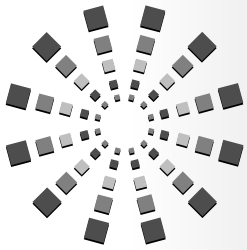

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A Systematic Review of the Symptom Distress Scale in Advanced Cancer Studies

KEY WORDS
Advanced cancer
Symptom Distress Scale
Systematic review

Background: The 13-item Symptom Distress Scale (SDS) is a widely used symptom measurement tool, yet a systematic review summarizing the symptom knowledge generated from its use in patients with advanced cancer is nonexistent. **Objectives:** This was a systematic review of the research literature in which investigators utilized the SDS as the measure of symptoms in patients with advanced cancer. **Methods:** We searched PubMed, CINAHL, EMBASE, and Web of Science for primary research studies published between 1978 and 2013 that utilized the SDS as the measurement tool in patients with advanced cancer. Nine hundred eighteen documents were found. Applying inclusion/exclusion criteria, 21 articles and 2 dissertations were included. **Results:** The majority of investigators utilized descriptive, cross-sectional research designs conducted with convenience samples. Inconsistent reporting of SDS total scores, individual item scores, age ranges and means, gender distributions, cancer types, cancer stages, and psychometric properties made comparisons difficult. Available mean SDS scores ranged from 17.6 to 38.8. Reports of internal consistency ranged from 0.67 to 0.88. Weighted means indicated fatigue to be the most prevalent and distressing symptom. Appetite ranked higher than pain intensity and pain frequency. **Conclusions:** The SDS captures the patient's symptom experience in a manner that informs the researcher or clinician about the severity of

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the respondents' reported symptom distress. **Implications for Practice:** The SDS is widely used in a variety of cancer diagnoses. The SDS is a tool clinicians can use to assess 11 symptoms experienced by patients with advanced cancer.

Oncology clinicians are well aware that patients with advanced cancer rarely present with just 1 symptom. Instead, patients are often polysymptomatic, frequently experiencing symptoms such as depression, anxiety, fatigue, pain, poor appetite, and dyspnea.[1] Symptom assessment and management affect the patient's quality of life, and symptom assessment tools contribute to the identification of symptoms. The Symptom Distress Scale (SDS)[2] has been widely used as a symptom measurement tool in patients with cancer, yet a systematic review summarizing the symptom knowledge generated from its use in patients with advanced cancer is nonexistent. Comprehending the knowledge generated from investigations utilizing the SDS is a prerequisite to determining if the tool provides essential data for further research and clinical practice. Therefore, we conducted a systematic review of the research literature in which investigators used the 13-item SDS as a measure of symptoms in patients with advanced cancer.

A Brief History of the Development of the SDS

The 13-item SDS is the seminal product of researchers McCorkle and Young.[2] The SDS was created to measure symptoms associated with cancer after the construct of symptom distress was induced from literature reviews, previously developed scales, and patient interviews. McCorkle and Young[2] defined symptom distress as "the degree of discomfort from the specific symptom as reported by the patient." It is important to note that "distress" was not differentiated according to whether it resulted from the disease itself or from its treatment.[3]

The first SDS was composed of 8 symptoms: nausea, mood disturbance, appetite, insomnia, pain, mobility, fatigue, and bowel pattern,[3] which were the major concerns identified from previous studies. A group of 60 participants (50% men) from oncology (87%) and medical clinics participated in studies to test the initial SDS. As these 60 participants were interviewed regarding the scale, the investigators added "concentration" to the initial SDS because several participants asked for questions and directions to be repeated. "Appearance" was also added during this phase of scale development because of the concern that several female participants expressed about recent weight gain apparently caused by treatment adverse effects. Eventually, "mood disturbance" was changed to "outlook," and "breathing" and "cough" were added based on respondents' reports of complications associated with breathing and coughing.[3]

The 13-Item SDS

The current 13-item SDS questionnaire measures 11 symptoms associated with cancer.[3] These items include nausea, appetite, insomnia, pain, fatigue, bowel pattern, concentration, appearance, breathing, outlook, and cough. Nine SDS item responses are designed on a 5-point Likert scale with responses ranging from "1" (representing normal or no distress for a given symptom) to "5" (representing extensive distress). Four items concerning the frequency and intensity of pain and nausea have a similar "1" to "5," scale where "1" represents "almost never/mild" and "5" represents "almost constantly/unbearable." Total SDS scores range from 13 to 65. Initial internal consistency results include α's of .83 for adults with lung cancer and .75 for adults with myocardial infarction.[4] Subjects typically require 5 to 10 minutes to complete the 13-item SDS.

Reliability and Validity of the 13-Item SDS

There are advantages to using the 13-item SDS in research and clinical situations. The SDS is 1 of the most widely tested instruments for the evaluation of symptom distress.[5] The SDS integrates the frequently identified symptoms acknowledged by cancer patients (Table 1). In addition, the SDS can be completed in a

Table 1 • Frequently Reported Symptoms of Cancer Patients in Hospice/Palliative Care (PC)

Author	Ng	Mercadante	Walsh	Potter	Stromgren
Setting	Hospice	PC	PC	PC	PC
Sample size	1000	400	100	400	175
Symptom	Percentages of Sample Reporting the Symptom				
Pain	49	87	84	64	80
Fatigue	81		69		57
Anorexia	70		66	34	8
Insomnia	23		49	12	
Constipation	35	33	52	32	18
Dyspnea	61	28	50	31	
Cough	52		38	15	
Nausea	30	25	36	29	26
Memory problems			12		8
Diarrhea		5	8	10	

Extracted from Mercadante et al (2000),[6] Ng and von Gunten (1998),[7] Potter et al (2003),[8] Stromgren et al (2006),[9] Walsh et al (2000).[10]

short length of time,[11] thereby limiting patient/participant burden. Peruselli and colleagues[5] emphasize that even though the SDS does not include all possible symptoms a patient may experience, it does consider common symptoms that are of most concern sometime through the course of a patient's cancer trajectory. The SDS does not include the symptom "vomiting," nor does it address oral mucositis, dry mouth, and taste changes, along with pain and dysfunction due to oral complaints. Rhodes and colleagues[12] are of the opinion that the symptom terminology (eg, bowel pattern) is confusing and may not be commonly understood. Notwithstanding these criticisms, clinicians and researchers often choose the 13-item SDS to quantify symptom distress in a variety of cancer populations.

Cutoff points categorizing participants into mild, moderate, or severe distress have not been validated with empirical evidence, but only suggested by the author based on professional experience.[3] Combining the results of studies over time may provide the empirical evidence necessary to determine what constitutes mild, moderate, and severe distress.

Concurrent validity between the SDS and numerous symptom assessment tools is available in the user's manual.[3] Table 2 contains additional information regarding concurrent validity from articles published after the 1995 user's manual was in print.

In their studies, authors demonstrated reliability of the 13-item SDS (test-retest [$r = 0.78$], Cronbach's $\alpha = .70$ to $.85$),[4,16] along with content validity[2] and construct validity[16] in cancer populations. The 13-item SDS was one of the initial valid and reliable symptom assessment tools developed for symptom assessment in oncology study participants[17] during the time when cancer study participants were surviving longer while experiencing terrible adverse effects.

Our purpose is to present a systematic review of empirical studies that utilized the 13-item SDS as the symptom measurement tool in participants with advanced cancer. Specifically, we aim to:

1. describe the characteristics of studies using the 13-item SDS to assess symptoms experienced by study participants with stage III and stage IV cancer;
2. examine 13-item SDS scores by cancer site; and
3. discuss the evidence for 13-item SDS scores that represent mild, moderate, and severe levels of distress.

Methods

A comprehensive, electronic search of PubMed, CINAHL, and EMBASE databases provided an initial list of potential articles for review; a hand search of reference lists provided additional articles. Because the 13-item SDS first appeared in the literature in 1978, searches included articles published beginning that year. Initial search terms included "symptom distress scale" and "cancer." We also used Web of Science to capture the articles that cited the first publication of the 13-item SDS. We found 918 articles before removing duplicates. A total of 551 articles (Figure) were identified for further review.

Inclusion and Exclusion Criteria

We reviewed abstracts of the 551 articles to determine if inclusion and exclusion criteria were met. English-language articles in which the 13-item SDS was used to measure symptom distress in participants with advanced cancer were included. Our definition of advanced cancer incorporated the descriptors "advanced cancer," "terminal," "hospice," and samples with greater than 50% of participants having stage III or IV cancer. We excluded studies focused on pediatric cancer populations. We included only studies utilizing the 13-item SDS and excluded studies using the 10-item SDS, studies modifying the 13-item SDS, studies using only the SDS item "fatigue," studies using a 14- or 15-item SDS, and studies using altered 13-item SDS scoring. We excluded articles that did not include numerical information about each component of the 13-item SDS. Also excluded were review articles, proxy studies, and clinical practice guidelines.

■ Results

A sample of 21 articles and 2 dissertations remained for the final review. We obtained hard copies of the 23 documents and extracted the following information: (*a*) author, publication year, first author's credentials, country; (*b*) setting, design, statistical techniques; (*c*) cancer stage; (*d*) age range (mean, SD); (*e*) gender sample size; (*f*) cancer type; (*g*) SDS total mean (SD); (*h*) Cronbach's α; (*i*) SDS range; (*j*) cutoff scores; (*k*) SDS item scores; and (*l*) findings.

Characteristics of the Studies

In Table 3, we present a summary of the literature included in this review. The publication timeframe of the reviewed studies ranged from 1985 through 2013. Nurses were first authors on the majority of studies (79%), with physicians (13%), a gerontologist, and an author with no professional credentials reported accounting for the remaining first authors. Two studies were dissertations conducted by nurses. Only 2 investigators reported that the paper version of the 13-item-SDS required 5 to 10 minutes to complete.

The 13-item SDS has been used in many countries and settings. The United States (n = 10) was the country where most studies were conducted. Other investigators were from Canada (n = 5),

Table 2 • Symptom Distress Scale (SDS) Concurrent Validity Studies

	Author	Year	Scale	Correlations With SDS Total Scores
1	Boehmke	2004	Rhodes Adapted Symptom Distress Scale	T1 $r = 0.90$, T2 $r = 0.84$, T3 $r = 0.77$
2	Moro	2006	Edmonton Symptom Assessment Scale—Italian	$r = 0.77$
3	Locke	2007	Linear Analog Scale Assessments	T1 $r = 0.53$, T2 $r = 0.56$, T3 $r = 0.57$

From Boehmke (2004),[13] Locke et al (2007),[14] Moro et al (2006).[15]

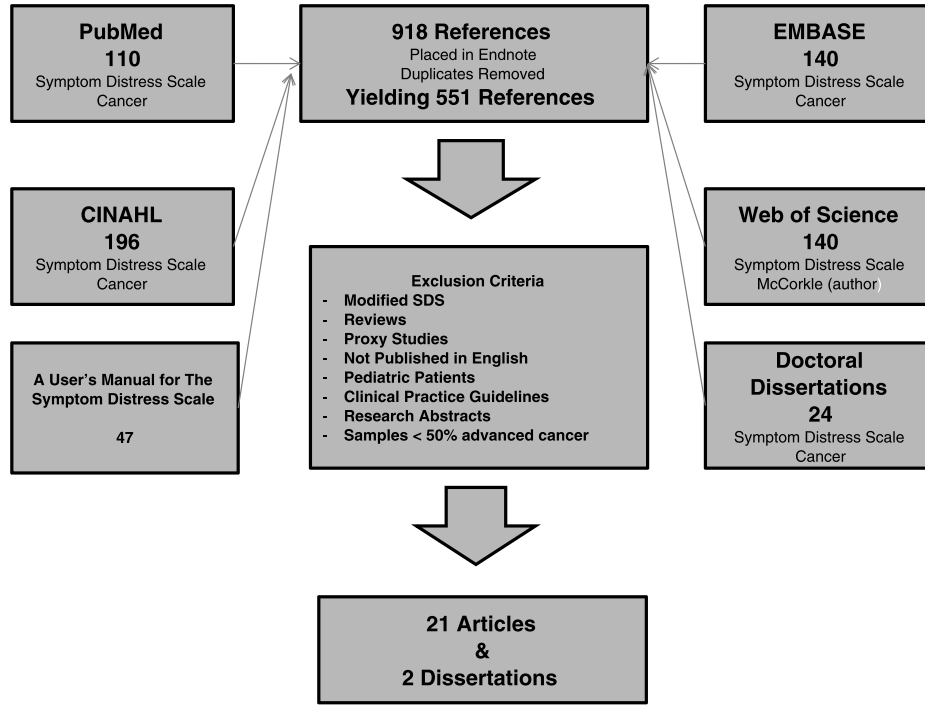

Figure ■ Search strategy.

Italy (n = 3), Australia (n = 2), Taiwan (n = 2), and Korea (n = 1). Studies were conducted in medical center clinics or inpatient units (n = 7), palliative care (n = 7), home or inpatient hospice settings (n = 4), or oncology clinics/units (n = 5).

Characteristics of Study Designs

Researchers used descriptive (n = 17), correlational (n = 4), interventional (n = 1), or mixed-methods (n = 1) designs. There were 14 studies utilizing a cross-sectional data collection process and 10 studies utilizing a longitudinal data collection process. Statistical analyses included bivariate (n = 16) and multivariate (n = 8) techniques.

Characteristics of Study Samples

Sample sizes ranged from 9 to 213 participants. There were 6 studies with less than 50 participants, 9 studies with samples between 51 and 100 participants, 6 studies with 101 to 200 participants, and 2 publications from a study of the same 213 participants.

Ages of participants ranged from 19 to 95 years,[25] with the mean ages of participants ranging from mean of 45 (SD, 11) years to mean of 69 (SD, 12.6) years. In 5 studies, 100% of the sample was female, with the remaining studies having nearly equal gender distribution or either 60% to 40% male-to-female or 60% to 40% female-to-male distributions.

Internal Consistency

Internal consistency was reported using Cronbach's α in 14 of the 23 studies meeting the inclusion criteria. These reported values ranged from α = .67 to .88.

Characteristics of Study Participants' Type of Cancer

Researchers who reported participants' cancer stages categorized their participants as advanced (n = 7), terminal (n = 6), life threatening (n = 1), or recurrent (n = 1). These researchers enrolled 55% to 86% of participants with stages III and IV cancer. Researchers investigated samples with single-site cancers including lung (n = 6), ovarian (n = 2), and breast (n = 1). In studies of mixed cancer sites, study participants with lung cancer ranged from 16% to 35%, breast cancer 7% to 30%, colorectal 7% to 44%, gastric (stomach) 11.4% to 23%, melanoma 11% to 42%, renal cell 38%, pancreas 22%, lymphoma 13%, and hematologic cancers 18%.[35] Overall, 1896 study participants are included in this review. The 3 most frequently enrolled subjects included study participants with lung cancer (n = 655 [37.5%]), ovarian cancer (n = 277 [15.9%]), and breast cancer (n = 238 [13.7%]).

Weighted Means

Weighted means allow the researcher to determine the relative importance of each item across studies with consideration of the size of the sample that contributed to the study mean score. To compare item scores across studies, we placed the SDS item scores from researchers reporting individual scores in a table and computed weighted means (WMs) for each item. We multiplied the mean scores for each SDS item by the number of participants in that study. We then added each product (mean score times number of participants) for each SDS item score across the 6 studies, dividing this number by the total number of participants, yielding WM results.

Table 3 • Summary of Literature using the Symptom Distress Scale (SDS) as the Symptom Assessment Tool

First Author, Year, First Author's Credentials, Country	Setting, Design, Statistical Techniques	Cancer Stage	Age Range (Mean, SD)	Gender	Cancer Type(s)	SDS Total Mean (SD)	Cronbach's α	SDS Range	Cutoff Scores	SDS Item Scores	Findings
Germino, 1985, nurse, United States[18]	Radiation, outpatient, descriptive, cross-sect	Life threatening	NR, NR	Male (62.5%), female (37.5%), N = 56	Lung (100%)	T1 = 26.8 (8.4), T2 = 26.4 (8.4)	.79	NR	1 = least distress; 2, 3, 4 = intermediate; 5 = extreme	No	Patients with cancer with high levels of symptom distress had higher levels of acknowledged awareness of symptoms
Degner, 1987, nurse, Canada[19]	Palliative care, corr, cross-sect	Terminal	33–89, 65.5	Male (52%), female (48%), N = 29	NR	T1 = 33.8, T2 = 25.7	T1 .67, T2 .72	NR	1 (No distress), 5 (extreme), higher = greater	No	Demonstrated the SDS was a useful measure to evaluate the effectiveness of palliative care
Frederickson 1991, nurse, United States[20]	Oncology unit, corr, cross-sect	Advanced, unresectable cancer	19–61, 45 (11)	Male (56%), female (44%), N = 45	Melanoma (42%), renal cell (38%), breast (7%), colon (7%)	17.6 (5.9)	NR	NR	NR	No	Demonstrated that perception of symptoms is positively correlated with psychosocial adaptation, not with actual psychological status
Peruselli, 1993, nurse, Italy[21]	Palliative care, corr, cross-Sect	Advanced cancer	45–88, 67	NR, N = 43	Lung (35%), genitourinary (26%), breast (9%), bowel (9%)	NR	.78	NR	4, 5 = Serious	No	Confirmed the validity of quality of life (QOL) monitoring system that uses self-rating assessment instruments

(continues)

Table 3 • Summary of Literature using the Symptom Distress Scale (SDS) as the Symptom Assessment Tool, Continued

First Author, Year, First Author's Credentials, Country	Setting, Design, Statistical Techniques	Cancer Stage	Age Range (Mean, SD)	Gender	Cancer Type(s)	SDS Total Mean (SD)	Cronbach's α	SDS Range	Cutoff Scores	SDS Item Scores	Findings
Sarna, 1993, nurse, United States[22]	Medical center private offices, descriptive, cross-sect	Advanced lung cancer	32–86, 61 (11)	Male (0 %), female (100%), N = 69	Lung (100%)	23.4 (6.9)	NR	NR	NR	No	Reported physical, emotional, and social disruptions in the QOL of women with lung cancer
Degner,[a] 1995, nurse, Canada[23]	Tertiary referral clinics, descriptive, cross-sect	Early (12%), late (72%)	NR, 64.2 (9.72)	Male (61%), female (39%), N = 82	Lung (100%)	26.97 (7.79)	.81	NR	NR	No	Measuring symptom distress was a significant predictor of survival in patients with lung cancer
Northouse, 1995, nurse, United States[24]	Clinic, descriptive, cross-sect	Recurrent breast cancer	30–82, 53.8 (12.0)	Female (100%), N = 81	Breast (100%)	NR	.84	NR	Higher = greater	No	Suggests that there are multiple factors that could influence a couple's adjustment to recurrent breast cancer
Barnes,[b] 1997, nurse, United States[25]	Hospice, home care, descriptive, long	NR	31–95, 66	Male (43.3%), female (56.7%), N = 30	NR	29.12 (8.58)	.79	NR	Higher = greater	No	Identified that caregiver perceived symptom distress was closely correlated to patient's actual distress
Lobchuk, 1997, nurse, Canada[26]	Palliative care, oncology units, descriptive, long	Stage I (11%), stage II (15%), stage III (59%), stage IV (15%)	NR, NR	Male (68%), female (32%), N = 41	Lung (100%)	27.76 (9.44)	.88	NR	Higher = greater	Yes	Demonstrated little differences between patients and primary family caregivers' perception of symptoms.

(continues)

Table 3 • Summary of Literature using the Symptom Distress Scale (SDS) as the Symptom Assessment Tool, Continued

First Author, Year, First Author's Credentials, Country	Setting, Design, Statistical Techniques	Cancer Stage	Age Range (Mean, SD)	Gender	Cancer Type(s)	SDS Total Mean (SD)	Cronbach's α	SDS Range	Cutoff Scores	SDS Item Scores	Findings
Peruselli, 1997, physician, Italy[5]	Palliative care, descriptive, long	Advanced cancer	30–85, NR	Male (52.1%), female (47.9%), N = 73	GI Tract (22%), bowel (18%), lung (16%), breast (9%)	T1 = 30.3, T2 = 29.2, T3 = 33.1	NR	NR	NR	No	Some individual trajectory of changes in palliative care patients could be identified relative to the treatments performed.
Sarna, 1993, nurse, United States[22]	Oncology unit, clinics, private offices, descriptive, cross-sect	Advanced lung cancer	33–80, 58.3 (9.7)	Male (0%), female (100%), N = 69	Lung (100%)	25.5 (6.94)	NR	14-44	≥3 = Serious distress	Yes	Identified clusters of symptoms in women with advanced lung cancer
Kristjanson, 1998, nurse australia[27]	Home hospice, descriptive, cross-sect	Stages III, IV	NR, 65.5 (10.8)	Male (51%), female (49%), N = 78	Breast (20.5%), genitourinary (15.4%), colon (15.4%), lung (14.1%)	29.6 (7.5)	.74	13-52	1 (No distress), 5 (extreme)	Yes	Supports previous work indicating family members may function as proxy to rate patient's symptom distress
Morasso 1999, N/A, Italy[28]	Palliative care, descriptive, cross-sect	Terminal	NR, 64.8 (11.1)	Male (57.3%), female (42.7%), N = 94	Lung (22.7%), breast (18.2%), stomach (11.4%), colorectal (11.4%)	31.0 (8.0)	.76	NR	1 (No distress), 5 (extreme), higher = greater	No	Addresses concerns that should be addressed during the late stage of cancer
Porock, 2000, nurse, Australia[29]	Home hospice, descriptive, long	Advanced cancer	51–77, 59.9 (9.8)	Male (34%), female (66%), N = 9	Bowel (44%), pancreas (22%), melanoma (11%), breast (11%)	NR	NR	22-27	Higher = greater	Yes	Patients with cancer in home hospice enjoyed the individual approach to exercise, and in no instance was fatigue made worse

(continues)

Table 3 • Summary of Literature using the Symptom Distress Scale (SDS) as the Symptom Assessment Tool, Continued

First Author, Year, First Author's Credentials, Country	Setting, Design, Statistical Techniques	Cancer Stage	Age Range (Mean, SD)	Gender	Cancer Type(s)	SDS Total Mean (SD)	Cronbach's α	SDS Range	Cutoff Scores	SDS Item Scores	Findings
Boucher,[b] 2002, nurse, United States[30]	Cancer clinic, exp, long	Early (28%), late (55%)	NR, 56.9 (10.9), 55.2 (14.5)	Male (44%), female (66%), N = 100	Breast (30%), lung (19%), lymphoma (13%), prostate (10%)	23.4 (5.60)	.71	NR	Higher = greater	No	Reduced symptom distress was related to positive mood states
Chochinov,[c] 2002, physician, Canada[31]	Palliative care, descriptive, cross-sect	Terminal	NR, 69 (12.6)	Male (45%), female (55%), N = 213	Lung (31%), gastrointestinal tract (23%), genitourinary (17%), breast (14%)	NR	NR	NR	Higher = greater	No	Identified when loss of dignity is a concern, more psychological and symptom distress is reported
Tang, 2003, nurse, Taiwan[32]	Hospice, descriptive, cross-sect	Terminal	34-88, 66.8	Male (41.7%), female (58.2%), N = 127	Lung (29.1%), breast (15.8%), ovarian (7.1%), colon (7.1%)	NR	.75	NR	Higher = greater	No	The availability of home hospice did not influence its use
Hack,[c] 2004, physician, Canada[33]	Palliative care, descriptive, cross-sect	Terminal	NR, 69.0 (12.6)	Male (45%), female (55%), N = 213	Lung (31%), gastrointestinal tract (23%), genitourinary (17%), breast (14%)	NR	NR	NR	Higher = greater	No	Dignity is a fundamental component of end-of-life care and should be addressed by healthcare professionals
Oh, 2004, nurse, Korea[34]	Respiratory and oncology units, descriptive, cross-sect	Stage I (3%), stage II (6%), stage III (32%), stage IV (54%)	NR, 60.9 (10.4)	Male (76.4%), female (23.6%), N = 106	Lung (100%)	32.74 (10.75)	.87	NR	NR	Yes	Korean patients with lung cancer appear to experience higher symptom distress scores than do Western countries

(continues)

Table 3 • Summary of Literature using the Symptom Distress Scale (SDS) as the Symptom Assessment Tool, Continued

First Author, Year, First Author's Credentials, Country	Setting, Design, Statistical Techniques	Cancer Stage	Age Range (Mean, SD)	Gender	Cancer Type(s)	SDS Total Mean (SD)	Cronbach's α	SDS Range	Cutoff Scores	SDS Item Scores	Findings
Tang, 2006, nurse, Taiwan[35]	Medical center oncology units, descriptive, cross-sect	Terminal	20–89, Median 60,	Male (43%), female (57%), N = 114	Hematologic (18.4%), lung (16.7%), breast (14.9%), colorectal (14.9%)	27.8 (9.0)	.85	NR	1 (No distress), 5 (extreme), higher = greater	Yes	Confirmed ability of family caregivers to act as reasonably reliable source of QOL data
Schulman-Green, 2008, gerontologist, United States[36]	Cancer center, descriptive, cross-sect	Early (33.8%), late (65.5%)	21–86, 60.8 (11.8)	Female (100%), N = 145	Ovarian (100%)	27.83 (8.98)	.74	13–52	Higher = greater	NR	Women undergoing ovarian surgeries for cancer have psychological needs that are considered secondary to their physical needs
McCorkle, 2009, nurse, United States[37]	Cancer center, exp, long	Early (33%), late (66%)	NR, I: 58.4 (11.3), C: 62.2 (12.7)	Female (100%), N = 123	Ovarian (61.8%)	Baseline I = 29.0 (6.7), C = 26.8 (6.6); 1 mo I = 25.3 (6.9), C = 23.2 (6.3); 3 mo I = 24.7 (6.2), C = 22.0 (6.4); 6 mo I = 22.9 (6.8), C = 19.9 (5.1)	NR	NR	NR	NR	Nurse interventions targeting both physical and psychological aspects of QOL produce stronger outcomes than targeting only 1 QOL aspect
Wallen, 2012, nurse, United States[38]	Outpatient clinic and surgical oncology, long, mixed methods	Advanced malignancy	NR	Male (53.2%), female (46.7%)	NR	Reported baseline and postop for PPCS and standard of care	NR	22.19 (6.6) 28.37 (6.9)	NR	NR	Participants in the PPCS group tended to have lower SDS scores, although not significantly different from the standard of care

(continues)

Table 3 • Summary of Literature using the Symptom Distress Scale (SDS) as the Symptom Assessment Tool, Continued

First Author, Year, First Author's Credentials, Country	Setting, Design, Statistical Techniques	Cancer Stage	Age Range (Mean, SD)	Gender	Cancer Type(s)	SDS Total Mean (SD)	Cronbach's α	SDS Range	Cutoff Scores	SDS Item Scores	Findings
van Cleave, 2013, nurse, United States[39]	Cancer center, long	Early (52.8%), late (35.9%), unknown (11.3%)	71.8 (5.4)	Male (49.7%), female (49.4%)	Digestive (22.4%), thoracic (27.6%), gynecologic (23.0%), genitourinary (27.0%)	Reported baseline, at 3 and 6 mo in 3 age categories	NR	17.0 (5.1) 29.3 (7.2)	NR	NR	Patients with heightened symptom distress had worse mental health and decreased function; thoracic, digestive, and gynecologic cancer patients experienced greater symptom distress; patients reporting ≥3 comorbidities experienced greater distress

Abbreviations: Corr, correlational; cross-sect, cross sectional; exp, experimental; gyne, gynecological; long, longitudinal; NR, not reported; PPCS, pain and palliative care service.
[a]Used only lung cancer participants because of inability to calculate cancer stage percentages in the mixed cancer sample.
[b]Dissertation.
[c]Used same sample.

Total 13-Item SDS and Individual Item Scores

TOTAL SDS SCORES

Seventeen investigators reported mean SDS total scores that ranged from 17.6 (SD, 5.9) to 32.74 (SD, 10.75). Five investigators reported means and SDs for the 13-item scores and SDS total scores (Table 4). Porock et al[29] reported mean scores without SDs for the 4 most distressing 13-item SDS symptom items and the 4 least distressing symptom items (Table 4).

In a comparison study investigating perceived awareness of life-threatening illness,[18] participants were surveyed at 1 and 2 months after initial diagnosis. Results indicate higher 13-item SDS total scores for study participants with cancer at 1 month (mean, 26.8 [SD, 8.4]) and 2 months (mean, 26.4 [SD, 8.4]) compared with study participants with myocardial infarction at 1 month (mean, 19.2 [SD, 4.6]) and 2 months (mean, 19.1 [SD, 4.8]).

SDS ITEM SCORES

Of the 6 studies in which investigators reported SDS item scores, fatigue ranked as the most distressing[26,27,40] or second most distressing symptom.[29,34,35] Nausea frequency, nausea intensity, bowel pattern, outlook, and breathing were the lowest item scores.

WEIGHTED MEANS

Table 4 also shows the calculated WMs from the 6 investigators who reported SDS item scores and demonstrated that fatigue (WM, 2.92) was the most distressing item with nausea frequency (WM, 1.90) as the least distressing item. Weighted mean results also indicated appetite ranked higher than pain frequency and pain intensity.

SDS Scores by Cancer Type

Degner and Sloan[23] recruited a sample of 434 newly diagnosed cancer study participants. Demographic and disease characteristics were reported for the total sample and a subsample of participants with lung cancer (n = 82). These researchers excluded 37% (n = 159) of the general sample because cancer stage information was unavailable. The remaining 63% (n = 275) of participants in the general sample with documented cancer stages were dichotomized as having early-stage cancer (n = 127) with SDS total scores (mean, 21.56, SD 5.60) and late-stage cancer (n = 148) with SDS scores (mean, 26.08 [SD, 7.80]). There was a statistically significant difference ($t_{273} = 5.44$, $P < .0001$) between participants with early-stage cancer and those with late-stage cancer indicating that participants with later stage cancer reported higher symptom distress. These researchers conducted a separate analysis of participants with lung cancer undergoing treatment. Fifty-nine (72%) of the participants were reported to have advanced-stage lung cancer, 11 (13%) early-stage cancer, and 12 (15%) had missing cancer stage information. There was only 1 reported SDS total score (mean, 26.97 [SD, 7.79]) for these 82 participants. However, there was no statistical difference ($t_{228} = 0.83$, $P < .40$) between participants with advanced-stage cancer and participants with lung cancer in this sample.

The majority of studies in this review included samples that were heterogeneous for type of cancer. Unlike Degner and Sloan,[23] who differentiated a subsample of participants with lung cancer from the remainder of the sample, other investigators did not report similarities or differences in SDS scores by different cancer types. However, findings from several researchers studying samples homogeneous for lung or ovarian[36,37] cancer allow for comparison of SDS total scores by cancer type. Mean SDS total scores for lung

Table 4 • Symptom Distress Scale (SDS) Item and Total Scores, Weighted Means, and Rank Order

	Lobchuk et al[26] (1997)		Sarna and Brecht[40] (1997)		Kristjanson et al[27] (1998)		Porock et al[29] (2000)		Oh[21] (2004)		Tang[35] (2006)			
	n = 41		n = 60		n = 78		n = 9		n = 106		n = 114		Weighted Mean	Rank Order
	Score	SD	Score	SD	Score	SD	Score	SD	Score	SD	Score	SD		
Fatigue	2.95	1.22	2.80	1.12	3.21	1.14	2.60	NR	2.97	1.20	2.75	1.30	2.92	1
Appetite	2.14	1.16	1.98	1.07	2.47	1.38	NR	NR	3.13	1.39	2.61	1.20	2.52	2
Pain (frequency)	2.35	1.27	2.23	1.28	2.60	1.30	2.80	NR	2.68	1.66	2.33	1.30	2.47	3
Appearance	1.92	0.92	1.70	0.83	2.53	1.29	NR	NR	2.78	1.37	2.58	1.20	2.37	4
Insomnia	2.22	1.25	2.12	1.25	2.18	1.10	NR	NR	2.49	1.27	2.76	1.30	2.37	4
Cough	2.57	1.07	2.07	1.07	1.97	1.01	1.28	NR	2.74	1.38	2.23	1.30	2.30	5
Outlook	2.24	1.26	2.27	0.88	2.23	1.13	2.56	NR	2.76	1.12	1.61	1.00	2.21	6
Pain (intensity)	1.87	0.95	1.80	0.96	2.12	0.95	NR	NR	2.56	1.45	2.04	1.10	2.09	7
Concentration	1.78	1.06	1.80	0.86	2.18	1.07	NR	NR	2.65	1.29	1.76	0.90	2.04	8
Breathing	2.22	1.26	2.27	0.88	2.23	1.13	2.56	NR	2.48	1.34	1.64	1.00	2.02	9
Bowel pattern	2.00	1.39	1.62	0.96	2.31	1.38	2.52	NR	1.85	1.06	1.85	1.10	1.93	10
Nausea (intensity)	1.72	0.91	1.73	1.01	1.77	1.15	1.52	NR	1.89	1.12	1.90	1.20	1.82	11
Nausea (frequency)	1.72	0.85	1.58	0.93	1.90	1.09	1.47	NR	1.90	1.34	1.81	1.10	1.80	12
Total SDS	27.76	9.44	25.50	6.94	29.59	7.54	NR	NR	32.74	10.75	27.80	9.00		
Gender		%		%		%		%		%		%		
	Male	68	Male	0	Male	51	Male	34	Male	76	Male	43		
	Female	32	Female	100	Female	49	Female	66	Female	24	Female	57		

cancer participants ranged from 23.4 (SD, 6.9)[22] to 32.7 (SD, 10.75),[34] whereas mean SDS total scores for ovarian cancer participants ranged from 27.83 (SD, 8.98)[36] to 29.0 (SD, 6.7).[37]

DETERMINING DISTRESS

Two investigators used the categories of "1" meaning the "least" amount of distress, "2, 3, 4" meaning the participant is experiencing "intermediate" amount of distress, and "5" indicating "extreme" distress.[18,21] No information was provided that would allow for analyzing the distribution of symptom distress by cancer type in these 2 articles, except Germino and McCorkle[18] recruited only participants with lung cancer. Only 1 investigator differentiated distress by 2 levels[23] identifying "1" or "2" as low distress and "3," "4," "5" identified as high distress. Degner and Sloan[23] report that participants with lung cancer have the highest symptom distress, and men with genitourinary cancer have the least distress. Peruselli and colleagues[5] dichotomized total symptom distress scores of less than 36 to indicate "low" symptom distress and 36 or greater to represent "high" symptom distress. Although a heterogeneous cancer sample was recruited, only total SDS scores were reported at the beginning of home palliative care, the total SDS score after 2 weeks, and the highest SDS score over the last 2 weeks of life. Therefore, we were unable to analyze SDS total scores by cancer type in this sample.

Twelve investigators described individual SDS item scores using 1 (normal or no distress) to 5 (extensive distress). Seven investigators reported SDS total scores ranging from 13 (lowest distress) to 65 (highest distress). Although these scores represent the complete range of possible scores, insufficient data regarding the distribution of cancer type were presented in these studies to determine individual SDS scores by cancer type.

Determining Mild, Moderate, and Severe Distress With the 13-Item SDS

Three investigators indicated that the higher the scores, the greater the symptom distress.[24,31,41] Specifically, Chochinov and colleagues[31] investigated dignity in the terminally ill study participants and identified that participants with a fractured sense of dignity had increased awareness of their appearance and increased pain intensity compared with those whose sense of dignity remained intact. The investigators report SDS item means and SDs for SDS items pain severity, pain frequency, bowel concerns, appearance, and outlook, but not for the 8 remaining SDS items. The investigators concluded those with a fractured sense of dignity experienced higher symptom distress. Total SDS scores, means, or SDs were not reported. Northouse and colleagues[24] identified a moderate correlation between a woman's symptom distress and hopelessness ($r = 0.53$, $P < .01$), emotional distress ($r = 0.42$, $P < .01$), and the decreased ability to carry out psychosocial roles ($r = 0.52$, $P < .01$), but did not report SDS total or item scores. Sarna[22] found a strong relationship between symptom distress and quality of life ($r = 0.72$, $P < .05$) as measured by CARES-SF (Cancer Rehabilitation Evaluation System).[42,43] Higher scores on the CARES-SF indicate increased disruption. Therefore, the higher the symptom distress, the lower the quality of life. However, Sarna[22] reports only the mean SDS score for the entire sample.

■ Discussion

We critically evaluated the literature where the 13-item SDS was utilized as the symptom measurement tool in patients with advanced cancer in an attempt to (1) describe the characteristics of the studies, (2) examine SDS scores by cancer site, and (3) discuss the evidence for SDS scores that represent mild, moderate, and severe levels of distress. The structure of the 13-item SDS captures 11 symptoms associated with cancer while allowing for individualized reflection of the symptom experience. Investigators' inconsistent reporting of SDS total scores, individual item scores, age ranges and means, and psychometric properties made comparisons challenging. Despite these difficulties, our review clearly demonstrates the 13-item SDS scale is a useful symptom measurement tool in the advanced cancer patient population. However, based on the evidence, we were unable to determine ranges that would support classifying mild, moderate, or severe symptom distress.

Study Characteristics

Our findings demonstrate the majority of investigators utilized descriptive, cross-sectional research designs conducted with convenience samples in a variety of settings. These settings included cancer centers, clinics, hospices, patient homes, and inpatient oncology units. Percentages of male and female participants appear to be representative of the general population unless the researchers were studying a gender-specific type of cancer such as ovarian cancer. Researchers reported moderate ($\alpha = .65$ to $.79$) to strong ($\alpha > .80$) reliability, thereby demonstrating the consistency of the SDS.

SDS Item Scores

This review of the 13-item SDS scale demonstrated pain often is not the most distressing symptom reported by the participants with advanced cancer. Investigators reporting SDS item scores indicated that fatigue scores (1-5) ranged from 2.6 (SD, not reported [NR]) to 3.21 (SD, 1.14), whereas pain frequency ranged from 2.23 (SD, 1.28) to 2.8 (SD, NR), and pain intensity ranged from 1.0 (SD, 0.95) to 2.76 (SD, 1.12). These findings, which are similar to findings from other investigators,[44,45] indicate fatigue is a highly prevalent and distressing symptom in lung, breast, ovarian, and prostate cancers.

Arguably, SDS items bowel pattern, concentration, appearance, and outlook are not what one thinks about when listing symptoms; rather, they represent a combination of symptoms. For example, when assessing for symptoms associated with the bowel, study participants are often asked questions regarding the presence of diarrhea or constipation along with the number of stools per day. The SDS bowel pattern item groups all bowel symptoms into 1 item and then asks if the patient is experiencing normal bowel patterns. If they are not experiencing normal bowel patterns, the SDS scale then elicits how an increasing intensity or increasing frequency of the bowel pattern leads to increasing distress for the participant. The SDS is a tool to screen for symptoms that may require a more in-depth assessment and/or measurement. For example, further investigation is warranted when a participant reports distress from

SDS item bowel pattern, before further measurement is conducted or treatment is provided.

There are other SDS item scores of interest. For example, SDS items "appearance" (mean, 2.53 [SD, 1.29]) and "appetite" (mean, 2.47 [SD, 1.38]) in a heterogeneous cancer sample[27] are ranked the third and fourth most distressing symptoms with "fatigue" (mean, 3.21 [SD, 1.14]) and "pain frequency" (mean, 2.60 [SD, 1.30]) ranked first and second. In describing the symptom experience of 106 Korean adults with lung cancer,[34] the 13-item SDS item "appetite" (mean, 3.13 [SD, 1.39]) ranked higher than "fatigue" (mean, 2.97 [SD, 1.20]) and "pain frequency" (mean, 2.68 [SD, 1.66]). Findings from these studies suggest multiple, distressing symptoms occur. Symptom Distress Scale items such as appearance and appetite, along with other SDS items scores taken individually, may not be the most distressing symptoms, but when co-occurring with other SDS items may add to respondents' symptom distress.

SDS Scores by Cancer Site

Patients with advanced lung, breast, gynecologic, and prostate cancers account for the majority of cancer sites within this review. A consistent finding in this analysis indicates that results generated from investigators who recruited a sample with high percentages of lung cancer participants tend to have higher total SDS scores. Degner and Sloan[23] in their cross-sectional sample of early stage, late stage, and participants with lung cancer demonstrate SDS scores increase with cancer stage. Oh[34] reports in a sample of Korean adults with lung cancer higher scores compared with scores reported in Western countries. Possible reasons for these higher scores may be due to 91% of the participants being diagnosed with stages III and IV cancers and the high proportion of participants who were receiving active treatment. These results add evidence to the growing body of knowledge indicating participants with lung cancer experience more symptom distress than do participants with other cancers. However, the SDS items focused on "breathing" and "cough" distress, which are 2 symptoms often seen in participants with lung cancer and may affect the total SDS scores. Further research is needed to explore the cumulative effect of SDS items "breathing" and "cough" on total SDS scores in participants with lung cancer who typically present with late-stage cancer. Determination if participants with lung cancer experience an overall greater symptom distress or whether there is greater symptom distress in each cancer stage compared with cancer study participants with other types of cancer. Additional research is also needed to determine if participants with lung cancer experience an overall greater symptom distress or whether there is greater symptom distress in each cancer stage compared with cancer study participants with other types of cancer.

Determining Levels of Distress

Findings from our analysis of studies using the 13-item SDS indicate participants with advanced cancer experienced total symptom distress scores ranging from a mean of 17.6 (SD, NR) to a mean of 33.8 (SD, NR). However, our investigation shows that determining the categories for the degree of symptom distress (mild, moderate, and severe) has not been accomplished from sufficient empirical evidence. Our review demonstrates that researchers defined symptom distress based on total SDS scores or individual SDS item scores. Researchers either followed suggested guidelines set by the SDS developers[37]; categorized symptom distress as least, intermediate, and severe; or dichotomized distress levels as low or high distress. When defining symptom distress, no researcher used another measurement tool to establish symptom severity levels. Conducting studies to establish concurrent validity with another measurement tool with defined degrees of distress may solve this issue.

■ Limitations

This review is not without limitations. First, we did not include *end of life* as one of our search terms, which may have captured articles not captured by the term *advanced cancer*. Second, nonreported or incomplete demographic, total SDS scores, individual item scores, cancer staging, or internal consistency information limits the interpretation of the results. Third, limiting inclusion criteria to articles using the English language may have excluded pertinent studies. Fourth, our definition of advanced cancer incorporated studies that included stages I and II cancers as long as 50% of the participants or greater were diagnosed with stage III or IV cancers. It is impossible to elicit whether inclusion of these participants with early cancer stages might have skewed the SDS scores. Fifth, the majority of included studies were descriptive, cross-sectional designs with limited generalizability. Finally, the primary author as the only reviewer may have introduced bias to the results of this review.

■ Implications for Practice

Findings from this study inform the knowledge gained from the utilization of the 13-item SDS scale by investigators exploring the symptom experience of participants with advanced cancer. The SDS scale provides a measure of distress on 11 symptoms experienced by participants with cancer. In an era of scarce resources, utilizing an established, valid, and reliable symptom assessment tool that measures symptoms in study participants with cancer is sensible.

The 13-Item SDS in Clinical Practice

Clinicians will find the SDS a valuable symptom measurement tool that determines the severity of symptom distress and is especially useful as a screening tool for symptoms commonly experienced by patients with cancer. The SDS can be used as part of the routine clinical monitoring of patients with cancer. Using suggested cutoff points for mild, moderate, and severe distress may provide the necessary data when triaging which study participants need your immediate assistance.

■ Future Research

We recommend future researchers who utilize the SDS report mean total scores with SDs, individual item scores by cancer type, cancer stage, and item correlations. Reporting these findings will

enhance the ability of researchers to address additional hypotheses that may be answered by combining findings from published studies using the SDS and performing meta-analyses. Further research is needed to empirically define cutoff scores. In addition, interventions may be developed to address study participants reporting mild, moderate, or severe distress.

■ Conclusions

The 13-item SDS scale is valid, reliable, and widely used in a variety of cancer diagnoses. These findings add to the knowledge generated regarding the experiences of study participants with cancer. In particular, this review supports research that demonstrates fatigue is the most prevalent symptom, not pain. Our review also demonstrates the SDS captures the patient's symptom experience in a manner that informs the researcher or clinician about the severity of the respondents' reported symptom distress. The use of simple yet informative measurement tools that capture the patient's symptom experience is paramount to providing effective symptom management in all phases of the cancer trajectory.

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