Development and Testing of the Symptom Experience Scale

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Abstract
The Symptom Experience Scale (SES) was designed to measure women’s experiences of symptoms associated with treatment for breast cancer. The SES, a modification of McCorkle’s Symptom Distress Scale, was developed and tested in a sample of 252 women with breast cancer. Exploratory factor analysis yielded six factors, which used all 24 SES items and accounted for 83.2% of the variance. The factors were nausea and appetite, fatigue and sleep, concentration, appearance, bowel pattern, and pain. Cronbach’s alpha internal consistency reliability coefficients ranged from 0.92 to 0.96; the alpha for the total SES was 0.94. Subscale to subscale correlations ranged from 0.21 to 0.56. Additional research is recommended with samples large enough to permit confirmatory factor analysis and determine the stability of the factor structure identified in the present study. Additional research also is recommended to determine the applicability of the SES for men and women of diverse ethnic groups with various types of cancer and other chronic illnesses. J Pain Symptom Manage. 1996;12:221–228.

Key Words
Breast cancer, symptom distress, symptom experience, measurement

Introduction
Symptoms associated with breast cancer diagnosis and treatment include nau"e, which typically follows surgery, and the side effects of chemotherapy and radiation. Women receiving chemotherapy may experience nausea and vomiting, hair loss, fatigue, and anorexia. In addition, fatigue is often associated with radiation therapy. According to McCorkle, the measurement of these symptoms is essential to assess patients’ needs, determine the effectiveness of nursing interventions targeted to symptom management, and assist patients in monitoring their own levels of health. The purpose of this article is to describe the development and psychometric testing of the Symptom Experience Scale (SES), which was derived from the Symptom Distress Scale (SDS), for women with breast cancer.
Background

McCorkle and Young\(^8\) developed the original version of the SDS to measure symptom distress in patients with chronic illness. They defined symptom distress as "the degree of discomfort reported by the patient in relation to his/her perception of the symptoms being experienced."\(^9\) The ten symptoms included in the SDS were nausea, mood, appetite, insomnia, pain, mobility, fatigue, bowel pattern, concentration, and appearance. During interviews, patients were given a separate 5-inch by 7-inch index card to complete for each symptom and were requested to circle a number from 1 to 5, with a score of 1 indicating the least distress, scores of 2, 3, and 4 indicating intermediate levels of distress, and a score of 5 indicating the greatest distress. The Cronbach's alpha internal consistency reliability coefficient was reported as 0.82 for a sample of 53 patients with chronic illness.

The SDS was later expanded for use specifically with patients who had either lung cancer or a myocardial infarction.\(^10\) This expanded version of the SDS contained 13 items, each of which was rated on a five-point scale of least distress to extreme distress. The items were frequency of nausea, intensity of nausea, appetite, insomnia, frequency of pain, intensity of pain, fatigue, bowel pattern, concentration, appearance, breathing, outlook, and cough. The possible range of scores for total symptom distress was 15 to 65, with higher scores reflecting greater levels of symptom distress. The Cronbach's alpha coefficients were reported as 0.78 and 0.79 for repeated administrations in a sample of 67 persons with lung cancer and 71 persons who had had myocardial infarctions.

McCorkle\(^8\) subsequently revised the 13-item SDS by adding descriptive words to operationalize each scale point. For example, the item for fatigue was operationalized as follows: 1 = "I seldom feel tired or fatigued;" 2 = "There are periods when I am rather tired or fatigued;" 3 = "There are periods when I am quite tired and fatigued;" 4 = "I am usually very tired and fatigued;" and 5 = "Most of the time I feel exhausted."

The 13-item SDS has been used to assess symptom distress in adult patients\(^11\)-\(^15\) and adolescents\(^14\) with various types of cancer. In addition, a linear analogue version of the SDS has been used to assess symptom distress in adults with cancer.\(^16\)

The McCorkle 13-item SDS\(^8\) was further modified by Samarel and colleagues\(^16\)-\(^17\) for use with women with breast cancer. They defined symptom distress as the amount of physical distress or unpleasant body sensations that the women experienced during treatment for breast cancer. Two items, breathing and cough, were omitted because they are not directly related to breast cancer. An additional item, outlook, was also omitted because it represents a psychological state rather than a symptom. The resulting SDS had ten items, representing eight symptoms that are directly relevant to breast cancer treatment: frequency of nausea, intensity of nausea, frequency of pain, intensity of pain, appetite, sleep disturbance, fatigue, bowel pattern, concentration, and appearance. Each item was rated on a scale of 1-5. Items were summed for a possible range of 10-50, with higher scores indicating greater symptom distress. The Cronbach's alpha internal consistency reliability coefficient was 0.82 in a sample of 181 women with early stage breast cancer.\(^17\)

Analysis of the data from Samarel et al.'s longitudinal study of the effects of support group participation on adaptation to breast cancer revealed no effects of support group participation on symptom distress as measured by the ten-item SDS.\(^16\) In contrast, analysis of qualitative data obtained from interviews with the women who participated in the study suggested that the frequency and intensity of treatment-related physical symptoms were not necessarily affected by support group participation but that perceived distress was an important dimension of the symptom experience. More specifically, the women reported that although support group participation did not always reduce the frequency or intensity of a symptom, participation often did reduce the distress experienced as a result of that symptom. However, the SDS does not permit separate measurement of the frequency, intensity, and distress for each symptom. In particular,
I never felt any nausea.

Table 1.
Symptom Experience Scale Descriptors for One Item: Nausea

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>I never felt any nausea.</td>
</tr>
<tr>
<td>1</td>
<td>I was occasionally nauseous.</td>
</tr>
<tr>
<td>2</td>
<td>I was frequently nauseous.</td>
</tr>
<tr>
<td>3</td>
<td>I was usually nauseous.</td>
</tr>
<tr>
<td>4</td>
<td>I was always nauseous.</td>
</tr>
<tr>
<td>0</td>
<td>I never felt any nausea.</td>
</tr>
<tr>
<td>1</td>
<td>When I had nausea, it was very mild.</td>
</tr>
<tr>
<td>2</td>
<td>When I had nausea, I felt fairly sick.</td>
</tr>
<tr>
<td>3</td>
<td>When I had nausea, I felt very sick.</td>
</tr>
<tr>
<td>4</td>
<td>When I had nausea, I felt as sick as I could possibly be.</td>
</tr>
<tr>
<td>0</td>
<td>I never felt any nausea.</td>
</tr>
<tr>
<td>1</td>
<td>When I had nausea, I was not at all upset.</td>
</tr>
<tr>
<td>2</td>
<td>When I had nausea, I was mildly upset.</td>
</tr>
<tr>
<td>3</td>
<td>When I had nausea, I was very upset.</td>
</tr>
<tr>
<td>4</td>
<td>When I had nausea, I was as upset as I could possibly be.</td>
</tr>
</tbody>
</table>

frequency and intensity are explicitly and separately rated only for nausea and pain, whereas distress is not explicitly or separately rated for either symptom. Furthermore, the scale point descriptors for concentration deal only with frequency, and those for appetite deal only with intensity. Moreover, the scale point descriptors for fatigue and sleep disturbance confound frequency and intensity, those for appearance confound frequency and distress, and those for bowel pattern confound frequency, intensity, and distress. In addition, none of the descriptors allow for the absence of a symptom. Consequently, the SES was designed to permit separate and explicit ratings for the frequency, intensity, and distress of each symptom, as well as the possibility of the absence of symptoms.

**Symptom Experience Scale**

The SES measures the frequency and intensity of breast cancer-related symptoms or unpleasant body sensations, and the distress experienced as a result of the symptoms or sensations. The SES includes the eight symptoms or sensations that were used for the Samarel et al. modification of the SDS: nausea, pain, appetite disturbance, sleep disturbance, fatigue, changes in bowel pattern, concentration disturbance, and changes in appearance. Content validity of the eight symptoms for the clinical situation of breast cancer was confirmed by a panel of postdoctoral fellows in psychosocial oncology. Each symptom is rated with regard to its frequency, intensity, and distress, for a total of 24 items. Each item is rated on a five-point Likert scale ranging from 0 (absence of the symptom) to 4 (most negative symptom experience). Descriptive words operationalize each point on the scale. The descriptors allow for total absence of a symptom (0) and are given for all items. Table 1 displays the items and descriptors for one symptom on the SES. The SES is administered as a 3-page self-report mailed questionnaire that can be completed in less than 10 min. Subjects are asked to complete the SES by circling the number corresponding to their experience for each item during the past week. Item scores are summed to obtain the total symptom experience score, which can range from 0 to 96; the higher the score, the greater the total negative symptom experience.

**Methods**

**Sample**

The sample included 252 English-speaking women who had been diagnosed with breast cancer within the past year. The subjects were recruited from the American Cancer Society Reach to Recovery program and from the radiation oncology and chemotherapy units in a major medical center. The demographic and treatment data for the sample are presented in Table 2. The women ranged in age from 30 to 89 years (M = 57.41). The vast majority (92%) of the women were white and had at least a high school education (85%). Almost two-thirds (63%) were married, and approximately three-quarters of the women were homemakers (24%) or had sales/clerical
(29%) or professional (21%) occupations. Forty-one percent of the women were employed at the time of data collection.

The data were collected from the women, on average, slightly more than 5 months after surgery (M = 23.8 weeks, SD = 18.66 weeks). Sixty-nine percent of the women had a mastectomy, and 18% had a lumpectomy; type of surgery was unknown for the remainder of the sample (13%). At the time of data collection, 50% of the women were receiving only chemotherapy, 7% were receiving only radiation, and 6% were receiving both chemotherapy and radiation.

Procedure
The study protocol was approved by two university human subjects committees. The women received the explanations of the research and the questionnaires via mail through the American Cancer Society or in person from radiation oncology or chemo-therapy nurses. The women completed the SES at home and returned it via mail in stamped self-addressed envelopes.

Results

Missing Data Analysis

Decision rules for missing data specified that (a) individual items would be dropped if more than 5% of all subjects had a missing value for that item, and (b) a case would be dropped if more than 10% of the items were missing for that subject. Visual inspection of the frequency displays revealed that none of the items or cases had to be dropped. One of the 252 subjects had missing data on one item and two additional subjects had missing data on another item. Consequently, the number of subjects met the criterion of ten subjects per item for factor analysis.18

No consensus exists concerning the most appropriate method for the imputation of values for item nonresponse.19 In this study, the sample mode was substituted for the three missing values.

Factor Analysis
The structure of the SES was examined by an exploratory principal components factor analysis with varimax orthogonal rotation. This approach eventually yielded a parsimonious and conceptually clear solution.20 The investigators expected that the SES would have three factors, representing the three dimensions for each symptom, that is, frequency, intensity, and distress. A forced three-factor solution, however, yielded conceptually confusing clusters of symptoms. A mathematical solution was then sought. The subsequent rotated principal factor solution yielded seven factors with eigenvalues greater than 1.00, accounting for a total of 87.6% of the variance. The seventh factor was dropped, however, because it barely met the standard inclusion criterion of an eigenvalue of at least 1.00 and was the point of flattening of the scree plot.21

The factor matrix after rotation with a six-factor solution is presented in Table 3. The six-factor solution, which accounted for 83.2% of the variance, used all 24 of the SES items and yielded conceptually clear results. All 24 items
Table 3

Factor Loadings in the Rotated-Factor Matrix for the Symptom Experience Scale (N = 252)

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 1: Nausea and appetite</th>
<th>Factor 2: Fatigue and sleep</th>
<th>Factor 3: Concentration</th>
<th>Factor 4: Appearance</th>
<th>Factor 5: Bowel pattern</th>
<th>Factor 6: Pain</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Nausea: Intensity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Frequency</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Appetite: Intensity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Distress</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Frequency</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

were retained because all loadings met the conservative criterion of at least 0.50.

The six factors were named on the basis of the content of the items. Factor 1 was labeled nausea and appetite; Factor 2, fatigue and sleep; Factor 3, concentration; Factor 4, appearance; Factor 5, bowel patterns; and Factor 6, pain.

Descriptive Statistics and Reliability of the SES

The SES subscales based on the six factors could be considered to be simple summations of the relevant items. Descriptive statistics and Cronbach's alpha internal consistency reliability coefficients for the six factor-based subscales and the total 24-item SES are presented in Table 4. The overall Cronbach's alpha was 0.94. The subscale alphas ranged from 0.92 to 0.96.

Subscale to Subscale Correlations

The cutoff point for acceptable subscale to subscale correlations is an r of less than 0.70. Higher correlations would suggest overlapping or redundant subscales. None of the correlations between the six factor-based subscales of the SES exceeded this cut-off point. A correlation of 0.56 was found between Factor 2, fatigue and sleep, and Factor 3, concentration, as well as between Factor 2 and Factor 4, appearance. The remaining correlations ranged between 0.21 (Factor 1, nausea and appetite with Factor 6, pain) and 0.54 (Factor 1 with Factor 5, bowel pattern). The correlation matrix for the six factor-based subscales is given in Table 5.
Descriptive Statistics and Reliability Coefficients for the Six Factor-Based Symptom Experience Scale Subscales (N = 252)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Mean</th>
<th>SD</th>
<th>Potential range</th>
<th>Obtained range</th>
<th>Cronbach's alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor 1: Nausea and appetite (six items)</td>
<td>2.73</td>
<td>4.1</td>
<td>0-24</td>
<td>0-25</td>
<td>0.92</td>
</tr>
<tr>
<td>Factor 2: Fatigue and sleep (six items)</td>
<td>7.61</td>
<td>5.1</td>
<td>0-24</td>
<td>0-24</td>
<td>0.92</td>
</tr>
<tr>
<td>Factor 3: Concentration (three items)</td>
<td>2.07</td>
<td>2.7</td>
<td>0-12</td>
<td>0-12</td>
<td>0.96</td>
</tr>
<tr>
<td>Factor 4: Appearance (three items)</td>
<td>1.42</td>
<td>2.6</td>
<td>0-12</td>
<td>0-12</td>
<td>0.94</td>
</tr>
<tr>
<td>Factor 5: Bowel pattern (three items)</td>
<td>2.13</td>
<td>2.9</td>
<td>0-12</td>
<td>0-11</td>
<td>0.95</td>
</tr>
<tr>
<td>Factor 6: Pain (three items)</td>
<td>1.97</td>
<td>2.5</td>
<td>0-12</td>
<td>0-11</td>
<td>0.94</td>
</tr>
<tr>
<td>Total scale (24 items)</td>
<td>17.95</td>
<td>14.6</td>
<td>0-96</td>
<td>0-71</td>
<td>0.94</td>
</tr>
</tbody>
</table>

Construct Validity

A low but statistically significant negative correlation was found between the number of weeks since surgery and total symptom experience, r(222) = -0.15, one-tailed P = 0.013. As expected, women who completed the SES closer to the time of surgery reported a more negative symptom experience with regard to fatigue and sleep disturbance (r = -0.16, P = 0.009), appearance (r = -0.11, P = 0.045), and pain (r = -0.13, P = 0.022) than those who completed the SES farther from the time of surgery. Also as expected, the correlations were not statistically significant for weeks since surgery and symptom experience with regard to nausea and appetite (r = -0.08, P = 0.12), concentration (r = -0.07, P = 0.159), and bowel pattern (r = -0.10, P = 0.078).

Furthermore, as expected, women currently receiving chemotherapy (N = 74) had a more negative total symptom experience than women who were receiving no adjuvant therapy (N = 143) [t(159) = 3.45, one-tailed P = 0.0005]. Scores for all symptom clusters were significantly more negative for the women receiving chemotherapy. In contrast to expectations, there was no evidence of a difference in symptom experience for the women who were currently receiving radiation (N = 18) and those who were receiving no adjuvant therapy (N = 143) [t(159) = 1.05, one-tailed P = 0.1465].

Discussion

The factor analysis for the 24-item SES yielded six factors. As can be seen in Table 4, the obtained range of scores for the total SES, compared with the possible range, indicates that the SES captures the variability in reports of symptoms. Although the mean scores indicate that the symptom experience associated with breast cancer at the time that the subjects completed the SES was not, on average, particularly negative, these scores reflect the nature of the response to cancer treatment per se and should not be interpreted as a flaw in the instrument.

As also can be seen in Table 4, the internal consistency reliabilities for all six factors and the total SES are more than adequate for research purposes. In fact, Nunnally and Bernstein maintain that a reliability coefficient of 0.70 is sufficient in the early stages of instrument development.

Factor analysis was used to explore the underlying structure of the symptom experience. Although we initially expected to find...
three factors based on the dimensions of the symptoms, namely, frequency, intensity, and distress, we found that the actual factor structure was instead the symptoms themselves, with the dimensions of the symptoms (frequency, intensity, and distress) as components of each factor. The factor analysis yielded six clusters of symptoms: nausea and appetite, fatigue and sleep, concentration, appearance, bowel pattern, and pain. These findings indicate that the three dimensions of the symptom experience are equally important. By measuring all three dimensions, researchers and clinicians should be able to target interventions to a specific aspect of a symptom or symptom cluster.

The present study results are similar to Portenoy and colleagues’ factor analysis of the Memorial Symptom Assessment Scale. In particular, they also found that the frequency, severity, and distress dimensions of symptoms were components of each symptom subscale.

Recommendations

The SES is a useful instrument for assessing symptoms associated with treatment for breast cancer. The high reliability coefficients for the SES subscales indicate that the use of either the total score or subscale scores would depend on the aims of the study. Further research is recommended with samples large enough to permit confirmatory factor analysis to determine the stability of the factor structure identified in the present study. Moreover, additional psychometric studies are recommended, with consideration given to other approaches to construct validity, assessment of criterion validity, and the sensitivity of the SES to measurement of change. In addition, further research is recommended to determine the psychometric properties of the SES for men and women of diverse ethnicity with varying types of cancer.

Acknowledgment

This research was funded by the American Cancer Society (PBR 64, Principal Investigator, Nelda Samarel) and by the National Cancer Institute (CAS9251, Principal Investigator, Nelda Samarel). The investigators gratefully acknowledge the consultation for the revised scale and comments on an earlier draft of the manuscript provided by Ruth McCorkle, PhD, FAAN. Appreciation is also expressed to Diane Hiller, Research Associate at William Paterson College, for assistance with data management.

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