at either T1 or T2. Of the 40 remaining women, 12(30%) identified the same 3 symptoms as “noticed most in the last week” at both T1 and T2. Another 15 (37.5%) identified two of the same symptoms at T2, and 8 (20%) identified only one of the same symptoms at T2. For five women, the three symptoms they selected at T2 were all different from those selected at T1.

Test re-test correlation coefficients using mean scores across the three most noticed symptoms were adequate for all subscales when comparing seven days post chemotherapy to 10 days post chemotherapy: identity (r=0.82); emotional representation (r=0.78); cause (r=0.68); timeline (r=0.65); consequences (r=0.76), and cure/control (r=0.66).

Evidence for Construct Validity: Correlations among subscales of the SRQ were evaluated, as were correlations between SRQ subscales, and the MDASI Interference Subscale. Significant correlations were all in expected directions (Table 2) based on the CSM. With respect to inter-correlations among subscales, higher emotional representations, stronger identity (higher severity), longer perceived timeline, and high perceived consequences were all significantly and positively inter-correlated (with the exception of identity and timeline). Cause was associated only with timeline: perceptions of cancer as the cause of symptoms was associated with longer perceived timeline of symptoms. A shorter perceived timeline and lower symptom identity (severity) was associated with higher perceived controllability.

Higher scores on the emotional representations, identity, and consequences subscales were associated with higher symptom interference with life activities (MDASI; Table 2).

Item reduction: The goal was to decrease the number of questions to three items per subscale. For those subscales with more than three items, the items that contributed most to the internal consistency of the scale were selected.

Once we were satisfied that it was feasible to conduct a multi-dimensional assessment of multiple symptoms and we had initial support for reliability and stability of the measure, we progressed to a large sample study to gather further evidence for construct validity.

Phase 3: Large Sample Psychometric Evaluation

Purpose—The purpose of this study was to evaluate SRQ reliability and construct validity in a large sample of women with a history of ovarian cancer.

Design, Sample and Procedure—This was a cross-sectional survey study of members of the National Ovarian Cancer Coalition (NOCC). The NOCC is a national information and education organization committed to raising awareness about ovarian cancer and providing support for women with ovarian cancer. The Institutional Review Board at the University of Wisconsin granted approval and exempt status to conduct the study.

Data managers at the NOCC compiled a list of all women in their database who had been classified as “patients” with a diagnosis of ovarian cancer (n = 3,152). From that list, a notification letter was sent by NOCC to a random sample of 3000 women selected using a random numbers table. Of the 3000 surveys mailed, 377 (12.5%) were returned as “undeliverable” by the postal service, leaving a potential sample size of 2623. Women who did not wish to receive the survey could notify the NOCC using a toll-free telephone number. Only seven women called to decline participation. After two weeks, the symptom experience survey was mailed and women were requested to complete and return the survey within a 10-day period.

Instruments

SRQ: One minor change was made based on the release of the revised IPQ. “My symptom is a serious condition” was replaced with “My symptom causes difficulties for those who are close to me,” because of concerns that the former item was tapping into multiple dimensions of symptom representations (30).

The following instruments were used for evaluation of construct validity of the SRQ: MDASI Interference Subscale, the Satisfaction with Symptom Management scale (SSM), and the Life Satisfaction Questionnaire (LSQ).

MDASI Interference Subscale: As described in Study 2, it was expected that participants’ scores on the identity, consequences, and emotional representations subscales would be significantly (r >0.50) related to scores on the MDASI.

SSM: Satisfaction with symptom management was assessed with a single item: How satisfied are you with how your symptoms have been controlled in the past week? The item is based on a question from the American Pain Society's Patient Outcome Questionnaire (42). Response options were on an 11-point scale of 0 (very dissatisfied) to 10 (very satisfied). In evaluating evidence for construct validity of the SRQ, it was expected that the identity, consequences, and emotional representations subscales would be negatively correlated and controllability would be positively correlated with the SSM.

LSQ: The LSQ was used to assess life satisfaction (43). Items are rated on an 11-point scale from 0 "not at all" to 10 "a great deal" for the first four questions and "extremely poor" to "excellent" for the last question. A Cronbach's alpha of 0.82 has been reported by Cameron et al. (40). In convergent construct validity testing, it was expected that the relationships among subscales of the SRQ and the LSQ would be in similar patterns and directions as with the MDASI, but that the strength of the association would be weaker because life satisfaction is a more distal outcome, affected by many issues in addition to symptom experiences.

Clinical Survey: An investigator-developed instrument was used to assess disease and treatment status (stage at diagnosis, time since diagnosis, current disease status, type of treatment currently receiving). This survey was completed by the participant.

Data Analysis Plan

Reliability: As in Study 2, a series of internal consistency analyses were conducted to evaluate reliability for the SRQ using a single symptom, fatigue; for the symptom noticed most by each subject in the past week; and using all items from the three SRQ's completed by each subject for their three most noticed symptoms.

Evidence for Construct Validity: As described in Phase II, the procedure that we have followed for reporting evidence for construct validity of the SRQ is based on The Standards for Educational and Psychological Testing (41).

Evidence for Construct Validity Based on Internal Structure: The internal structure of the SRQ was evaluated using principal axis factoring with oblique rotation. All 15 items from the emotional representation, identity, timeline, cause, consequences, and cure/control subscales were entered into the analysis. Separate analyses were conducted for each set of SRQ symptom reports (symptom noticed most in past week, symptom noticed second most, and symptom noticed third most).

Evidence for Construct Validity Based on Relationships with Other Variables: Independent sample *t*-tests were computed, comparing the symptom representations of long-term survivors (n=134) with women with active disease (n=279) for each of the subscales of the SRQ. The final evaluation of construct validity was conducted by calculating correlation coefficients between the symptom representation subscales and scores on the MDASI Interference Scale, the SSM), and the LSQ.

Results

Sample Characteristics: The sample includes 713 women with a history of ovarian cancer. The 713 completed surveys represent a 27.2% response rate based on the 2,623 surveys delivered. However, we also received responses from family members of 157 women who had died of ovarian cancer, and from 55 women who reported that they had never been diagnosed with cancer. Therefore, we also calculated the response rate based on the number of *eligible* women who received the survey. In order to do this, we extrapolated based on the percentages of the three groups of responders – family members of deceased (17.0% of all responders), women without a history of ovarian cancer (5.9% of all responders), and women with ovarian cancer (77.1% of all responders) – because it most likely reflects the percentages of those who received the survey. In other words, it is likely that 17% of surveys (n = 446) were delivered to addresses where a woman had died from ovarian cancer and another 5.9% of surveys (n =155) were delivered to women who had never been diagnosed with ovarian cancer. This would leave 2,022 eligible women with a history of ovarian cancer receiving surveys. Based on this calculation, our best estimate is that the 713 completed surveys represent a 35.3% response rate from the eligible population.

The final sample of 713 survivors comprised 134 long-term survivors (no evidence of disease for ≥ 5 years); 300 without evidence of disease for less than 5 years; and 279 with active ovarian cancer. The mean age was 53.4 years (SD = 11.4); mean time since diagnosis was 59.0 months (SD = 48.94). This was a highly educated group of women, with 85% having at least some college education. The median income range reported was $30,000 – $60,000 per year.

Internal Consistency: Internal consistency was good for all subscales of the SRQ. Table 3 compares reliabilities for a single symptom (fatigue), for all symptoms identified by women as their symptom "noticed most in the past week," and across all three symptoms. It should be noted that the reliability of the cure/control subscale improves for individual symptoms if the two personal control items are evaluated separately from the treatment control item (α ranging from 0.71 – 0.81), but is unchanged when looking across all three symptoms (α = 0.66).

Evidence for Construct Validity Based on Internal Structure: For each set of SRQs (noticed most, noticed second most, noticed third most), the best solution based on a scree plot was a four-factor solution: the first factor included all items from the hypothesized emotional representation, identity, and consequence subscales; the second factor included items from the cure/control subscale, the third factor included all items from the timeline subscale, and the fourth factor included the cause items. Table 4 shows clear factor loadings for every item on the SRQ for the symptom noticed most in the past week. Based on the initial factor extraction, these four factors explained approximately 64% of the SRQ variance (Table 5).

The same factor structure was found for the symptoms identified as second and third "noticed most in past week," adding additional support for the stability of these findings. In addition, the same factor structure was also found when conducting the factor analysis within the different subgroups of women (long-term survivors, women with no evidence of disease < 5 years, and women with active disease). The only exception was that the two cause items did not load clearly on any factor for women with active disease.

Inter-correlations among factors were small to moderate. The strongest correlations were between the emotional representation/identity/consequence factor and the timeline and cause factors (−0.29 to −0.38) and between the cure/control factor and the timeline factor (−0.31 to −0.38). The cure/control factor and the emotional representation/identity/consequence factor were uncorrelated. All other inter-factor correlations were in the 0.15 range (see Table 6 for intercorrelations among factors for Symptom #1).

Evidence for Construct Validity Based on Relationships with Other Variables:
Differences between known groups. Women with active disease had significantly different representations of symptoms than did long-term survivors, except for the timeline subscale. Those with active disease had more serious representations than long-term survivors: they had more severe symptoms, had stronger emotional representations of their symptoms, were more likely to attribute their symptoms to cancer, believed their symptoms had greater consequences, and perceived less control over their symptoms than long-term survivors (Table 7).

Relationships with other variables. Results are shown in Table 8. All inter-subscale correlations are in expected directions. Furthermore, as anticipated, there were strong, positive correlations between the MDASI and the emotional representation, identity, and consequences subscales of the SRQ. Also as expected, similar patterns, but with slightly weaker associations, were found for the LSQ. In evaluating relationships with the SSM, there was one unexpected finding. There was no relationship between perceptions of symptom controllability and satisfaction with symptom management.

Discussion

The dimensional structure of the SRQ was consistent with, but not identical to, the theoretical underpinnings of Leventhal's Common-Sense Model. With one exception, the pattern of loadings from the SRQ supported the theoretically-derived subscales. The three timeline items clearly loaded onto their own factor, as did the three cure/control items and the two cause items. The only unexpected finding is that in each case, all three emotional representation items, the single identity item, and all three consequence items loaded onto the first factor. In future research, these seven items, therefore, could be combined into a single subscale (alpha = 0.83) to reflect a global "symptom seriousness" scale. However, in many studies, the distinction between emotional representations and the cognitive representation dimensions of identity and consequences may be theoretically important.

In addition, it should be noted that the operationalization of symptom identity as "symptom severity" likely contributed to the overlap of these scales. In the CommonSense Model, identity is conceptualized as the concrete symptoms and abstract labels associated with an illness (8). For illness representations, symptoms are a key component of the identity dimension. In looking at representations of symptoms, there may be a better analogous conceptualization than symptom severity. One possibility could be the use of verbal descriptors of symptoms such as "throbbing, stabbing, or burning" for pain, or "chemo brain, fuzzy, or forgetful" for memory problems. This of course, would add to the length and complexity of the SRQ, a factor that should be considered carefully especially when using the SRQ to assess multiple symptoms.

Internal consistency was good for all subscales of the SRQ. In addition, reliabilities were good regardless of whether reliability was evaluated for one symptom, across three symptoms for each woman, or for different symptoms that had been identified by women as their symptom "noticed most in the past week". This lends strong support for the appropriateness of using the SRQ for assessing either single or multiple, participant identified symptoms. There was one exception to this general pattern. For fatigue, reliability of the cure/control subscale was poor (0.33). For that subscale, the reliability improves (0.63) if the treatment control item is removed. This is likely due to the fact that in the case of cancer-related fatigue, it is often treatment that is causing the fatigue. Therefore, an item such as "treatment will be effective in controlling this symptom" could have been confusing for women experiencing treatment-related fatigue.

The comparison of SRQ scores between women with active disease and long-term survivors provided good evidence for concurrent construct validity. Women with active disease, in general, had more serious representations of their symptoms than did long-term survivors. Specifically, women with active disease were experiencing symptoms of higher severity, had more symptom-related distress, higher perceived consequences, and reported lower perceived control over their symptoms than did long-term survivors. Perceived cause of symptoms also differed between the two groups, with women with active disease more likely to attribute their symptoms to cancer than long-term survivors.

The exception to the pattern of women with active disease having more serious representations was that symptom timeline did not differ between women with active disease and long-term survivors. The timeline questions tap into aspects of both permanency and duration of symptoms. It is possible that women with active disease do not expect their symptoms to last a long time because they do not expect to live a long time.

In looking further at evidence for construct validity, expected patterns and directions of relationships were found between the SRQ subscales, measures of symptom interference with life activities, satisfaction with symptom management, and life satisfaction. The only exception was that there was no relationship between perceived controllability of symptoms and

satisfaction with symptom management. There may be a logical explanation for this lack of association. There may be no relationship between the two because perceptions of controllability set expectations regarding the extent to which symptom management is expected to be successful. In other words, patients with low levels of perceived symptom controllability can be satisfied because they do not have expectations for good symptom management.

Limitations

Limitations of the study included issues related to self-report information, a low response rate in recruitment for Phase III, and generalizability. First, all data, including diagnosis and treatment-related information, was self-report and not able to be validated with medical record review. Although women with ovarian cancer are typically well-informed and knowledgeable regarding their disease and treatment history, we were unable to corroborate self-report information with objective data. Second, a cross-sectional survey design was used for Phase III of instrument development because it yielded the large number of participants needed to establish internal consistency and final psychometric properties of the instrument. However, the low response rate (27–35%) could lead to potential bias in that those that responded may not be truly representative of this population of women. Finally, women recruited for Phase III of the study belonged to a national cancer coalition. Persons who belong to a group such as this may inherently have different characteristics than the general population of women with ovarian cancer. The next phase of instrument testing should target groups of women in clinical sites, regardless of their participation in national organizations or support groups.

Conclusions

The SRQ appears to be a psychometrically sound and versatile instrument for assessing cognitive and emotional representations of a wide variety of cancer-related symptoms. Reliability was strong for single symptoms as well as across multiple symptoms. Construct validity was supported by differences in symptom representations between women with active disease and long-term survivors, and by expected associations between representations, symptom interference, and life satisfaction. The SRQ can be used by researchers and clinicians to better understand the cognitive and emotional responses to cancer-related symptoms. It can also be used to assess key relationships between representations of symptoms, use of specific symptom management strategies, and important health related outcomes for patients after a diagnosis of cancer. Finally, it may also prove useful for identifying potential targets of educational interventions to optimize cancer symptom management. Work is currently underway to evaluate changes in symptom representations as potential mediators of the effectiveness of a representational intervention to improve symptom management for cancer patients (32).

Symptom Representation Questionnaire – Part 1

Listed below are a number of symptoms that you may or may not experience. Please report on all symptoms that you have experienced in the <u>past week</u> regardless of whether they were associated with your cancer, whether they were side effects of your cancer treatment, or whether they were due to other causes.

Thinking about the symptoms you experienced during the <u>past week</u>, circle the number that best describes how bad it was when it was at its <u>worst</u>, where:

0 = “did not have the symptom” and 10 = “as bad as I can imagine”

1. Abdominal Bloating.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

2. Bowel Disturbances (e.g. Constipation, Diarrhea, Cramping).....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
3. Depression.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
4. Dizziness.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
5. Drowsiness.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
6. Fatigue.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
7. Hair Loss.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
8. Headaches.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
9. Hot Flashes.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
10. Lack of Appetite.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
11. Memory Problems.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
12. Mood Swings.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
0 = did not have it 10 = as bad as I can imagine											
13. Nausea.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
14. Numbness/Tingling.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
15. Pain.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
16. Sexuality Concerns.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
17. Shortness of Breath.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
18. Sleep Disturbance.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
19. Urinary Problems.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
20. Vomiting.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
21. Weight Gain.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
22. Weight Loss.....	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
23. Other_____	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
24. Other_____	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

Please list the 3 symptoms that you noticed most in the last week.

Symptom #1 (noticed most)_____

Symptom #2 (noticed 2nd most)_____

Symptom #3 (noticed 3rd most)_____

Symptom Representation Questionnaire – Part 2

We are interested in your own personal views about how you now see your symptoms.

For the following questions, please respond with regard to Symptom #1 (the symptom you noticed most in the past week) listed on the previous page.

Please indicate how much you agree or disagree with the following statements about Symptom #1 by checking the appropriate box.

Symptom #1: _____(please write in as a reminder)

	VIEWS ABOUT SYMPTOM #1	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
S1.1	It is difficult to take my mind off this symptom.....					
S1.2	What I do can determine whether this symptom gets better or worse.....					
S1.3	This symptom has had major consequences on my life.....					

	VIEWS ABOUT SYMPTOM #1	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
S1.4	There is a lot which I can do to control this symptom.....					
S1.5	Treatment for my cancer is causing this symptom.....					
S1.6	Worry about this symptom often intrudes on my other thoughts and activities.....					
S1.7	This symptom is likely to be permanent rather than temporary.....					
S1.8	My symptom causes difficulties for those who are close to me.....					
S1.9	I have been emotionally upset or distressed about this symptom.....					
S1.10	My cancer is causing this symptom.....					
S1.11	This symptom has not had much effect on my life.....					
S1.12	This symptom will last for a long time.....					
S1.13	Treatment will be effective in controlling this symptom.....					
S1.14	This symptom will improve in time.....					

Subjects then repeat part 2 for Symptom #2 and Symptom #3

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Table 1

SRQ Reliabilities for Study 2

	Fatigue only (*n* = 27)	Symptom identified as "noticed most" (*n* = 49)	Across all 3 symptoms (*n* = 49)
Emotional Representation	.83	.88	.92
Identity	n/a	n/a	.84
Cause	n/a	n/a	.83
Consequences	.79	.82	.81
Timeline	.37	.71	.76
Cure/Control	.86	.76	.83

Table 2

Correlations Among Dimensions of the SRQ and Symptom Interference with Life Activities, Study 2.

	Emotion	Identity	Cause	Timeline	Conseq	Control	MDASI
Emotion	--						
Identity	.56*	--					
Cause	.24	.05	--				
Time	.31*	.16	.34*	--			
Conseq	.76*	.43*	.28	.46*	--		
Control	−.05	−.37*	.19	−.36*	−.09	--	
MDASI	.65*	.70*	.23	.15	.59*-	−.15	--

AU: WHAT DOES THE ASTERISK REPRESENT? PLEASE REPLACE WITH A SUPERSCRIPT “a” AND DEFINE

Table 3

Comparison of Symptom Representation Questionnaire Reliabilities for Fatigue Only, Symptom Noticed Most in the Past Week, and Across All 3 Symptoms, Study 3

	Fatigue only (*n*=110)	Symptom identified as "noticed most" (*n*=662)	Across all 3 symptoms (*n*=608)
Identity	n/a single item	n/a single item	0.84
Cause	n/a single item	n/a single item	0.80
Consequences	0.81	0.79	0.85
Timeline	0.76	0.85	0.84
Cure/Control			
Personal & Treatment	0.33	0.61	0.67
Personal only	0.63	0.71	0.66
Emotional Representation	0.87	0.81	0.88
Total Scale	0.84	0.82	0.91

Table 4

SRQ Principal Axis Factoring with Oblique Rotation and Extraction of 4 Factors (Symptom #1)

	Factor 1	Factor 2	Factor 3	Factor 4
Emotional/Identity/Consequences				
It is difficult to take my mind off this symptom	**.68**	−.08	−.06	.04
Worry about this symptom often intrudes on my other thoughts and activities.	**.75**	.11	−.02	.04
I have been emotionally upset or distressed about this symptom.	**.79**	<.01	.03	−.06
Symptom 1 severity (identity)	**.52**	−.19	−.03	.10
This symptom has major consequences on my life.	**.77**	.05	.12	<.01
My symptom causes difficulties for those who are close to me.	**.64**	.07	.13	.01
This symptom has not had much effect on my life.	**−.68**	.03	−.05	.07
Cure/Control				
What I do can determine whether this symptom gets better or worse.	−.04	**.68**	.02	−.05
There is a lot which I can do to control this symptom.	−.20	**.76**	.02	−.06
Treatment will be effective in controlling this symptom.	.17	**.36**	−.14	.05
Timeline				
This symptom is likely to be permanent rather than temporary.	.06	.09	**.87**	.07
This symptom will last for a long time.	.09	.03	**.80**	.09
This symptom will improve in time.	<.01	.18	**−.67**	.06
Cause				
Treatment for my cancer is causing this symptom.	−.13	−.03	−.02	**.90**
My cancer is causing this symptom.	.10	.01	.09	**.50**

AU: PLEASE DEFINE THE BOLDED NUMBERS IN A LEGEND

Table 5

Total SRQ Variance Explained (Symptom #1)

	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings[a]
Factor	**Total**	**% of Variance**	**Cumulative %**	**Total**	**% of Variance**	**Cumulative %**	**Total**
Emotional/Identity/ Consequences	4.87	32.46	32.46	4.44	29.57	29.57	3.97
Cure/Control	2.15	14.36	46.82	1.71	11.38	40.95	1.55
Timeline	1.40	9.32	56.14	1.02	6.80	47.75	2.65
Cause	1.27	8.47	64.61	.84	5.59	53.34	1.67

[a]When factors are correlated, sums of squared loadings cannot be added to obtain a total variance.

Table 6

SRQ Factor Correlation Matrix (Symptom #1)

Factor	Emotional/Identity/ Consequences	Cure/Control	Timeline	Cause
Emotional/Identity/ Consequences	1.00	--	--	--
Cure/Control	−.05	1.00	--	--
Timeline	.31[a]	−.31[a]	1.00	--
Cause	.33[a]	−.14[a]	.19[a]	1.00

[a] $P < 0.01$.

Table 7

Comparison of SRQ Subscales Between Long-Term Survivors and Women with Active Disease, Study 3.

	Long-Term Survivors (*n*=114) M (SD)	Active Disease (*n*=274) M (SD)	*t*
Identity	5.02 (2.49)	6.27 (2.10)	−5.00[a]
Emotional Representation	1.60 (0.92)	1.94 (0.82)	−3.55[a]
Cause	0.95 (1.02)	2.33 (0.79)	−14.22[a]
Timeline	1.96 (0.83)	1.90 (0.82)	−0.68
Consequences	1.83 (0.81)	2.10 (0.75)	−3.05[a]
Cure/Control	2.15 (0.66)	1.96 (0.58)	−2.93[a]

M (SD) = mean (standard deviation).

[a] $P<0.01$.

Table 8

Correlation Between Symptom Representations (SRQ Subscales) and Symptom Interference with Life Activities (MDASI), Satisfaction with Symptom Management (SSM), and Life Satisfaction (LSQ), Study 3.

	MDASI	SSM	LSQ
Emotional Representation	.54[a]	−.39[a]	−.47[a]
Identity	.59[a]	−.37[a]	−.37[a]
Cause	.28[a]	−.11[a]	−.16[a]
Timeline	.10[a]	−.16[a]	−.15[a]
Consequences	.56[a]	−.37[a]	−.45[a]
Cure/Control	−.06[a]	.03	−.10[a]

[a] $P < 0.01$.