A USER'S MANUAL FOR THE SYMPTOM DISTRESS SCALE

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BACKGROUND INFORMATION ABOUT THE AUTHORS

Ruth McCorkle PhD., FAAN, is a Professor of Nursing at Yale University School of Nursing. In addition, she is Director of the Center for Excellence in Chronic Illness Care. Her nursing career started at Maryland General Hospital in Baltimore, Maryland. Her research career began as a Clinical Nurse Specialist in Oncology in Iowa. Subsequently, Dr. McCorkle has established a nationally recognized graduate program in cancer nursing. She has been on the faculty at both University of Washington and University of Pennsylvania. Dr. McCorkle is internationally known for her research with patients living with cancer and the measurement of patient and family outcomes to improve the quality of their lives. Since the early eighties, she has studied the effects of nursing interventions by advanced practice nurses on clinical outcomes.

Mary E. Cooley PhD., AOCN, is a post-doctoral fellow in Psychosocial Oncology at the University of Pennsylvania School of Nursing. She has worked as an advanced practice nurse in oncology since 1986 and is certified as an Advanced Oncology Nurse through the Oncology Nursing Society. Dr. Cooley is supported by Research Training Grant T32NR07035, National Institute of Nursing Research, Dr. Ruth McCorkle, Program Director. Her dissertation was patterns of symptom distress in adults receiving treatment for lung cancer. She has published extensively in clinical journals.

Judy A. Shea PhD., is a health services researcher and psychometrician in the Division of General Internal Medicine, Department of Medicine, University of Pennsylvania. From 1983 through 1991 she was a psychometrician at the American Board of Internal Medicine. There she conducted traditional psychometric analyses of the certification examinations, and had a lead role in several research projects. From 1991 through 1995 she managed the AHCPR funded Biliary Tract PORT study at the University of Pennsylvania. Currently, Dr. Shea works with faculty designing and evaluating quality of life tools in rehabilitation medicine, HIV-AIDS, breast cancer, and head and neck cancer, among others. Her research interests include descriptions of the natural fluctuations in quality of life over time, prediction of transitions of quality of life, and linking quality of life assessments to clinical data. She has extensive experience in study design and analysis, and has published numerous articles that address psychometric attributes of tests and similar research instruments.

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PREFACE

When cancer is diagnosed, the patient faces new adjustments; among the most difficult is adjustment to distressing physical symptoms associated with cancer and its treatment (McCorkle, 1973). To facilitate control and management of symptom distress, psychometrically strong assessment tools are necessary. The Symptom Distress Scale (SDS) was one of the first scales developed to measure the construct of symptom distress, defined as "the degree of discomfort from the specific symptom being experienced as reported by the patient" (McCorkle & Young, 1978, p. 374).

This manual provides information about the development and use of the SDS as an assessment and clinical outcome measure. The manual consists of five chapters. The first chapter describes the historical development, method of administration, and scoring procedures for the SDS. The second chapter presents information about the psychometric properties of the SDS from a variety of perspectives. In addition, summary data about the psychometric properties are presented in a tabular format to enable users to compare results of the SDS scores obtained in their samples with the SDS scores obtained in similar samples. Information about the translation of the SDS into French-Canadian, Italian, Spanish and Swedish versions is presented in chapter three. A summary of the use of the SDS in various studies, suggestions for future research, and information about obtaining the SDS are given in chapter four. The final chapter provides an annotated bibliography of studies that used the SDS.

ACKNOWLEDGEMENTS

There have been a number of people who have been instrumental in providing information and advice in the development of the SDS. A brief historical overview citing the formal connections is included in this manual but a few people need to be singled out for their unique contributions.

In the early 1970's, Drs. Saunders and Twycross at St. Christopher's Hospice were responsible for instilling essential values related to evaluating the effectiveness of interventions on relieving patient symptoms. Jeanne Quint Benoliel also played a critical role in the development of the SDS by providing daily consultation and collaboration. Understanding patients' symptom experiences and their meaning was an integral part of the graduate program, "Oncology Transition Services", that Drs. McCorkle and Benoliel developed in community health nursing at University of Washington. Pat Altice, a Hospice of Seattle board member, was a patient who spent many hours validating her symptoms and the relief she obtained through interventions provided by the Oncology Transitions Services staff. Also, Dr. Kathy Young Graham was a doctoral student in Sociology at the University of Washington who worked as a research assistant to help establish the initial psychometric properties of the SDS. Finally, the data would not have been provided without the willingness and candor of the patients who completed the scales. We are also grateful to Drs. Jacqueline Fawcett, Lesley Degner, and Carol Moinpour for their review of the manual's content and recommendations to strengthen it.

This manual was developed with resources from an Institutional National Research Service Award entitled "Nursing Research: Psychosocial Oncology", Grant No. T32 NR07036, National Institute of Nursing Research, Dr. Ruth McCorkle, Program Director.

TABLE OF CONTENTS

TABLE OF TABLES

TABLE OF APPENDICES

Chapter 1

Overview of the Symptom Distress Scale

Background

The construct of Symptom Distress was induced from a review of the literature, extension of previously developed scales, and in-depth interviews with patients (Beecher, 1957; Hinton, 1963; McCorkle & Young, 1978; Schneider, 1976; Twycross, 1972). Based upon earlier works by Beecher (1957), Hinton (1963), and Twycross (1972), the SDS became one of the first scales to measure symptoms associated with cancer.

Attempts toward the measurement of distress were reported in the literature as early as 1957. Beecher (1957), in his studies of pain management, discussed the problems related to the definition of pain, its perception, threshold, psychic processing and assessment for analgesics. Similarly, Hinton (1963) attempted to measure physical and mental distress by interviewing 204 patients during hospitalization. The sample consisted of a total of 102 pairs, each consisting of one patient who subsequently died of a fatal illness within six months of hospitalization and a control patient who survived. More than 80 percent of patients who died had neoplastic diseases.

Hinton (1963) defined physical distress as physical discomfort that was severe enough to warrant treatment directed toward its relief. The types of physical distress he included were pain, dyspnea, nausea or vomiting, malaise, and persistent cough. He selected easily identifiable levels of distress to enable patients to give quick, simple answers to interview questions about the efficacy of available treatment. The levels of distress were:

Absent: no symptoms sufficient to cause physical distress.
Relieved: treatment has resulted in the symptoms ceasing to distress the patient.
Unrelieved and inconstant: in spite of treatment the physical discomfort remains distressing but for less than half the time of wakefulness.
Unrelieved and constant: physical distress persists for more than half of the time in spite of treatment.

In addition, Hinton viewed mental distress in terms of depression, anxiety, level of consciousness, and the patient's awareness of dying. For example, he defined depression as an unpleasant feeling of sadness and misery. The interviewer graded the intensity of the patient's mental distress from the patient's description of mood or awareness of dying, the clinical signs exhibited at the interview, and the nurse's reported observation of the patient's distress. The interviewer scored the degree of mental distress on a continuum from no distress to severe distress and the amount of awareness of dying from no awareness to awareness of dying in the near future. Clearly, Hinton's work was a help in measuring the effectiveness of treatment protocols, but because symptoms were not measured using the same methods consistently (patient self report, interviewer administered, or nurse observation), its application was limited.

Subsequently, Twycross (1972) developed scales to measure the effects of two different analgesics (diamorphine and morphine) as he sought to provide adequate pain relief from terminal cancer for patients at St. Christopher's Hospice. Specific factors included were presence or absence of pain, nausea, vomiting, appetite, constipation, mood, coughing, anxiety, and dyspnea. Each factor was represented on a card as a range of two extremes on a straight line, i.e., most extreme pain imaginable to complete freedom from pain. Patients were asked to mark across this straight line the point that represented how much distress they were experiencing for each day. Twycross's technique was useful for comparing symptom changes on a day to day basis, but his scale did not include a mechanism for quantifying the amount of distress experienced by the patient.

Historical Development of the Symptom Distress Scale

Two pilot studies were conducted to identify patient concerns and to generate items for the SDS (McCorkle & Young, 1978; Schneider, 1976). Subsequent field testing of the instrument was conducted to refine the use of the SDS as a clinical outcome measure in patients with cancer (McCorkle & Benoliel, 1981). In the first pilot study, conducted during the first three months of 1976, concerns of patients receiving active cancer treatments in the medical oncology clinic and the radiation therapy division at a university hospital medical center were identified through an interview (Schneider, 1976). The sample included twenty-six subjects; twelve from a medical oncology clinic and fourteen from a radiation oncology clinic. More than 80% (n=10) of the patients on chemotherapy identified physical symptoms as major concerns, compared with only 29 % (n=4) of those receiving radiation therapy. Although the types of symptoms identified in this initial pilot study were similar to those reported by others, the findings suggested that newly diagnosed cancer patients were more concerned about problems related to acceptance of the disease and anxiety over the future, whereas long term cancer patients were more concerned about physical discomforts that interfered with their daily living (Schneider, 1976, p. 97).

Since it seemed important to go a step further and assess the degree of physical distress that a patient experiences and the points at which a symptom becomes unbearable, tolerable or absent, a second pilot study was conducted from January through April 1977 (McCorkle & Young, 1978). Its purpose was to develop a Symptom Distress Scale that could facilitate measurement of the degree of distress reported by the patient. This approach differed from previous methods because it relied solely on patients' self-report of their symptoms (McCaffery, 1979). Symptom distress was defined as "the degree of discomfort from the specific symptom as reported by the patient" (McCorkle & Young, 1978, p. 374). Distress was not differentiated according to whether it resulted from the disease itself or from the treatment.

Sixty patients (30 men and 30 women) volunteered for the study from the radiation oncology clinic and the medical clinics within a university hospital medical center. Although the subjects ranged in age from 18 to 89 years, the majority (61.7%) were between 50 and 69 years. Most (87%) had cancer while the remainder had a medical diagnosis of another nature.

The initial scale included eight symptoms: nausea, mood disturbance, appetite, insomnia, pain, mobility, fatigue, and bowel pattern. These eight symptoms had been the major concerns identified by cancer patients in the first pilot study. Early in the interview process, however, the

investigators decided to include "concentration" in the SDS because some respondents kept apologizing for the need to have questions repeated. "Appearance" was also added since several women reported distress from the weight gain after adrenalectomy.

During subsequent field testing, the mobility item was dropped because it did not contribute to scale homogeneity and was redundant with other instruments. The mood disturbance item was changed to outlook, and breathing and cough were added as symptoms based on patient report of these problems (McCorkle & Benoliel, 1981). The revised SDS has 13 items (see Appendix A). The level of symptom distress for 11 symptoms (nausea, appetite, insomnia, pain, fatigue, bowel pattern, concentration, appearance, outlook, breathing, and cough) is assessed. Frequency of nausea and pain is also assessed. One of the common criticisms of the SDS is the fact that it mixes the response dimensions of distress and frequency. It is important to understand that the descriptions of the symptom response options grew out of the way that patients' explained differing degrees of their problems. For example, although patients' did not experience pain or nausea all the time, they wanted the interviewer to understand that when they did have these symptoms, in some circumstances, it was almost unbearable. Therefore, the mixed dimension response choices of frequency and distress have clinical significance even though they violate psychometric protocol.

Method of Administration

The SDS was developed as a self administered, self-report questionnaire. Five-by-seven cards were prepared, each presenting a symptom and a scale numbered from one to five on which patients rated their distress. A score of one represents normal or no distress for a given symptom and a score of five represents extensive distress, with scores of two, three, and four representing intermediate levels of distress. The two items about frequency are also on a scale of one to five, where one represents almost never experiencing the symptom and five represents experiencing the symptom almost constantly. This standardized Likert type format for response items was chosen because many patients were in the advanced stages of disease and it was imperative for the instructions to be brief and simple enough for them to understand. According to Cronbach (1970: 502-503), "No matter what special procedures are used to reduce distortion, inventory responses depend upon how much the subject is willing and able to report...If the relationship between tester and subject makes this a reasonable expectation, then no subtleties of test design are required." It may also be noted here that patients were aware that the interviewer had no influence on the treatment regimen.

Thirteen cards representing the eleven symptoms are given to each patient; one at a time and in the order listed in Appendix A. The interviewer was present while patients completed the SDS. Patients were asked to put a circle around the number that most closely represented how they perceived their distress for that day. Just five minutes were required to complete responses for all thirteen items.

Over the years, the administration of the scale has taken several formats. The developer of the scale has been consistent in using the card format. Some of the studies discussed in this manual, however, have administered the SDS as consecutive items on 2 pages

or in phone interviews (Kurtz, Given, Kurtz, & Given, 1994; Kurtz, Kurtz, Given & Given, 1995). No formal studies have been conducted assessing the comparability of SDS scores gathered by patients and interviewers, or by self and phone administrations.

Scoring Procedure

Total symptom distress can be obtained as the unweighted sum of the 13 items with scores ranging from 13 to 65. Higher scores indicate higher degrees of symptom distress. Researchers have requested that the level of response be changed from the 1 to 5 Likert scale to a 0 to 4 Likert scale. If the researcher prefers to use this type of scoring, scores would range from 0 to 52. In the case that the researcher uses the alternative scoring procedure, adding 13 would enable the researcher to use the reference tables reported in this manual.

Chapter 2

Psychometric Properties of the Symptom Distress Scale

This chapter provides information about the psychometric properties of the SDS from a variety of perspectives. First, definitions of the psychometric terms used in this chapter are presented. Second, information about the psychometric properties of the SDS from the original studies is included. This is followed by information about the reliability, validity, responsiveness, and reference values of the SDS as reported in published studies. Finally, information about the psychometric properties of the SDS derived from four data sets of newly diagnosed cancer patients is presented. Newly diagnosed is defined as within 100 days of the diagnosis. Results from Weisman and Worden's (1976) classic study identified that patients with newly diagnosed cancer experience a crisis called an "existential plight" during the first 100 days after the diagnosis. The results of their study provided the rationale for the operational definition of the term "newly diagnosed" used in this manual. In order to enable users to compare results obtained in their samples with the SDS scores obtained in similar samples, summary data about the psychometric properties from published studies and from the data of newly diagnosed cancer patients are presented in a tabular format.

Definition of Psychometric Terms

Reliability

Reliability refers to the ability of an instrument to measure phenomena in a consistent manner. Two types of reliability are often studied: internal consistency and repeatability. *Internal consistency* refers to the degree that items within an instrument (or within distinct subscales) appear to measure the same attribute. Cronbach's alpha is the most common method of measuring internal consistency. The recommended Cronbach alpha for an instrument depends on the use of the instrument. A Cronbach alpha of 0.70 is sufficient if the instrument is used to make group level comparisons. If the data are used to make decisions about individuals, a Cronbach alpha of at least 0.90 is recommended (Nunnally & Bernstein, 1994; Polit & Hungler, 1995).

A second type of reliability assesses *repeatability* or stability of the measurement from one time to another time. The most common assessment is *test-retest reliability*. Documenting stability of response over short periods of time strengthens an attribution of change in scores to the phenomena of interest over a longer time period (McCorkle, 1987). When choosing a time for test- retest reliability, selecting an interval where the phenomena are not expected to change is important.

Validity

Validity refers to the ability of an instrument to measure the phenomena it is supposed to be measuring (Lynn, 1986). Accumulation of evidence to support the interpretations drawn from the use of an instrument in a particular setting is a process that occurs over time. Traditionally, three types of validity are commonly recognized: *content, construct, and criterion*.

Content validity is concerned with whether the items adequately represent the domain of the phenomena measured by the instrument. Experts in the content area usually judge whether the items represent the hypothetical domain to be measured. Establishing content validity is usually the first step in constructing a new measure.

Construct validity attempts to measure the underlying attribute (construct) of the

instrument by assessing whether the measurement of one concept is logically related to another concept (Frank-Stromborg & Olsen, 1997). Establishing the extent to which the measure behaves as expected is the major purpose of construct validity (DeVellis, 1991). Therefore, using a hypothesis driven approach is important. *A priori* hypotheses are identified before conducting the study to assess this type of validity. The use of extreme groups is one method that may be used to help establish construct validity (Streiner & Norman, 1995). When using this method, the instrument is administered to two groups known to differ in relation to the construct being measured. Testing for convergent or discriminant validity is also useful when trying to establish construct validity. *Convergent validity* means that the measure is related to other variables to which it should be related; whereas, *discriminant validity* means that when different constructs are measured, observed relationships are weak (or weaker than convergent relationships) suggesting the instruments are measuring different constructs (Frank-Stromborg & Olsen, 1997). These relationships should also be identified *a priori.*

Criterion validity is concerned with establishing the relationship between the instrument and another measure, usually a "gold standard" because it has been used successfully in the field (Polit & Hungler, 1987; Streiner & Norman, 1995). Two types of criterion validity are often discussed: concurrent and predictive. In the case of *concurrent validity*, two measures are administered at the same time and the relationship (e.g., correlation) is assessed between the two instruments. Conversely, *predictive validity* refers to correlating the measure of interest to a future assessment.

Responsiveness

Responsiveness is the ability of a measure to detect a clinically important treatment effect, even if that effect is small. It is important to note that this attribute is particularly important for instruments that are used as outcome measures (Stewart & Archbold, 1992).

Cut Score

A *cut* score is a point along the scale of scores that is used to discriminate the presence or absence of significant levels of the phenomenon, for example, levels of symptom distress (Streiner & Norman, 1995; Waltz, Strickland & Lenz, 1991).

Reference Values

Reference values facilitate interpretation of symptom distress scores by enabling users to compare an individual's score with the scores of other people of similar sociodemographic and health characteristics.

Psychometric Properties of the SDS: Original Studies

The SDS was developed in 1977 based on interviews with patients between 1973 and 1976. At that time, the field of psychometrics was evolving and the process for health-related instrument development was rudimentary. It has only been within the last decade that rapid advances in health related measurement have taken place (Streiner & Norman, 1995; Waltz, Strickland & Lenz, 1984). Despite the limitations of the knowledge of psychometrics when the scale was initiated, the SDS has evolved to be a psychometrically strong assessment instrument. An overview of the psychometric properties of this instrument as reported in the original studies is summarized.

Reliability

Initially, internal consistency and test-retest reliability were established for the SDS (McCorkle & Benoliel, 1981). Cronbach alpha internal reliability coefficients were found to be

0.83 for adults with lung cancer and 0.75 for adults with myocardial infarction. One month test-retest reliability was reported to be 0.78 in a sample of patients with lung cancer and myocardial infarction (McCorkle & Benoliel, 1981).

Validity

Content, construct, and criterion validity were supported for the SDS. A review of the literature and patient interviews were used to generate items for the SDS (McCorkle & Young, 1978; Schneider, 1976). In order to establish content validity, the items were presented to individuals with cancer. Revisions in the SDS were made based on feedback from the patients (McCorkle & Young, 1978). Further field testing was done to ensure that the items represented the phenomena of interest (McCorkle & Benoliel, 1981).

McCorkle and Benoliel (1983) used a known group method to establish construct validity for the SDS. The researchers hypothesized that two groups, patients with lung cancer and those with myocardial infarction, differed regarding symptom distress. As expected, the patients with lung cancer were found to experience significantly more symptom distress than those with myocardial infarction (mean score for the SDS in patients with lung cancer was 26.7 (s.d. 8.4) as compared with 19.3 (s.d. 4.9) for patients with myocardial infarction.

Kukall and colleagues (1986) first established the predictive validity of the SDS. Fifty-three patients with inoperable lung cancer were followed for three and one-half years. Psychosocial and demographic variables were obtained one and three months after diagnosis. Post diagnosis symptom distress was found to be the most important predictor of survival after adjusting for age, functional status, and personality traits. Newly diagnosed cancer patients with a symptom distress score of 25 or greater were found to be less likely to survive than patients with lower scores.

Responsiveness

McCorkle and colleagues (1989) used the SDS as an outcome measure to evaluate the effectiveness of a home nursing care intervention in adults with advanced stage lung cancer. The symptom distress measure demonstrated the ability to detect change over time. A significant difference in symptom distress between the time profiles of the two home care groups (specialized home care with advanced practice oncology nurses and standard home care) and the office care group (routine care) was evident (24.23, 24.71, versus 26.79, $p = 0.03$). Although the entire sample experienced increased symptom distress over time, the office care group experienced elevated symptom distress 6 weeks earlier than the other two groups.

Cut Scores

Cut scores have not been established for this scale. Clinical guidelines are suggested, however, based on the experience of the developer of the SDS. Patients with a score of 25 or greater have moderate distress and need to be evaluated for symptom relief. Patients with scores of 33 or greater are considered to have severe distress and warrant immediate intervention. Additional testing is ongoing.

Psychometric Properties of the SDS: Review of Literature

A comprehensive review of the literature was conducted to identify studies that had used the SDS as an explanatory or clinical outcome measure. Computer searches of published articles from 1982 to October 1996 were conducted using MEDLINE, Cumulative Index for Nursing and Allied Health Literature, and Psychological Abstracts. Three different computer searches were performed using the key words symptom distress and cancer; symptom distress and chronic

illness; and Symptom Distress Scale. In addition, a hand search of the articles identified through the computer searches was conducted to identify additional published articles. Earlier versions of the SDS included eight- and ten- item scales. The articles discussed in this manual, however, are restricted to the 13-item version of the SDS. Forty-seven articles were identified as appropriate for this discussion. Chapter 5 presents an annotated bibliography of the published studies and reports information regarding the purpose, design, sample, measures, and central findings. Because the reliability, validity, and responsiveness of an instrument accumulate over time for a given instrument, information regarding these aspects of the SDS was extracted from the studies and is discussed in the following section.

Reliability

It is important to recognize that the reliability of a measure relates to the particular population and setting in which it is used (Streiner & Norman 1995). The SDS has been used in a variety of patient populations and settings and information exists about the internal consistency reliability of this measure from 47 different studies. The studies are listed in Table 1 in alphabetical order. Some of the studies are repeated in the table because the researchers reported more than one reliability coefficient. Reported Cronbach alphas have ranged from 0.70 when used with patients with various types of cancers (McCorkle et al., 1994) to 0.92 for human immunodeficiency virus infection, acquired immunodeficiency syndrome- related complex and acquired immunodeficiency syndrome patients (Ragsdale & Morrow, 1990). Most of the studies that used the SDS reported Cronbach alpha levels greater than 0.80 (see Table 1). Table 1 presents information about the internal consistency reliability of the SDS. The table lists the investigator, sample size, sample characteristics and the Cronbach alpha reliability.

Table 1: Internal Consistency Reliability for Forty -Seven Studies Using the SDS Scale

Investigator	n	Sample	Cronbach Alpha Reliability
Cowan, Graham & Cochrane (1992)	30 malignant melanoma 27 myocardial infarction	Malignant melanoma and myocardial infarction	0.85
Dean et al. (1995)	30	Malignant melanoma receiving interferon alpha treatment	NR
Degner, Henteleff & Ringer (1987)	29	Various types of cancer admitted to palliative care	0.72
Degner & Sloan (1992)	436	Newly diagnosed cancer	0.80
Degner & Sloan (1992)	482	General public	NR
Degner & Sloan (1995)	434	Newly diagnosed cancer	0.81
Donaldson, McCorkle, Georgiadou & Quint Benoliel (1986)	56	Lung cancer	0.83
Donaldson, McCorkle, Georgiadou & Quint Benoliel (1986)	65	Myocardial infarction	0.75
Ehlke (1988)	107	Breast cancer receiving chemotherapy in the outpatient setting	NR
Frederickson, Jackson, Strauman & Strauman (1991)	45	Various types of cancers receiving IL-2/LAK cell immunotherapy	NR
Germino & McCorkle (1985)	56	Lung cancer (1 month post diagnosis)	0.83
Germino & McCorkle (1985)	56	Lung cancer (2 months post diagnosis)	0.80
Germino & McCorkle (1985)	65	Myocardial infarction (1 month post diagnosis)	0.75
Germino & McCorkle (1985)	65	Myocardial infarction (2 months post diagnosis)	0.76
Given & Given (1992)	21 newly diagnosed breast cancer	Newly diagnosed breast cancer	0.83

Table 1: Internal Consistency Reliability for Forty -Seven Studies Using the SDS Scale – (Continued)

Investigator	n	Sample	Cronbach Alpha Reliability
Given & Given (1992)	28 recurrent breast cancer	Recurrent breast cancer	0.81
Given et al. (1993)	196	Various types of cancers	0.84
Jackson, Strauman, Frederickson & Strauman (1991)	45	Various types of cancers receiving IL-2/LAK cell immunotherapy	NR
Kukull, McCorkle & Driever (1986)	53	Lung cancer	0.79
Kurtz, Kurtz, Given & Given (1995)	150	Various types of cancers	0.83
Lev (1995)	49	Various types of cancers receiving outpatient chemotherapy	NR
Lovejoy et al. (1992)	162	HIV+	0.86
Lovejoy, Paul, Freeman & Christianson (1991)	162	HIV+	0.86
McCorkle & Quint-Benoliel (1983)	56 lung cancer 65 myocardial infarction	Newly diagnosed lung cancer and myocardial infarction	0.79
McCorkle et al (1989)	166	Lung cancer	0.83
McCorkle et al. (1993)	17	Various types of solid tumor cancers	0.77
McCorkle et al. (1994)	60	Various types of cancers at hospital discharge	0.70
McCorkle et al. (1994)	60	Various types of cancers at three months after discharge	0.85
Moinpour (1994)	211 vinorelbine or 5FU and leukovorin 166 oral vinorelbine	Clinical trial Lung cancer	NR
Molassiotis, VanDen, Akker, Milligan, Goldman & Boughton (1996)	26	Bone marrow transplant	0.83
Northouse, Dorris & Charron-Moore (1995)	81	Women with recurrent breast cancer	0.84

Table 1: Internal Consistency Reliability for Forty -Seven Studies Using the SDS Scale – (Continued)

Investigator	n	Sample	Cronbach Alpha Reliability
Northouse, Dorris & Charron-Moore (1995)	74	Husbands of women with recurrent breast cancer	0.85
Northouse, Laten & Reddy (1995)	81	Women with recurrent breast cancer	0.84
Northouse, Laten & Reddy (1995)	74	Husbands of women with recurrent breast cancer	0.85
O'Hare, Malone, Lusk & McCorkle (1993)	63	Black persons with a variety of solid tumor cancers	NR
Pasacreta (1997)	79	Women with breast cancer	0.78
Peruselli et al. (1992)	40	Various types of cancers receiving home care for terminal illness (Italian version)	0.78
Peruselli et al. (1993)	43	Advanced cancer (Italian version)	0.78
Pickett (1991)	60	Various types of cancers receiving outpatient chemotherapy	0.71
Portenoy et al. (1994a)	60 colon 63 prostate 70 breast 50 ovarian	Colon, prostate, breast, and ovarian cancer	NR
Portenoy et al. (1994b)	60 colon 38 prostate 70 breast 50 ovarian	Colon, prostate, breast, and ovarian cancer	NR
Ragsdale & Morrow (1990)	56 AIDS 24 HIV+ 15 ARC	HIV+, ARC, AIDS	0.92
Samarel, Fawcett & Tulman (1993)	77	Newly diagnosed breast cancer	NR
Sarna (1993a)	69	Women with lung cancer	NR
Sarna (1993b)	69	Women with lung cancer	NR
Sarna (1995)	65	Women with lung cancer	NR

Table 1: Internal Consistency Reliability for Forty -Seven Studies Using the SDS Scale – (Continued)

Investigator	n	Sample	Cronbach Alpha Reliability
Sarna (1997)	60	Women with advanced lung cancer	NR
Sarna (1998)	48	Lung cancer	0.80
Sarna et al. (1993)	28	Lung cancer	NR
Sarna, Lindsey, Dean, Brecht & McCorkle (1994)	60	Lung cancer	0.89
Sims (1986)	6	Breast cancer	NR
Strauman (1986)	29	Various types of cancers receiving phase 1 chemotherapy with taxol	NR
Strauman, Frederickson & Jackson (1987)	20	Various types of cancer receiving IL-2/LAK cell immunotherapy	NR
Taylor (1993)	74	Recurrent cancer	0.83
Taylor, Baird, Malone & McCorkle (1993)	165	Various types of solid tumor cancers	NR
Yost et al. (1993)	130	Various types of cancers	NR

NR = Not reported

Validity

Studies were identified in the literature that assessed the validity of the SDS. Several studies supported the construct validity of the scale. Portenoy et al. (1994a) examined the relationship between symptom distress and patient characteristics in a sample of 246 patients with cancer. He hypothesized that hospitalized patients would have more symptom distress than ambulatory patients and that patients with a lower performance status would have more symptom distress than those with a higher performance status. Results of this study supported the hypotheses. Patients who were hospitalized had significantly more symptom distress (mean 28.5, s.d. 9.0) than patients who were in the ambulatory care setting (22.5, s.d. 2.1). Similarly, patients with a low performance status (30.1, s.d. 8.8) had significantly more symptom distress than those with a high performance status (22.4, s.d. 7.0). Degner and Sloan (1995) tested hypotheses about the relationship among symptom distress and age, gender, stage of disease, and type of disease in 482 newly diagnosed ambulatory care patients with cancer. The results of their study supported three of the four hypotheses: more symptom distress was reported by women (23.78, s.d. 7.33) than men (22.38, s.d. 6.90), more symptom distress was reported by patients with advanced disease (26.08, s.d. 7.80) than those with less advanced disease (21.56, s.d. 5.60), and significant

differences in symptom distress were identified between various cancers (e. g., male genitourinary mean SDS 19.09, s.d. 5.06; lung cancer mean SDS 26.30, s.d. 7.74). The researchers found an inverse relationship between age and symptom distress, in that younger patients had more symptom distress.

Evidence of both concurrent and predictive validity was observed in various studies. Table 2 presents information about concurrent validity between the SDS and the scores on other instruments. The investigator, sample, instrument, simple (i.e., raw) correlations and corrected correlations are presented. It is important to recognize that although simple correlations are often reported between an instrument and a criterion, this statistic does not account for the error that is present in both measurements. Therefore, the correlation should be disattenuated to give a more accurate estimate of the true correlation (corrected correlation) (DeVellis, 1991).

As expected, instruments that also measure physical symptoms, such as the physical subscale of the CARES- SF, are highly correlated with the SDS (Sarna, 1993). It might also be noted that since the SDS was the first scale developed to measure physical symptoms in patients with cancer, previous studies have used the SDS as the gold standard measure to establish validity for another instrument (Portenoy et al., 1994b; Dean, Spears, Ferrell, Quan, Groshon & Mitchell, 1995). Portenoy and colleagues (1994b) administered the SDS and a battery of instruments designed to measure various dimensions of quality of life to assess the reliability and validity of the Memorial Symptom Assessment Scale in 246 patients with cancer. The Memorial Symptom Assessment Scale and the SDS showed a strong, negative correlation with the Functional Living Index- Cancer. Similarly, the Memorial Symptom Assessment Scale and the SDS were inversely related to functional status, mood, and well being. In another study, Dean and colleagues (1995) used the SDS and the Piper Fatigue Scale to describe fatigue in cancer patients receiving interferon. The Piper Fatigue Scale demonstrated strong, positive correlations with the SDS, thus lending support for the validity of the Piper Fatigue Scale.

Table 2: Concurrent Validity Between the SDS and Other Instruments

Investigator	Sample	Instrument	Raw Correlation	Corrected Correlation
Cowan, Graham & Cochrane (1992)	30 Malignant melanoma	Symptoms of Stress Inventory	.69	.76
Cowan, Graham & Cochrane (1992)	30 Malignant melanoma	Psychosocial Adjustment to Illness Scale	.51	.57
Cowan, Graham & Cochrane (1992)	30 Malignant melanoma	Quality of Life Index	-.73	-.82
Dean et al. (1995)	30 Malignant melanoma	Piper Fatigue Scale (Total)	.78	*.98

Table 2: Concurrent Validity Between the SDS and Other Instruments – (Continued)

Investigator	Sample	Instrument	Raw Correlation	Corrected Correlation
Frederickson, Jackson, Strauman & Strauman (1991)	45 various types of cancer receiving IL-2/ LAK cell immunotherapy	Sickness Impact Profile	.60	*.80
Lovejoy, Paul, Freeman & Christianson (1991)	93 HIV+ men	Profile of Mood States	.52	.58
Lovejoy, Paul, Freeman & Christianson (1991)	93 HIV+ men	Karnofsky Performance Status	-.43	NR
Portenoy et al. (1994b)	205 Colon, prostate, breast, and ovarian cancer	FLIC	-.81	NR
Portenoy et al. (1994b)	210 Colon, prostate, breast and ovarian cancer	Karnofsky Performance Status	-.59	NR
Portenoy et al. (1994b)	201 Colon, prostate, breast, and ovarian cancer	Rand Well Being	-.59	NR
Portenoy et al. (1994b)	201 Colon, prostate, breast, and ovarian cancer	Rand Distress	.58	NR
Portenoy et al. (1994b)	205 Colon, prostate, breast and ovarian cancer	Mood VAS	-.40	NR
Sarna (1993)	69 Women with lung cancer	Cancer Rehabilitation Evaluation Scale- Short Form	.72	*.87
Sarna (1993)	69 Women with lung cancer	Physical subscale	.80	*.99

Table 2: Concurrent Validity Between the SDS and Other Instruments – (Continued)

Investigator	Sample	Instrument	Raw Correlation	Corrected Correlation
Sarna (1993)	69 Women with lung cancer	Psychological Subscale	.65	*.76
Sarna (1993)	69 Women with lung cancer	Karnofsky Performance Status	-.70	NR
Taylor (1993)	74 Recurrent cancer	Psychosocial Adjustment to Illness Scale	.66	.76

* = estimated on previously published reliability coefficients
NR = not reported in the study

A number of studies supported the predictive validity of the SDS. Symptom distress was a significant predictor of survival in patients with various types of cancer (Degner & Sloan, 1995; Frederickson, Jackson, Strauman & Strauman, 1991; Kukull, McCorkle & Driever, 1986; Taylor, Baird, Malone & McCorkle, 1993). Three studies (Degner & Sloan, 1995; Frederickson, Jackson, Strauman & Strauman, 1991; Kukull, McCorkle & Driever, 1986) showed that patients with a symptom distress score of 25 or greater were less likely to survive than patients with a lower score, whereas a fourth study showed that patients with symptom distress scores higher than 33 were less likely to survive than patients with lower scores (Taylor, Baird, Malone & McCorkle, 1993). Another study showed that patients with moderate to high levels (31-65) of symptom distress were more likely to receive home nursing care than those with lower symptom distress scores (Yost, McCorkle, Buhler-Wilkerson, Schultz & Lusk, 1993).

Responsiveness

Jackson, Strauman, Frederickson & Strauman (1991) addressed the responsiveness of the SDS in a study assessing the biopsychosocial effects of interleukin-2 therapy. Forty-five patients with various cancers received treatment with interleukin-2. Patients completed the SDS prior to treatment, during treatment and 1, 6, and 12 months after therapy completion. SDS scores changed significantly during the treatment and returned to baseline by one month following treatment. Prior to treatment, the mean score was 21. By the start of leukopheresis, it increased to 29 and remained there during treatment. Scores returned to baseline (mean 20.5) by one month after the treatment representing recovery from the treatment.

Reference Values

The SDS was conceptualized as a measure whose lowest score of 13 would indicate the least amount of symptom distress and 65 would indicate the greatest amount of symptom distress. Therefore, when interpreting the symptom distress scores, it is helpful to have scores from a similar reference sample. Table 3 provides information for the samples (and subsamples)

of patients reported in the literature; including the mean SDS scores, standard deviations and the range of scores reported in each article. Users may utilize this table to compare the SDS scores obtained in their samples with the SDS scores obtained in similar samples that were reported in the literature.

Table 3: Mean SDS Scores, Standard Deviation, and Range for Forty -Seven Studies

Investigator	n	Sample	Mean SDS and Range	s.d.
Cowan, Graham & Cochran (1992)	30	Malignant melanoma	NR	NR
Cowan, Graham & Cochran (1992)	27	Myocardial infarction	NR	NR
Dean et al. (1995)	30	Malignant melanoma	NR	NR
Degner, Henteleff & Ringer (1987)	29	Various types of cancers admitted to a palliative care unit (at time of admission)	33.8	NR
Degner, Henteleff & Ringer (1987)	29	One week after admission	25.7	NR
Degner & Sloan (1992)	436	Newly diagnosed cancer	NR	NR
Degner & Sloan (1992)	482	General public	NR	NR
Degner & Sloan (1995)	434	Newly diagnosed outpatients with cancer	23.1 (13 - 50)	7.1
Degner & Sloan (1995)	225	Men	22.4	6.9
Degner & Sloan (1995)	209	Women	23.8	7.3
Degner & Sloan (1995)	13	Oral cavity, pharynx	21.7	6.3
Degner & Sloan (1995)	98	Respiratory system	26.3	7.7
Degner & Sloan (1995)	62	Breast	21.4	5.1

Table 3: Mean SDS Scores, Standard Deviation, and Range for Forty -Seven Studies – (Continued)

Investigator	n	Sample	Mean SDS and Range	s.d.
Degner & Sloan (1995)	52	Genitourinary (Female)	23.6	7.3
Degner & Sloan (1995)	69	Genitourinary (Male)	19.1	5.1
Degner & Sloan (1995)	40	Lymphatic, hematopoietic	22.9	6.6
Degner & Sloan (1995)	31	Digestive organs	23.0	7.8
Degner & Sloan (1995)	82	Lung cancer	26.9	7.8
Donaldson, McCorkle, Georgiadou & Quint-Benoliel (1986)	56	Lung cancer 1 month post diagnosis	26.7	8.4
Donaldson, McCorkle, Georgiadou & Quint-Benoliel (1986)	56	Lung cancer 2 months post diagnosis	26.1	8.4
Donaldson, McCorkle, Georgiadou & Quint-Benoliel (1986)	65	Myocardial infarction 1 month post diagnosis	19.3	4.9
Donaldson, McCorkle, Georgiadou & Quint-Benoliel (1986)	65	Myocardial infarction 2 months post diagnosis	19.1	4.9
Ehlke (1988)	107	Breast cancer receiving outpatient chemotherapy	23.5	NR

Table 3: Mean SDS Scores, Standard Deviation, and Range for Forty -Seven Studies – (Continued)

Investigator	n	Sample	Mean SDS and Range	s.d.
Frederickson, Jackson, Strauman & Strauman (1991)	45	Various cancers receiving IL-2/ LAK immunotherapy at baseline	17.6	5.9
Germino & McCorkle (1985)	56	Lung cancer 1 month post diagnosis	26.8	8.4
Germino & McCorkle (1985)	56	Lung cancer 2 months post diagnosis	26.4	8.4
Germino & McCorkle (1985)	65	Myocardial infarction 1 month post diagnosis	19.2	4.6
Germino & McCorkle (1985)	65	Myocardial infarction 2 months post diagnosis	19.1	4.8
Given & Given (1992)	21	Newly diagnosed breast cancer	NR	NR
Given & Given (1992)	28	Recurrent breast cancer	NR	NR
Given et al. (1993)	196	Various types of cancer	NR	NR
Jackson, Strauman, Frederickson & Strauman (1991)	28	Various types of cancers receiving IL-2/ LAK immunotherapy survivors at baseline	19.2	NR
Jackson, Strauman, Frederickson & Strauman (1991)	15	Non-survivors at baseline	25.0	NR
Kukull, McCorkle & Driever (1986)	56	Lung cancer 1 month post diagnosis	26.8	8.6

Table 3: Mean SDS Scores, Standard Deviation, and Range for Forty -Seven Studies – (Continued)

Investigator	n	Sample	Mean SDS and Range	s.d.
Kukull, McCorkle & Driever (1986)	56	Lung cancer 2 months post diagnosis	26.5	8.6
Kurtz, Kurtz, Given & Given (1995)	150	Various types of cancers	NR	NR
Lev (1995)	49	Various types of cancers receiving chemotherapy	NR	NR
Lovejoy, Paul, Freeman & Christianson (1992)	162	Men who are HIV+ and outpatients	24.5	7.3
Lovejoy et al. (1992)	158	HIV+ men	24.5 (13 - 51)	7.3
McCorkle et al. (1989)	166	Lung cancer	26.5	8.2
McCorkle & Quint Benoliel (1983)	56	Lung cancer 1 month post diagnosis	26.7	8.4
McCorkle & Quint Benoliel (1983)	56	Lung cancer 2 months post diagnosis	26.1	8.4
McCorkle & Quint Benoliel (1983)	65	Myocardial infarction 1 month post diagnosis	19.3	4.9
McCorkle & Quint Benoliel (1983)	65	Myocardial infarction 2 months post diagnosis	19.2	4.9
McCorkle et al. (1993)	17	Various types of cancers at discharge from the hospital	25.5	5.0
McCorkle et al. (1993)	17	3 months after discharge from the hospital	20.9	7.2

Table 3: Mean SDS Scores, Standard Deviation, and Range for Forty -Seven Studies – (Continued)

Investigator	n	Sample	Mean SDS and Range	s.d.
McCorkle et al. (1993)	17	6 months after discharge from the hospital	22.2	7.1
McCorkle et al. (1994)	49	Various types of cancers who received home care following hospital discharge	28.1	6.8
McCorkle et al. (1994)	11	No home care following hospital discharge	22.5	5.5
McCorkle et al. (1994)	49	Home care group 3 months after hospital discharge	25.9	9.0
McCorkle et al. (1994)	11	No home care group 3 months after hospital discharge	27.3	7.9
Moinpour (1994)	211	Lung cancer	NR	NR
Moinpour (1994)	162	Lung cancer	NR	NR
Molassiotis, Van Den Akker, Milligan, Goldman & Boughton (1996)	26	Bone marrow transplant	29.3	8.4
Northouse, Doris & Charron-Moore (1995)	81	Women with recurrent breast cancer	NR	NR
Northouse, Laten & Reddy (1995)	81	Women with recurrent breast cancer	25.0 (13 - 48)	8.2

Table 3: Mean SDS Scores, Standard Deviation, and Range for Forty -Seven Studies – (Continued)

Investigator	n	Sample	Mean SDS and Range	s.d.
O'Hare, Malone, Lusk & McCorkle (1993)	63	Black persons with a variety of solid tumor cancers	30.6	9.9
Pasacreta (1997)	79	Women with breast cancer three to seven months after the initial diagnosis	21.4 (13 - 40)	5.8
Peruselli et al. (1992)	40	Advanced cancer	NR	NR
Peruselli et al. (1993)	43	Advanced cancer	NR	NR
Pickett (1991)	60	Various types of cancers receiving outpatient chemotherapy	NR	NR
Portenoy et al. (1994a)	243	Breast, colon, prostate and ovarian cancer	25.6	8.8
Portenoy et al. (1994a)	123	Inpatients	28.5	9.0
Portenoy et al. (1994a)	120	Outpatients	22.5	2.1
Portenoy et al. (1994a)	121	Karnofsky performance status less than 80	30.1	8.8
Portenoy et al. (1994a)	122	Karnofsky performance status greater than 80	22.4	7.0
Portenoy et al. (1994b)	218	Colon, prostate, breast, and ovarian cancer	NR	NR
Ragsdale & Morrow (1990)	24	HIV+	21.4	5.7

Table 3: Mean SDS Scores, Standard Deviation, and Range for Forty -Seven Studies – (Continued)

Investigator	n	Sample	Mean SDS and Range	s.d.
Ragsdale & Morrow (1990)	15	ARC	32.3	11.1
Ragsdale & Morrow (1990)	56	AIDS	31.6	10.4
Samarel, Fawcett & Tulman (1993)	77	Newly diagnosed stage I or II breast cancer	16.4	5.7
Sarna (1993a)	69	Women with lung cancer	NR	NR
Sarna (1993b)	69	Women with lung cancer	23.4 (13 - 44)	6.9
Sarna (1995)	9	Women with lung cancer who never smoked	20.1	5.9
Sarna (1995)	5	Smoker	26.0	7.0
Sarna (1995)	5	Former smoker less than 6 months	28.0	10.0
Sarna (1995)	5	Former smoker 6 months to 1 year	28.8	5.2
Sarna (1995)	41	Former smoker greater than 1 year	22.8	6.8
Sarna (1997)	60	Women with advanced lung cancer	25.5 (14 - 44)	6.9
Sarna (1998)	48	Lung cancer	NR	NR
Sarna et al. (1993)	28	Lung cancer 2 months following radiation therapy	25.6 (13 - 44)	7.8
Sarna et al. (1993)	17	3.5 months following radiation therapy	23.4 (14-37)	6.6
Sarna et al. (1993)	13	5 months following radiation therapy	23.0 (15 - 30)	4.8

Table 3: Mean SDS Scores, Standard Deviation, and Range for Forty -Seven Studies – (Continued)

Investigator	n	Sample	Mean SDS and Range	s.d.
Sarna et al. (1993)	10	6.5 months following radiation therapy	24.2 (19 - 38)	5.3
Sarna et al. (1993)	9	8 months after radiation therapy	22.0 (17 - 30)	4.7
Sarna, Lindsey, Dean, Brecht & McCorkle (1994)	60	Lung cancer 2 months after diagnosis	27.0 (16 - 51)	8.0
Sarna, Lindsey, Dean, Brecht & McCorkle (1994)	60	Lung cancer 3.5 months after diagnosis	26.0 (14 - 45)	7.0
Sarna, Lindsey, Dean, Brecht & McCorkle (1994)	60	Lung cancer 5 months after diagnosis	27.0 (14 - 51)	8.0
Sarna, Lindsey, Dean, Brecht & McCorkle (1994)	46	Lung cancer 6.5 months after diagnosis	26.0 (15 - 44)	4.0
Sarna, Lindsey, Dean, Brecht & McCorkle (1994)	32	Lung cancer 8 months after diagnosis	25.0 (14 - 48)	10.0
Sims (1986)	6	Breast cancer	NR	NR
Strauman (1986)	29	Various types of cancers receiving phase 1 chemotherapy with taxol	NR	NR
Strauman, Frederickson & Jackson (1987)	20	Various types of cancers receiving IL-2/ LAK immunotherapy baseline	19.9	NR
Strauman, Frederickson & Jackson (1987)	20	day 8	30.3	NR

Table 3: Mean SDS Scores, Standard Deviation, and Range for Forty -Seven Studies – (Continued)

Investigator	n	Sample	Mean SDS and Range	s.d.
Strauman, Frederickson & Jackson (1987)	20	day 15	28.9	NR
Strauman, Frederickson & Jackson (1987)	20	day 30	20.8	NR
Taylor (1993)	74	Recurrent cancer	24.1 (13 - 44)	7.6
Taylor, Baird, Malone & McCorkle (1993)	52	Various types of cancer following hospital discharge	26.2	7.1
Taylor, Baird, Malone & McCorkle (1993)	52	3 months after hospital discharge	24.0	7.3
Taylor, Baird, Malone & McCorkle (1993)	52	6 months after hospital discharge	24.9	8.5
Taylor, Baird, Malone & McCorkle (1993)	52	*Patients who continued in the study	27.1	8.0
Taylor, Baird, Malone & McCorkle (1993)	49	*Patients who died	33.2	8.1
Taylor, Baird, Malone & McCorkle (1993)	18	*Patients who withdrew	23.8	7.2
Taylor, Baird, Malone & McCorkle (1993)	16	*Patients who were lost to follow-up	26.1	6.5
Yost et al. (1993)	130	Various types of cancer	NR	NR

NR = Not reported

* = Symptom distress was measured at entry into the study. All patients were within 30 days of hospitalization.
* = Some studies are reported more than once in the table because the researchers reported more than one SDS score.

Psychometric Properties of the Symptom Distress Scale: Newly Diagnosed Cancer Patients

Previously unpublished data about the psychometric properties of the SDS when used with newly diagnosed cancer patients are provided. The primary goal of this summary data is to provide item and scale level data that show how this scale performs, from a psychometric perspective, when used with cancer patients who were diagnosed within the first 100 days. The secondary goal is to provide enough data to enable other users to compare results obtained in their samples with results we have obtained. Data from four data sets were combined for the psychometric analyses. The data come from four research studies funded by the National Institutes of Health. Patients who were within 100 days of diagnosis of their cancer were included in this sample. The four studies are described in the following section.

Overview of the Four Studies

The first study, "Evaluation of Cancer Management", Grant Number NU01001, 1/1/83 - 6/30/86, was designed as a randomized clinical trial to compare the psychosocial responses and the coping effectiveness of persons with lung cancer who were assigned to one of three treatment groups (routine care, standard home care, or specialized home care with advanced practice oncology nurses) over a six month period. The sample consisted of 80 males and 50 females. Only patients with Stage II lung cancer or higher at diagnoses were recruited into the study. Their diagnoses were made by surgical biopsy, bronchial washings, or thoracotomy. The majority of subjects had advanced disease (stage III or higher) and received primary treatment with radiation therapy.

The second study, "Evaluation of Home Care for Cancer Patients", Grant Number NR01914, 9/28/87 - 7/31/91, was in response to an RFA from the National Cancer Institute and was designed to describe the impact of home care services on patients with cancer discharged from the hospital with complex nursing care requirements and a family member caregiver. The total sample consisted of both newly diagnosed patients and patients living with cancer. The subsample reported here are all newly diagnosed with multiple sites, including colorectal, lung, head and neck, breast, ovarian, and prostate. This subsample consisted of 38 males and 47 females. These patients were diagnosed with surgery and received adjuvant therapy after they recovered from their surgery and during the study period.

The third study, "Factors Affecting Recovery from Colorectal Cancer Surgery", Grant Number NR02324, 9/1/89 - 8/31/94, was designed to examine the associations among psychological distress, symptom distress, expectations about outcome, functional dependency, and immune response over time. The sample consisted of 57 males and 35 females. Patients in this study were young and early staged. They recovered quickly from their primary surgical treatment of their cancer and required little additional treatment over the course of the study.

The fourth study, "Nursing's Impact on Quality of Life Outcomes in Elders", Grant Number NR03229, 9/30/92 - 8/31/97, was designed to test the effects of a standardized nursing intervention protocol (SNIP) on quality of life and survival outcomes for post surgery older cancer patients over time. The sample included 172 males and 191 females. Patients in this study were all over 60 years of age. All were newly diagnosed, and many of them had early

staged cancers, including breast, prostate, colorectal, lung, and head and neck. These patients were discharged with complex problems requiring ongoing monitoring. Many received adjuvant cancer therapies during the study period.

Description of Summary Data

In the following tables, the first study is labeled "*Lung Cancer*", the second study is labeled "*Homecare Multiple Sites*", the third study is labeled "*Colorectal Cancer*", and the fourth study is labeled "*Elders Multiple Sites*".

Tables 4 through 7 present data for each of the four studies separately and overall. There was a statistically significant difference among cancer sites when looking at the overall SDS score. Specifically, the mean for the colorectal study (22.8; s.d. = 6.4) was significantly lower than the means for the other studies (see Table 7 for details). Although the colorectal group differs from the other three groups, combining these data may provide a useful summary for the typical user. The combined data are listed in the right hand column under the heading "total". These tables may be useful for research conducted in specific settings such as home care where a mix of cancer sites would be expected. Tables 9 through 11 provide some of the same data by cancer site. These latter tables should be helpful to researchers studying patients with specific diagnoses.

Table 4 provides an overview of the participants' demographics for the four different studies and overall. Within each study, with the exception of some variables for the Lung Cancer study, there was diversity among the patients in gender, race, marital status, education, religion, employment status, age, stage of cancer, and status (dead or alive) at the end of the study. Note, however, that two studies were restricted to single cancer sites. Also, stage of cancer was quite different among the four studies.

Table 4: Summary of Demographics for the Cancer Patients
n = 683

	Lung Cancer	Homecare Multiple Sites	Colorectal Cancer	Elders Multiple Sites	Total
Gender					
Male	80 (61.5%)	38 (44.7%)	57 (62.0%)	172 (47.4%)	347 (51.8%)
Female	50 (38.5%)	47 (55.3%)	35 (38.0%)	191 (52.6%)	323 (48.2%)
Missing = 13					
Race					
White	143 (100%)	62 (72.9%)	82 (89.1%)	267 (73.6%)	554 (81.1%)
Black	-----	21 (24.7%)	9 (9.8%)	88 (24.2%)	118 (17.3%)
Asian	-----	1 (1.2%)	-----	5 (1.4%)	6 (0.9%)
Hispanic	-----	1 (1.2%)	-----	2 (0.6%)	3 (0.4%)
Other	-----	------	1 (1.1%)	1 (0.3%)	2 (0.3%)
Missing = 0					
Marital Status					
Single	10 (7.1%)	13 (15.3%)	56 (60.9%)	20 (5.5%)	99 (14.5%)
Married	84 (59.6%)	46 (54.1%)	14 (15.2%)	239 (65.8%)	383 (56.2%)
Divorced	22 (15.6%)	8 (9.4%)	17 (18.5%)	32 (8.8%)	79 (11.6%)
Widowed	25 (17.7%)	18 (21.2%)	5 (5.4%)	72 (19.8%)	120 (17.6%)
Missing = 2					
Education					
< 12 years	47 (33.1%)	33 (38.8%)	14 (15.2%)	83 (22.9%)	177 (26.0%)
12 years	42 (29.6%)	28 (32.9%)	30 (32.6%)	121 (33.4%)	221 (32.5%)
> 12 years	53 (37.3%)	24 (28.2%)	48 (52.2%)	158 (43.7%)	283 (41.6%)
Missing = 2					
Religion					
None	36 (25.2%)	1 (1.2%)	37 (25.2%)	19 (5.3%)	93 (13.6%)
Protestant	69 (48.3%)	44 (51.8%)	36 (39.1%)	192 (44.6%)	311 (45.5%)
Catholic	28 (19.6%)	29 (34.1%)	10 (10.9%)	127 (35.0%)	194 (28.4%)
Jewish	4 (2.8%)	9 (10.6%)	7 (7.6%)	47 (13.0%)	67 (9.8%)
Other	6 (4.2%)	2 (2.4%)	2 (2.2%)	8 (2.2%)	18 (2.6%)

Table 4: Summary of Demographics for the Cancer Patients – (Continued)
n = 683

	Lung Cancer	Homecare Multiple Sites	Colorectal Cancer	Elders Multiple Sites	Total
Employment					
Full time	19 (13.5%)	18 (21.2%)	--------	72 (19.8%)	109 (18.5%)
Part time	12 (8.5%)	5 (5.9%)	--------	22 (6.1%)	39 (6.6%)
Unemployed	5 (3.6%)	1 (1.2%)	--------	5 (1.4%)	11 (1.9%)
Disabled	42 (29.8%)	14 (16.5%)	--------	13 (3.4%)	69 (11.7%)
Retired	52 (36.9%)	37 (43.5%)	--------	211 (51.8%)	300 (50.9%)
Homemaker	11 (7.8%)	10 (11.8%)	--------	40 (11.0%)	61 (10.4%)
Missing = 94					
Age					
< 65	77 (54.2%)	46 (54.1%)	47 (51.1%)	124 (34.2%)	294 (43.1%)
65 – 75	50 (35.2%)	28 (32.9%)	36 (39.1%)	185 (51.0%)	299 (43.8%)
> 75	15 (10.6%)	11 (12.9%)	9 (9.8%)	54 (14.9%)	89 (13.1%)
Missing = 1					
Cancer Site					
Breast/gyn	--------	13 (15.3%)	--------	97 (26.7%)	110 (16.1%)
Colorectal	--------	34 (40.0%)	92 (100%)	71 (19.6%)	197 (28.8%)
Head/neck	--------	13 (15.3%)	--------	30 (8.3%)	43 (6.3%)
Lung	142 (99.3%)	19 (22.4%)	--------	68 (18.7%)	229 (33.5%)
Prostate	--------	6 (7.1%)	--------	94 (25.9%)	100 (14.6%)
Other	1 (0.7%)	--------	--------	3 (0.8%)	4 (0.6%)
Stage of Cancer					
Early	5 (10.5%)	20 (29.9%)	--------	249 (68.8%)	284 (49.7%)
Late	128 (89.5%)	47 (70.2%)	--------	113 (31.2%)	288 (50.4%)
Missing = 2					
Status at End of Study					
Alive	26 (18.2%)	18 (26.5%)	--------	272 (75.1%)	316 (55.2%)
Dead	117 (81.8%)	50 (73.5%)	--------	90 (24.9%)	257 (44.9%)
Missing = 17					

Table 5 provides the frequency distribution for each item, that is, the number and percentage

of study participants who chose each option. This analysis is important because it shows that for the total sample and within most studies all options were selected by at least some of the study participants. This suggests that the content of the 13 items and response options are relevant to the newly diagnosed cancer patients. Furthermore, the analysis shows that response distributions followed a predictable pattern in that distributions were unimodal and that there are no obvious problems with either floor or ceiling effects. Such effects would be evident only if more than 70% of the respondents chose a single extreme option (either the highest or lowest). With this table, it is possible to see which symptoms were reported least (frequency and severity of nausea) and most (fatigue, insomnia, and frequency of pain) often. In the following table, 1 indicates the least amount of distress, whereas 5 indicates the greatest degree of symptom distress.

Table 5: Item Frequency Distributions by Study Site

	Lung Cancer	Homecare Multiple Sites	Colorectal Cancer	Elders Multiple Sites	Total
Item 1 – Frequency of Nausea					
1	79 (55.2%)	53 (62.4%)	62 (69.7%)	258 (71.2%)	452 (66.5%)
2	36 (25.2%)	22 (25.9%)	25 (28.1%)	68 (18.7%)	151 (22.2%)
3	16 (11.2%)	5 (5.9%)	2 (2.3%)	26 (7.2%)	49 (7.2%)
4	8 (5.6%)	2 (2.4%)	--------	5 (1.4%)	15 (2.2%)
5	4 (2.8%)	3 (3.6%)	--------	6 (1.7%)	13 (1.9%)
Missing = 3					
Item 2 – Severity of Nausea					
1	71 (49.7%)	53 (62.4%)	60 (77.9%)	272 (74.9%)	456 (68.3%)
2	37 (25.9%)	22 (25.9%)	7 (9.1%)	47 (13.0%)	113 (16.9%)
3	26 (18.2%)	8 (9.4%)	7 (9.1%)	23 (6.3%)	64 (9.6%)
4	6 (4.2%)	1 (1.2%)	3 (3.9%)	11 (3.0%)	21 (3.1%)
5	3 (2.1%)	1 (1.2%)	_____	10 (2.8%)	14 (2.1%)
Missing = 15					
Item 3 – Appetite					
1	53 (37.1%)	25 (29.4%)	45 (48.9%)	111 (30.6%)	234 (34.3%)
2	34 (23.8%)	20 (23.5%)	24 (26.1%)	83 (22.9%)	161 (23.6%)
3	24 (16.8%)	19 (22.4%)	18 (19.6%)	59 (16.3%)	120 (17.6%)
4	29 (20.3%)	19 (22.4%)	5 (5.4%)	58 (16.0%)	111 (16.3%)
5	3 (2.1%)	2 (2.4%)	--------	52 (14.3%)	57 (8.4%)
Missing = 0					

Table 5: Item Frequency Distributions by Study Site – (Continued)

	Lung Cancer	Homecare Multiple Sites	Colorectal Cancer	Elders Multiple Sites	Total
Item 4 – Insomnia					
1	38 (26.6%)	27 (31.8%)	33 (35.9%)	102 (28.1%)	200 (29.3%)
2	49 (34.3%)	25 (19.4%)	34 (37.0%)	84 (23.1%)	192 (28.1%)
3	11 (7.7%)	13 (15.3%)	11 (12.0%)	56 (15.4%)	91 (13.3%)
4	26 (18.2%)	11 (12.9%)	10 (10.9%)	60 (16.5%)	107 (15.7%)
5	19 (13.3%)	9 (10.6%)	4 (4.4%)	61 (16.8%)	93 (13.6%)
Missing = 0					
Item 5 – Frequency of Pain					
1	40 (28.0%)	27 (31.8%)	27 (29.4%)	80 (22.0%)	174 (25.5%)
2	35 (24.5%)	33 (38.3%)	43 (46.7%)	137 (37.7%)	248 (36.3%)
3	17 (11.9%)	8 (9.4%)	7 (7.6%)	48 (13.2%)	80 (11.7%)
4	36 (25.2%)	11 (12.9%)	12 (13.0%)	64 (17.6%)	123 (18.0%)
5	15(10.5%)	6 (7.1%)	3 (3.3%)	34 (9.4%)	58 (8.5%)
Missing = 0					
Item 6 – Severity of Pain					
1	48 (33.6%)	40 (47.1%)	52 (59.8%)	122 (33.6%)	262 (38.6%)
2	46 (32.2%)	30 (35.3%)	27 (31.0%)	133 (36.6%)	236 (34.8%)
3	35 (24.5%)	8 (9.4%)	7 (8.1%)	67 (18.5%)	117 (17.3%)
4	11 (7.7%)	4 (5.9%)	1 (1.2%)	25 (6.9%)	42 (6.2%)
5	3 (2.1%)	2 (2.4%)	--------	16 (4.4%)	21 (3.1%)
Missing = 5					
Item 7 – Fatigue					
1	8 (5.6%)	15 (17.7%)	11 (12.0%)	46 (12.7%)	80 (11.7%)
2	42 (29.6%)	27 (31.8%)	47 (51.1%)	112 (30.9%)	228 (33.4%)
3	50 (35.2%)	23 (27.1%)	17 (18.5%)	104 (28.7%)	194 (28.5%)
4	30 (21.1%)	12 (14.1%)	9 (9.8%)	57 (15.7%)	108 (15.8%)
5	12 (8.5%)	8 (9.4%)	8 (8.7%)	44 (12.1%)	72 (10.6%)
Missing = 1					

Table 5: Item Frequency Distributions by Study Site – (Continued)

	Lung Cancer	Homecare Multiple Sites	Colorectal Cancer	Elders Multiple Sites	Total
Item 8 – Bowel Pattern					
1	72 (50.7%)	32 (37.7%)	15 (16.5%)	103 (28.4%)	222 (32.6%)
2	47 (33.1%)	23 (27.1%)	35 (38.5%)	107 (29.5%)	212 (31.1%)
3	11 (7.8%)	8 (9.4%)	12 (13.2%)	42 (11.9%)	74 (10.9%)
4	9 (6.3%)	1 (1.2%)	6 (6.6%)	26 (7.2%)	42 (6.2%)
5	3 (2.1%)	21 (24.7%)	23 (25.3%)	84 (23.1%)	131 (19.2%)
Missing = 2					
Item 9 – Concentration					
1	69 (47.9%)	52 (61.2%)	59 (64.1%)	190 (52.3%)	369 (54.1%)
2	49 (34.5%)	19 (22.4%)	29 (31.5%)	99 (27.3%)	196 (28.7%)
3	14 (19.9%)	11 (12.9%)	2 (2.2%)	32 (8.8%)	59 (8.7%)
4	8 (5.6%)	3 (3.5%)	1 (1.1%)	26 (7.2%)	38 (5.6%)
5	3 (2.1%)	--------	1 (1.1%)	16 (4.4%)	20 (2.9%)
Missing = 1					
Item 10 - Appearance					
1	64 (45.7%)	39 (45.9%)	59 (64.1%)	184 (50.7%)	346 (50.9%)
2	54 (38.6%)	23 (27.1%)	19 (20.7%)	66 (18.2%)	162 (23.8%)
3	13 (9.2%)	7 (8.2%)	6 (6.5%)	69 (19.0%)	95 (14.0%)
4	9 (5.7%)	8 (9.4%)	4 (4.4%)	19 (5.2%)	39 (5.7%)
5	1 (0.7%)	8 (9.4%)	4 (4.4%)	25 (6.9%)	38 (5.6%)
Missing = 3					
Item 11 – Breathing					
1	56 (39.4%)	42 (49.4%)	83 (90.2%)	255 (70.3%)	436 (63.9%)
2	47 (33.1%)	29 (34.1%)	6 (6.5%)	70 (19.3%)	152 (22.3%)
3	26 (18.3%)	7 (8.2%)	1 (1.1%)	17 (4.7%)	51 (7.5%)
4	10 (7.0%)	3 (3.5%)	2 (2.2%)	11 (3.0%)	26 (3.8%)
5	3 (2.1%)	4 (4.7%)	--------	10 (2.8%)	17 (2.5%)
Missing = 1					
Item 12 - Outlook					
1	47 (32.9%)	22 (25.9%)	34 (37.0%)	175 (48.2%)	278 (40.7%)
2	75 (52.5%)	32 (37.7%)	47 (51.1%)	99 (27.3%)	253 (37.0%)
3	15 (10.5%)	7 (9.2%)	5 (5.4%)	31 (8.5%)	58 (8.5%)
4	6 (4.2%)	16 (18.8%)	2 (2.2%)	35 (9.6%)	59 (8.6%)
5	-------	8 (9.4%)	4 (4.4%)	23 (6.3%)	35 (5.1%)
Missing = 0					

Table 5: Item Frequency Distributions by Study Site – (Continued)

	Lung Cancer	Homecare Multiple Sites	Colorectal Cancer	Elders Multiple Sites	Total
Item 13 - Cough					
1	41 (28.7%)	42 (49.4%)	60 (66.7%)	173 (47.7%)	316 (46.4%)
2	56 (39.2%)	27 (31.8%)	24 (26.7%)	146 (40.2%)	253 (37.2%)
3	26 (18.2%)	13 (15.3%)	3 (3.3%)	31 (8.5%)	73 (10.7%)
4	16 (11.2%)	3 (3.5%)	3 (3.3%)	9 (2.5%)	31 (4.6%)
5	4 (2.8%)	--------	--------	4 (1.1%)	8 (1.2%)
Missing = 2					

Table 6 summarizes the item distributions as means and standard deviations. Standard deviations of 1 to 1.5 on the five-point scale show reasonable spread or dispersion.

Table 6: Item Means and Standard Deviations by Study Site

	Lung Cancer	Homecare Multiple Sites	Colorectal Cancer	Elders Multiple Sites	Total
Item 1 – Frequency of Nausea					
Mean	1.76	1.59	1.33	1.44	1.51
s.d.	1.04	0.97	0.52	0.82	0.87
Item 2 – Severity of Nausea					
Mean	1.83	1.53	1.39	1.46	1.54
s.d.	1.01	0.81	0.81	0.94	0.94
Item 3 – Appetite					
Mean	2.27	2.45	1.82	2.61	2.41
s.d.	1.22	1.20	0.94	1.43	1.32
Item 4 – Insomnia					
Mean	2.57	2.41	2.11	2.71	2.56
s.d.	1.40	1.34	1.14	1.45	1.40
Item 5 – Frequency of Pain					
Mean	2.66	2.25	2.14	2.55	2.48
s.d.	1.39	1.23	1.09	1.27	1.28
Item 6 – Severity of Pain					
Mean	2.13	1.81	1.51	2.12	2.00
s.d.	1.03	0.99	0.70	1.09	1.04
Item 7 – Fatigue					
Mean	2.97	2.66	2.52	2.84	2.80
s.d.	1.04	1.20	1.10	1.20	1.16

Table 6: Item Means and Standard Deviations by Study Site – (Continued)

	Lung Cancer	Homecare Multiple Sites	Colorectal Cancer	Elders Multiple Sites	Total
Item 8 – Bowel Pattern					
Mean	1.76	2.48	2.86	2.67	2.48
s.d.	0.99	1.59	1.46	1.53	1.48
Item 9 – Concentration					
Mean	1.80	1.59	1.43	1.84	1.74
s.d.	0.98	0.85	0.70	1.13	1.03
Item 10 – Appearance					
Mean	1.77	2.09	1.64	1.99	1.91
s.d.	0.89	1.33	1.08	1.24	1.17
Item 11 – Breathing					
Mean	1.99	1.80	1.15	1.49	1.59
s.d.	1.03	1.06	0.53	0.93	0.96
Item 12 – Outlook					
Mean	1.86	2.48	1.86	1.99	2.00
s.d.	0.77	1.31	0.94	1.24	1.14
Item 13 – Cough					
Mean	2.20	1.73	1.43	1.69	1.77
s.d.	1.07	0.85	0.72	0.82	0.90

Table 7 summarizes the item-total correlations, overall scale internal consistency coefficients (Cronbach's alpha), and summary total score statistics. Item-total correlations show the relationship between a single item and all other items in the scale. In general, within a scale measuring a single construct or dimension, one would want to see positive correlations of moderate (0.30- 0.60) magnitude, suggesting each item is related to the whole. If correlations are too low, it suggests that the item is measuring something different from the remaining items. If correlations are too high, it suggests there is considerable overlap and perhaps redundancy in the items. For the combined group of participants, item-total correlations ranged from 0.30 to 0.54. The internal consistency reliability coefficients ranged from 0.74 to 0.81 (unstandardized) and 0.75 to 0.82 (standardized to remove effects of skewed item distributions). General guidelines recommend 0.70 for scales used to make group interpretations and comparisons and 0.90 and higher for scales used to make decisions about individuals (Nunnally & Bernstein, 1994; Polit & Hungler, 1995).

Table 7: Item-total Correlations, Reliabilities and Mean Scores by Study Site

Item	Lung Cancer	Homecare Multiple Sites	Colorectal Cancer	Elders Multiple Sites	Total
Symptom 1	0.50	0.42	0.35	0.35	0.40
Symptom 2	0.50	0.54	0.31	0.34	0.39
Symptom 3	0.50	0.23	0.32	0.51	0.47
Symptom 4	0.52	0.37	0.39	0.44	0.45
Symptom 5	0.41	0.41	0.48	0.36	0.40
Symptom 6	0.53	0.39	0.49	0.39	0.44
Symptom 7	0.59	0.50	0.46	0.53	0.54
Symptom 8	0.29	0.37	0.41	0.37	0.30
Symptom 9	0.51	0.46	0.46	0.43	0.46
Symptom 10	0.52	0.38	0.54	0.41	0.44
Symptom 11	0.37	0.34	0.22	0.35	0.35
Symptom 12	0.34	0.32	0.58	0.28	0.31
Symptom 13	0.35	0.14	0.26	0.33	0.31
Alpha	0.81	0.74	0.77	0.77	0.77
std alpha	0.82	0.75	0.78	0.77	0.78
Mean	27.5	26.9	22.8	27.4	26.7
s.d.	7.8	7.4	6.4	7.9	7.8
Minimum	13	13	13	13	13
Maximum	51	56	47	58	58

Table 8 summarizes performance on the scale for various subgroups of study participants. For the total groups and numerous subgroups, scores are provided for the 25th, 50th, and 75th percentiles as well as the lowest observed (0 percentile) and highest observed (100 th percentile). Percentile scores indicate the percentage of the group that achieved a score identical to or lower than the one shown. For example, for the total group, 75% of the participants scored at 32 or lower; 25% of the participants scored at 21 or lower. Below the percentiles are the group sizes, means and standard deviations. Because the total SDS scale distribution is not too skewed, most means are close to the 50th percentile or median. The p-value indicates the result from an ANOVA that compared subgroup means within a particular demographic characteristic. Means were significantly different for sex (women had higher scores), living status (those with partners had higher scores), religion (Catholics had higher

scores), type of cancer (participants with head and neck or lung cancer had higher scores), and stage of cancer (those with advanced cancer had higher scores).

Table 8: Comparisons of Group Means on Demographic and Clinical Characteristics

Total Group

Percentile	n
100%	58
75%	32
50%	26
25%	21
0%	13
n	683
Mean	26.7
s.d.	7.8

Gender

Percentile	Male	Female
100%	58	54
75%	30	33
50%	25	26
25%	21	21
0%	13	14
n	347	323
Mean	26.0	27.4
s.d.	7.6	7.9
p = .02		

Race

Percentile	White	Nonwhite
100%	58	56
75%	32	30
50%	26	25
25%	21	20
0%	13	13
n	554	129
Mean	27.0	25.6
s.d.	7.7	7.9
p = .07		

Table 8: Comparisons of Group Means on Demographic and Clinical Characteristics - (Continued)

Living Status

Percentile	Partner	No Partner
100%	58	56
75%	33	30
50%	27	24
25%	22	20
0%	13	13
n	383	298
Mean	27.6	25.6
s.d.	7.8	7.6
p = .0009		

Education

Percentile	< 12	12	> 12
100%	51	58	45
75%	31	32	31
50%	25	26	26
25%	21	21	21
0%	13	13	13
n	177	221	283
Mean	26.5	27.2	26.5
s.d.	7.7	8.4	7.3
p = .56			

Religion

Percentile	None	Protestant	Catholic	Other
100%	44	56	58	47
75%	28	32	33	30
50%	23	26	27.5	24
25%	21	20	22	19
0%	14	13	13	13
n	93	311	194	85
Mean	24.7	26.6	28.4	25.5
s.d.	6.5	7.8	8.1	7.5
p = .0005				

Table 8: Comparisons of Group Means on Demographic and Clinical Characteristics - (Continued)

Employment status

Percentile	Full Time	Part Time	Disabled	Retired	Homemaker
100%	45	45	56	58	47
75%	33	28	35	32	36
50%	25	23	27	27	28
25%	20	20	21	22	22
0%	14	13	14	13	15
n	109	39	69	311	61
Mean	26.7	24.9	28.4	27.3	28.7
s.d.	7.9	7.1	8.8	7.5	8.3
p = .11					

Age

Percentile	< 65	65+	65 - 75	75+
100%	56	58	58	45
75%	32	31	31	31
50%	26	26	26	24
25%	21	21	21	20
0%	14	13	13	13
n	294	388	299	89
Mean	26.8	26.7	27.0	25.6
s.d.	7.5	8.0	8.0	7.6
p = 0.32				

Cancer Site

Percentile	Breast/Gyn	Colorectal	Head/Neck	Lung	Prostate
100%	45	47	58	56	41
75%	31	30	35	34	29.5
50%	26	25	27	27	24
25%	20	21	23	22	30
0%	14	13	16	13	13
n	110	197	43	229	100
Mean	26.0	25.8	28.7	28.3	24.8
s.d.	7.4	7.3	8.3	8.3	6.6
p = .0002					

Table 8: Comparisons of Group Means on Demographic and Clinical Characteristics - (Continued)

Stage of Cancer

Percentile	Early Stage	Late Stage
100%	54	58
75%	31.5	33.5
50%	26	27
25%	21	22
0%	13	13
Mean	26.7	28.0
s.d.	7.7	7.7
p = 0.04		

Status at End of Study

Percentile	Alive	Dead
100%	54	58
75%	32	33
50%	26	27
25%	31	22
0%	13	13
Mean	27.1	27.8
s.d.	7.9	7.7
p = 0.26		

Tables 9 through 11 provide similar information to earlier tables, but the columns are based on cancer site rather than study identification. Researchers working with a specific patient population may find this information useful for comparative purposes. As shown in Table 9, with only a few exceptions, all options were chosen for each item within each patient group. Table 10 translates the details about item distribution into means and standard deviations. Here, observations can be made that support the construct validity of the scale. For example, patients with lung cancer reported more distress with breathing than patients in other groups. And patients with head and neck cancer reported more distress regarding their appearance. Finally, Table 11 shows moderate item-total correlations across all groups and reasonable internal consistency coefficients.

Table 9:Item Frequency Distributions by Cancer Site

	Breast/Gyn n = 110	Colorectal n = 197	Head/Neck n= 43	Lung n = 229	Prostate n = 100	Total n = 679
Item 1 – Frequency of Nausea						
1	75 (68.2%)	130 (67.0%)	32 (74.4%)	137 (59.8%)	74 (74.0%)	452 (66.5%)
2	19 (17.3%)	50 (25.8%)	7 (16.3%)	55 (24.0%)	20 (20.0%)	151 (22.2%)
3	9 (8.2%)	12 (6.2%)	2 (4.7%)	22 (9.6%)	4 (4.0%)	49 (7.2%)
4	2 (1.8%)	1 (0.5%)	2 (4.7%)	9 (3.9%)	1 (1.0%)	15 (2.2%)
5	5 (4.6%)	1 (0.5%)	--------	6 (2.6%)	1 (1.0%)	13 (1.9%)
Missing = 7						
Item 2 – Severity of Nausea						
1	78 (70.9%)	132 (72.5%)	33 (76.7%)	130 (56.8%)	79 (79.0%)	456 (68.3%)
2	15 (13.6%)	25 (13.7%)	3 (7.0%)	54 (23.6%)	16 (16.0%)	113 (16.9%)
3	9 (8.2%)	16 (8.8%)	6 (14.0%)	31 (13.5%)	2 (2.0%)	64 (9.6%)
4	2 (1.8%)	5 (2.8%)	1 (2.3%)	10 (4.4%)	3 (3.0%)	21 (3.1%)
5	6 (5.5%)	4 (2.2%)	--------	4 (1.8%)	--------	14 (2.1%)
Missing = 19						
Item 3 – Appetite						
1	39 (35.5%)	59 (30.0%)	9 (20.9%)	84 (36.7%)	42 (42.0%)	234 (34.3%)
2	30 (27.3%)	46 (23.4%)	9 (20.9%)	51 (22.3%)	25 (25.0%)	161 (23.6%)
3	15 (13.6%)	41 (20.8%)	13 (30.2%)	37 (16.2%)	13 (13.0%)	120 (17.6%)
4	17 (15.5%)	28 (14.2%)	6 (14.0%)	48 (21.0%)	11 (11.0%)	111 (16.3%)
5	9 (8.2%)	23 (11.7%)	6 (14.0%)	9 (3.9%)	9 (9.0%)	57 (8.4%)
Missing = 4						
Item 4 – Insomnia						
1	40 (36.4%)	60 (30.5%)	9 (20.9%)	61 (26.6%)	30 (30.0%)	200 (29.3%)
2	25 (22.7%)	60 (30.5%)	12 (27.9%)	68 (29.7%)	26 (26.0%)	192 (28.1%)
3	17 (15.5%)	30 (15.2%)	6 (14.0%)	24 (10.5%)	14 (14.0%)	91 (13.3%)
4	16 (14.5%)	23 (11.7%)	8 (18.6%)	38 (16.6%)	19 (19.0%)	107 (15.7%)
5	12 (10.9%)	24 (12.2%)	8 (18.6%)	38 (16.6%)	11 (11.0%)	93 (13.6%)
Missing = 4						
Item 5 – Frequency of Pain						
1	24 (21.8%)	59 (30.0%)	8 (18.6%)	48 (21.0%)	32 (32.0%)	174 (25.5%)
2	51 (46.4%)	84 (42.6%)	20 (46.5%)	62 (27.1%)	30 (30.0%)	248 (36.3%)
3	12 (10.9%)	18 (9.1%)	3 (7.0%)	33 (14.4%)	14 (14.0%)	80 (11.7%)
4	13 (11.8%)	30 (15.2%)	8 (18.6%)	54 (23.6%)	18 (18.0%)	123 (18.0%)
5	10 (9.1%)	6 (3.1%)	4 (9.3%)	32 (14.0%)	6 (6.0%)	58 (8.5%)
Missing = 4						

Table 9: Item Frequency Distributions by Cancer Site - (Continued)

	Breast/Gyn n = 110	Colorectal n = 197	Head/Neck n= 43	Lung n = 229	Prostate n = 100	Total n = 679
Item 6 – Severity of Pain						
1	43 (39.1%)	98 (51.0%)	15 (34.9%)	64 (28.0%)	39 (39.0%)	262 (38.6%)
2	36 (32.7%)	65 (33.9%)	15 (34.9%)	84 (36.7%)	35 (35.0%)	236 (24.8%)
3	20 (18.2%)	18 (9.4%)	7 (16.3%)	55 (24.0%)	17 (17.0%)	117 (17.3%)
4	7 (6.4%)	8 (4.2%)	3 (7.0%)	18 (7.9%)	6 (6.0%)	42 (6.2%)
5	4 (3.6%)	3 (1.6%)	3 (7.0%)	8 (3.5%)	3 (3.0%)	21 (3.1%)
Missing = 9						
Item 7 – Fatigue						
1	26 (23.6%)	18 (9.1%)	7 (16.3%)	16 (7.0%)	12 (12.0%)	80 (11.7%)
2	32 (29.1%)	81 (41.1%)	10 (23.3%)	67 (29.4%)	38 (38.0%)	228 (33.4%)
3	25 (22.7%)	50 (25.4%)	12 (27.9%)	72 (31.6%)	34 (34.0%)	194 (28.5%)
4	15 (13.6%)	28 (14.2%)	11 (25.6%)	44 (19.3%)	10 (10.0%)	108 (15.8%)
5	12 (10.9%)	20 (10.2%)	3 (7.0%)	29 (12.7%)	6 (6.0%)	72 (10.6%)
Missing = 5						
Item 8 – Bowel Pattern						
1	40 (36.4%)	35 (17.9%)	12 (27.9%)	103 (44.7%)	32 (32.0%)	222 (32.6%)
2	32 (29.1%)	62 (31.6%)	18 (41.9%)	74 (32.5%)	26 (26.0%)	212 (31.1%)
3	12 (10.9%)	26 (13.3%)	4 (9.3%)	19 (8.3%)	12 (12.0%)	74 (10.9%)
4	5 (4.6%)	13 (6.6%)	2 (4.7%)	17 (7.5%)	5 (5.0%)	42 (6.2%)
5	21 (19.1%)	60 (30.6%)	7 (16.3%)	16 (7.0%)	25 (25.0%)	131 (19.2%)
Missing = 6						
Item 9 – Concentration						
1	62 (56.4%)	115 (58.4%)	30 (70.0%)	112 (49.1%)	48 (48.0%)	369 (54.1%)
2	23 (20.9%)	58 (29.4%)	9 (20.9%)	73 (32.0%)	31 (31.0%)	196 (28.7%)
3	9 (8.2%)	16 (9.1%)	3 (7.0%)	20 (8.8%)	11 (11.0%)	59 (8.7%)
4	11 (10.0%)	5 (2.5%)	--------	14 (6.1%)	8 (8.0%)	38 (5.6%)
5	5 (4.6%)	3 (1.5%)	1 (2.3%)	9 (4.0%)	2 (2.0%)	20 (2.9%)
Missing = 5						

Table 9: Item Frequency Distributions by Cancer Site - (Continued)

	Breast/Gyn n = 110	Colorectal n = 197	Head/Neck n= 43	Lung n = 229	Prostate n = 100	Total n = 679
Item 10 – Appearance						
1	58 (52.7%)	107 (54.3%)	13 (30.2%)	103 (45.6%)	64 (64.0%)	346 (50.9%)
2	22 (20.0%)	40 (20.3%)	5 (11.6%)	74 (32.7%)	19 (19.0%)	162 (23.8%)
3	18 (16.4%)	26 (13.2%)	12 (27.9%)	25 (11.1%)	14 (14.0%)	95 (14.0%)
4	9 (9.2%)	9 (4.6%)	4 (9.3%)	16 (9.1%)	1 (1.0%)	39 (5.7%)
5	3 (2.7%)	15 (7.6%)	9 (20.9%)	8 (3.5%)	2 (2.0%)	38 (5.6%)
Missing = 7						
Item 11 – Breathing						
1	91 (82.7%)	150 (76.1%)	23 (53.5%)	83 (36.4%)	87 (87.0%)	436 (63.9%)
2	12 (10.9%)	33 (16.8%)	15 (34.9%)	80 (35.1%)	11 (11.0%)	152 (22.3%)
3	4 (3.6%)	7 (3.6%)	1 (2.3%)	37 (16.2%)	2 (2.0%)	51 (7.5%)
4	1 (0.9%)	6 (3.1%)	2 (4.7%)	16 (7.0%)	--------	26 (3.8%)
5	2 (1.8%)	1 (0.5%)	2 (4.7%)	12 (5.3%)	--------	17 (2.5%)
Missing = 5						
Item 12 – Outlook						
1	44 (40.0%)	77 (39.1%)	16 (37.2%)	81 (35.4%)	58 (58.0%)	278 (40.7%)
2	33 (30.0%)	77 (39.1%)	15 (34.9%)	100 (43.7%)	27 (27.0%)	253 (37.0%)
3	8 (7.3%)	17 (8.6%)	3 (7.0%)	24 (10.5%)	6 (6.0%)	58 (8.5%)
4	16 (14.6%)	14 (7.1%)	5 (11.6%)	17 (7.4%)	7 (7.0%)	59 (8.6%)
5	9 (8.2%)	12 (6.1%)	4 (9.3%)	7 (3.1%)	2 (2.0%)	35 (5.1%)
Missing = 4						
Item 13 – Cough						
1	66 (60.0%)	111 (56.9%)	12 (27.9%)	69 (30.1%)	57 (57.0%)	316 (46.4%)
2	41 (37.3%)	67 (34.4%)	16 (37.2%)	92 (40.2%)	36 (36.0%)	253 (37.2%)
3	3 (2.7%)	10 (5.1%)	13 (30.2%)	40 (17.5%)	6 (6.0%)	73 (10.7%)
4	-------	7 (3.6%)	--------	22 (9.6%)	1 (1.0%)	31 (4.6%)
5	-------	--------	2 (4.7%)	6 (2.6%)	--------	8 (1.2%)
Missing = 6						

Table 10: Item Means and Standard Deviations by Cancer Site

	Breast/Gyn n = 110	Colorectal n = 197	Head/Neck n= 43	Lung n = 229	Prostate n = 100	Total n = 679
Item 1 – Frequency of Nausea						
Mean	1.57	1.42	1.40	1.66	1.35	1.51
s.d.	1.04	0.68	0.79	0.99	0.70	0.87
Item 2 – Severity of Nausea						
Mean	1.57	1.48	1.42	1.71	1.29	1.54
s.d.	1.09	0.93	0.82	0.98	0.66	0.94
Item 3 – Appetite						
Mean	2.34	2.54	2.79	2.33	2.20	2.41
s.d.	1.32	1.36	1.32	1.27	1.33	1.32
Item 4 – Insomnia						
Mean	2.41	2.45	2.86	2.67	2.55	2.56
s.d.	1.39	1.35	1.44	1.45	1.38	1.40
Item 5 – Frequency of Pain						
Mean	2.40	2.19	2.53	2.83	2.36	2.48
s.d.	1.21	1.12	1.26	1.37	1.27	1.28
Item 6 – Severity of Pain						
Mean	2.03	1.71	2.16	2.22	1.99	2.00
s.d.	1.08	0.91	1.19	1.05	1.04	1.04
Item 7 – Fatigue						
Mean	2.59	2.75	2.84	3.01	2.60	2.80
s.d.	1.29	1.13	1.19	1.13	1.02	1.16
Item 8 – Bowel Pattern						
Mean	2.41	3.01	2.40	2.00	2.65	2.48
s.d.	1.49	1.53	1.38	1.21	1.08	1.48
Item 9 – Concentration						
Mean	1.85	1.59	1.44	1.84	1.85	1.74
s.d.	1.20	0.86	0.83	1.08	1.04	1.03
Item 10 – Appearance						
Mean	1.88	1.91	2.79	1.90	1.58	1.91
s.d.	1.12	1.24	1.50	1.08	0.91	1.17
Item 11 – Breathing						
Mean	1.28	1.35	1.72	2.10	1.15	1.59
s.d.	0.74	0.74	1.05	1.13	0.41	0.96
Item 12 – Outlook						
Mean	2.21	2.02	2.21	1.99	1.68	2.00
s.d.	1.33	1.15	1.32	1.02	1.00	1.14
Item 13 – Cough						
Mean	1.43	1.55	2.16	2.14	1.51	1.77
s.d.	0.55	0.75	1.00	1.04	0.66	0.90

Table 11: Item-Total Correlations by Cancer Site

	Breast/Gyn n = 110	Colorectal n = 197	Head/Neck n = 43	Lung n = 229	Prostate n = 100	Total n = 679
Sx1	0.36	0.34	0.29	0.45	0.42	0.40
Sx2	0.40	0.31	0.47	0.45	0.24	0.39
Sx3	0.47	0.42	0.51	0.53	0.46	0.47
Sx4	0.42	0.43	0.29	0.52	0.46	0.45
Sx5	0.38	0.39	0.40	0.40	0.36	0.40
Sx6	0.36	0.44	0.39	0.52	0.38	0.44
Sx7	0.48	0.54	0.42	0.59	0.44	0.54
Sx8	0.36	0.35	0.57	0.39	0.39	0.30
Sx9	0.46	0.47	0.47	0.51	0.44	0.46
Sx10	0.36	0.42	0.50	0.51	0.33	0.44
Sx11	0.09	0.41	0.45	0.37	0.16	0.35
Sx12	0.25	0.35	0.41	0.34	0.17	0.31
Sx13	0.09	0.28	0.51	0.30	0.25	0.31
Alpha Std alpha	0.73 0.72	0.76 0.77	0.80 0.81	0.81 0.82	0.72 0.72	0.77 0.78
Mean s.d.	26.0 7.4	25.8 7.3	28.7 8.3	28.3 8.3	24.8 6.6	26.7 7.8
Minimum Maximum	14 45	13 47	16 58	13 56	13 41	13 58

Chapter 3

Translation of the Symptom Distress Scale

Cultural and Linguistic Equivalence of the Symptom Distress Scale

Dutch, French-Canadian, Italian, Spanish, Swedish, and Taiwanese translations of the SDS have been done. To gather information regarding the cultural equivalence of various versions of the SDS for this manual, a review of the literature was conducted and investigators were surveyed. Information about the French-Canadian, Italian, Spanish, and Swedish versions of the SDS were available at the time of publication of the manual.

Flaherty et al. (1988) recommend a five-step process of evaluating the cross cultural equivalence of an instrument: 1) determine that each item is relevant; 2) determine that each item has the same meaning; 3) ascertain that the method of administration yields comparable data; 4) establish criterion validity; 5) establish construct validity. It should be noted that not all steps are done for each translation.

The use of the SDS in the various cultures is discussed and the evaluation process used by the researchers to establish cross-cultural equivalence is highlighted. French-Canadian, Italian and Spanish versions of SDS use the 13 item format, whereas the Swedish version uses a 15 item format. It is important to recognize that because the Swedish version is a 15-item scale, comparison of scores between the Swedish version and the 13 item versions is not possible.

French-Canadian (contributed by Andrea Laizner M.Sc. (A).

The desire to develop a French-Canadian version of the SDS was motivated by an interest in the concept of symptom distress, as well as the need to identify French versions of instruments for use in Canadian oncology research. The recently formed National Cancer Institute of Canada Sociobehavioral Cancer Research Network is committed to conducting a series of studies that include Quebec (Iverson,1994). Since French is the primary language of Quebec, such studies will require that psychometrically acceptable instruments and questionnaires be available in French-Canadian and English versions.

The search for a previously translated French-Canadian version of the Symptom Distress Scale included consultation with nurses involved with persons with cancer and medical oncologists at Université de Montréal, Université de Sherbrooke, and McGill University, as well as their affiliated institutions. The only French-Canadian translation found was available through a clinical trials group and was being used in a drug study. This initial French-Canadian translation was developed using simple translation from English to French-Canadian. Because there was no back translation or validation done on that translation, a careful review of the cultural equivalence of this instrument was done. Laizner identified several inconsistencies or errors in translation (A. Laizner, personal communication, April 6, 1997). Therefore, changes were made to improve the cultural equivalence of the French-Canadian version of the SDS. Four categories of concern were identified in the original translation:

1) Words or phrases difficult to translate from English to French-Canadian because there may be words in French-Canadian that carry several different meanings, depending on the context. For example:

Nausea 2: "feel sick" translated as "mal" rather than "malade" in the first translation. The word "mal" is a term that can mean many different things depending on the context. It can refer to a hurt, something bad, a headache, or a stomach ache. The word "malade" means "ill, sick, or unwell", which is a better term when referring to nausea.

2) Desire for consistency across items when using adjective descriptions or words. For example:

Nausea 2: "very mild" can be translated as "très supportable" or "tolerable". The Collins-Robert English/French Dictionary provides the word "insupportable" for "unbearable". In French-Canadian, the word "intolerable" is used sometimes when referring to pain but not for nausea. After some discussion, we decided that using "très supportable" was appropriate when dealing with nausea. Having made this decision for nausea, we used the same term with pain (2). The first translation used "mal" and "douleur" to refer to the same situation. The translators used the word "douleur" which is more commonly used when referring to pain.

3) The initial translator, not familiar with the SDS, made several assumptions about meaning of words or phrases without consulting documentation about the development of the original scale or contacting the scale's developers to clarify the intent of the item. For example:

The original translation used "parfois d'insomnie" to refer to "occasional spells of sleeplessness". The term "insomnia" is only used as a heading for the item and not in any of the phrases in the original English version. The translator believed the item referred to difficulty getting to sleep; therefore, we translated it as "parfois la difficulté à dormir" which means that a person sometimes has difficulty sleeping.

The original French-Canadian version translated the response set to reflect the frequency of the bowel movements such as constipation. Believing that this item was attempting to examine changes in the pattern that is normal for the person, be it one that includes constipation or more liquid stool, the revised translation referred to bowel pattern as fecal elimination, its pattern as well as whether it created discomfort.

Should this new French-Canadian translation be used with people of very limited education, it might be necessary to use the words "Je vais normalement à la selle". The translators intend to test the revised French-Canadian version of the SDS with patients, to clarify the need to change this item. The present translation is acceptable for individuals with a sixth grade education.

4) Errors in translation that would have been identified had a back-translation been done. For example:

Outlook: "I am not fearful or worried" was translated as "I don't cry and I'm not worried" in the first translation. The error was corrected.

Having established that the original French-Canadian translation required revision, it, along with the original English version, were submitted to a reviewer for comments and corrections. All comments were discussed and the French-Canadian translation was revised after a consensus was reached. Then this second draft of the French-Canadian translation was submitted to the next expert along with the original English. This time the first French-Canadian translation was not included with the hope that each subsequent revision would eventually lead to an acceptable French-Canadian translation. Revisions were again made after discussion and consensus. The final draft was examined and corrected by another reviewer and then compared with the original English version of the scale.

Finally, the title "Symptom Distress Scale" is not easy to translate in French. Given the intent of the scale, the translators have called it "Échelle de la nature des symptômes," which might literally be translated "The Nature of Symptoms Scale." Items were evaluated for relevancy and back translation was done. The instrument is currently being used in a clinical trial to evaluate reliability and validity (see Appendix B).

Italian Version (information extracted from published articles using Italian version of the SDS)

Peruselli and colleagues (1992, 1993) conducted several studies using the Italian version of the SDS. The authors reported evaluating the instrument for cross-cultural equivalence. Peruselli et al. (1993) acknowledged that the symptoms assessed by the SDS are the most common symptoms experienced by patients with advanced cancer. A literal translation of each item was done and then this translation was validated for meaning. The format and administration of the Italian SDS is the same as the English version. Internal consistency reliability was reported as 0.78 in a sample of patients with advanced cancer receiving home care. Patients were able to complete the instrument in 5 to 10 minutes and found it simple and easy to understand.

Southwest Oncology Group Spanish Version (contributed by Carol M. Moinpour PhD)

The following information is based on a National Cancer Institute grant (CA61674) obtained to translate the Southwest Oncology Group (SWOG) Quality of Life (QOL) Questionnaire into Spanish and to validate the translation. These data have not been published; preliminary findings for the SDS are presented below. An eleven-item version of the SDS is included in the SWOG QOL questionnaire; cough and outlook items are excluded in the questionnaire used in Phase III trials but included in the questionnaire used for Phase II trials since symptom status is emphasized in our Phase II trials. All 13 items were translated. Response choices for the SWOG version of the SDS in English differ for the first ten items because an earlier version of the scale was used when SWOG QOL studies were first activated. In most cases these differences are minor (e.g., SWOG: 'I seldom if ever have nausea'; Manual: 'I seldom feel any nausea at all'). However, some item responses reflect more substantial differences (e.g., SWOG: 'The worsening of my physical appearance is a constant, preoccupying concern'; Manual: 'My appearance has changed drastically from what it was'). Therefore, the translation provided and examples of translation problems reflect the SWOG English version of the SDS. The Spanish version is provided in Appendix C.

A single assessment was obtained from prostate and breast cancer patients in San Antonio, Texas and Los Angeles, California. In the U.S., there are three main sources of colloquial variation in the Spanish language: Mexican, Cuban, and Puerto Rican. The SWOG translation emphasized idiomatic variation used by Hispanics of Mexican descent. The translation methodology was achieved through a number of translation iterations, including translation of the Spanish "back" into English. The initial translation occurred in San Antonio, Texas, and was then back translated into English in both San Antonio and Los Angeles. Suggested revisions from translators and project staff in both cities were resolved through additional back translations and conference calls. Focus groups were held in both cities with Hispanic patients with breast or prostate cancer and feedback was obtained regarding the adequacy of the translation of the SDS. There was less input from Hispanic men with prostate cancer because few of those approached were willing to participate in discussion groups. A meeting of project staff and consultants was held to discuss the translations, as well as requesting Dr. McCorkle to review the English back translation of the SDS. Additional outside consultant reviews of the Spanish translation and English back translation were obtained, culminating in a conference call with consultants and project staff. Problems associated with the Spanish translation of the SDS are based on the above process.

In the validation study, breast or prostate cancer patients were asked to complete three questionnaires: SWOG QOL Questionnaire; CARES-SF; FACT-B, or FACT-P. Monolingual Hispanic patients completed the three questionnaires in Spanish. Bilingual Hispanic patients completed the SWOG QOL Questionnaire in Spanish and English and one of the other two questionnaires in Spanish. Non-Hispanic White patients completed the three questionnaires in English. Preliminary psychometric data for the Spanish translation come from the validation study.

Translation of the SDS items presented some difficulties in achieving consensus because of the number of words involved in the response choices. However, consensus was achieved. The main problem encountered in translating the SDS had to do with attempting literal translations of the English SDS. This resulted in Spanish text that was difficult to understand, not the way things are said in general usage, or simply inappropriate. This problem first occurred with the title of the scale, which was first translated as 'Escala de los Sintomas de Angustia' but later changed to 'Escala de los Sintomas'. 'Bowel pattern' also required some adjustments. Attempts to translate this term literally resulted 'Patron Intestinal'. Although the back translation was correct, the term 'patron' was not used correctly. This term usually refers to a pattern or form for making something. The final translation used 'Regularidad Intestinal'. The English version also explains this term as 'problems with frequency or pain during bowel movement'. The first translation was 'Problemas en cuanto a la freceuencia o el dolor durante los movimientos intestinales'. In the response choices, the term 'I have a normal bowel pattern' was translated first as 'tengo mi normal patron intestinal', next as 'mi frecuencia intestinal es normal', and finally as 'mis moviemientos intestinales son normales'. There were revisions for all five levels of the bowel item. The term 'Outlook' first generated 'Perspectiva'; later 'Percepcion/Perspectiva' was used. 'I am worried and a little frightened about things' required the following translation iterations: 'estoy preocupado y un poco asustado sobre cosas'; estoy preocupada y un poco asustado (did not translate 'things' because it was too literal); estoy muy

preocupada y temeroso de las cosas; estoy preocupada y un poco temeroso de las cosas. In this case, we returned to a literal translation strategy. The multiple word features of SDS response categories often presented this literal vs conceptual translation dilemma. This translation project began its translation of the SDS with a Spanish version translated in Miami, Florida for a pharmaceutical company sponsored trial. Our study translators suggested a number of revisions for this translation, many of which accounted for the bulk of changes for the SDS. The most likely explanation for the lack of agreement was the Miami version's emphasis on literal translation of SDS response choices. The following examples illustrate literal translations that result in inappropriate usage: usually was first translated as 'usualamente' and later changed to 'generalmente'; 'almost constant' was first translated as 'casi constantemente' and then changed to'casi siempre'; 'considerable difficulty' was first translated as 'considerable problemas' and revised to 'bastante problemas'; 'I usually breathe normally' was first translated as usualmente respiro con normalidad' and changed to 'usualmente respiro normal'.

SDS coefficient alphas for breast cancer patients by language group and city are presented in the following table.

Table 12: Spanish Translation of the Symptom Distress Scale: Preliminary Internal Consistency Reliability Data

Breast Cancer Patient Groups	n	Coefficient Alpha
San Antonio		
Hispanic Monolingual	48	0.72
Hispanic Bilingual	58	0.80
Los Angeles		
Hispanic Monolingual	49	0.90
Hispanic Bilingual	37	0.93
All Hispanic Breast Cancer	192	0.89
All Non-Hispanic White Breast Cancer	176	0.88

Swedish version (contributed by Carol Tishelman PhD, RN)

The Swedish version of the SDS is a 15-item instrument (Tishelman, Taube & Sachs, 1991) (see Appendix D). Tishelman (personal communication, November 20, 1996) combined symptoms reported by patients in the pilot studies conducted by McCorkle and colleagues (McCorkle & Young, 1978; McCorkle & Benoliel, 1983). Similar to the Italian version, a literal translation of each item was done and then this translation was validated for meaning. The format and administration of the Swedish SDS is the same as the English version. Internal consistency was 0.81 in a sample of patients with various cancers. Development of the Swedish version of

the SDS is ongoing. Qualitative interviews using the SDS were conducted with patients with lung cancer and the translation of fatigue will be changed from a word indicating more "tiredness" (trotthet) to "lack of energy" (orkesloshet). The new version will be tested in the future.

Further information about the use of the various cultural translation versions of the SDS can be obtained by contacting the following individuals:

French-Canadian: Andrea Laizner M.Sc.(A.) , McGill University, Department of Oncology, Gerald Bronfman Centre for Clinical Research in Oncology, 546 Pine Avenue West, Montreal, Quebec, H2W 1S6.

Italian: Carlo Peruselli MD., Pain Therapy and Palliative Care Service, Merate Hospital, Largo Mandic 1, 22055 Merate (LC), Italy.

Spanish: Carol Moinpour PhD., Southwest Oncology Group, Fred Hutchinson Cancer Research Center, MPSS7, 1100 Fairview Avenue North, Box 19024, Seattle, Washington, 98109-1024.

Swedish: Carol Tishelman PhD., Department of Public Health Sciences, Division of International Health Care Research (IHCAR), Karolinska Institute, Norrbacka 2tr., SE-171 76, Stockholm, Sweden

Canadian-English, Swedish: Lesley Degner PhD., St. Boniface General Hospital Research Centre, 351 Tache Ave., Winnipeg, Manitoba R2H2A6

Chapter 4

Summary of the Use of the Symptom Distress Scale

The SDS has been used as both an explanatory variable and as a clinical outcome measure in various studies for more than twenty years. It has been used in groups of patients with different types of cancer, human immunodeficiency virus infection, and myocardial infarction. Similarly, it has been used in many health care settings: home care, hospice, outpatient (ambulatory), and the hospital. There now is a substantial body of literature supporting the reliability and validity of the SDS. Results of studies have underscored the usefulness of the SDS to examine the relationship between symptom distress and quality of life. The clinical utility of using the SDS to improve patient outcomes has also been documented in a number of studies. In fact, the use of the SDS has been recommended as an instrument to screen patients who may be in need of closer follow-up (Degner & Sloan, 1995; Lovejoy, Paul, Freeman & Christianson, 1991; Peruselli et al., 1992).

As with any instrument, ongoing research is essential to realize the full potential of the SDS in clinical practice and future research. The development of this manual has provided an opportunity to assess areas that require further research. The major areas for future research involve examining various issues related to administration of the SDS, determining the appropriate use and validity of the SDS in groups who do not have cancer, identifying a cut-off score, and establishing the relationship between symptom distress and patient outcomes.

The symptoms in the SDS are listed in a particular order. The impact of presenting symptoms in the same sequence versus a varied sequence on the psychometric properties of the SDS should be examined. Also, the SDS was developed to be self-administered. Future clinical trials examining the impact of various methods of administration, such as self-administered, in-person interviewer administered, and phone administered, on the psychometric properties of the SDS is required to broaden the scope of administration methods.

Similarly, the SDS has been used extensively in patients with cancer. Although several studies have suggested that it is also useful in patients with myocardial infarction and patients with human immunodeficiency virus, use of the scale in groups of patients who are experiencing other chronic illnesses should be explored.

Identification of a cut-off score would be useful for both clinical practice and research. A cut off score helps to discriminate the presence or absence of significant symptom distress (Streiner & Norman, 1995). Prospective clinical trials provide an opportunity to identify a cut-off score that would allow screening of patients who may be in need of further intervention or who may have difficulty tolerating a more toxic regimen.

Finally, further work is needed to examine the relationship between symptom distress and patient outcomes. Though beginning research in this area is promising, clinical trials targeted toward enhancing symptom management and improving quality of life in patients with chronic illness is needed.

Copyright Information

The use of the SDS is encouraged. Although the SDS is copyrighted to assure quality control, permission to use this instrument is granted upon request. Potential users should contact:

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Chapter 5

Annotated Bibliography for Forty- Seven Studies Using the 13-Item Symptom Distress Scale

An annotated bibliography of 47 published studies using the 13-item SDS is presented in this chapter. The purpose, design, sample, measures, and central findings of each study using the 13-item SDS is presented. Twenty-one other studies using either the eight-item, ten-item or a modified version of the SDS are listed at the end of this chapter. All studies are listed in alphabetical order.

1. Cowan, M. J., Graham, K. Y. & Cochrane, B. L. (1992). Comparison of a theory of quality of life between myocardial infarction and malignant melanoma: A pilot study. *Progress in Cardiovascular Nursing*, 7, 18-28.
Purpose: Describe the relationships among manifest symptom distress (three instruments were used to measure different dimensions of symptom distress), functional alterations, cognitive adaptation and quality of life using the Graham-Cowan model for perceived quality of life in chronic illness and compare the results between subjects with myocardial infarction and malignant melanoma.
Design: Cross-sectional. Subjects were recruited from physician offices at a large medical center.
Sample: Fifty-seven patients with chronic illness; 27 with myocardial infarction and 30 with malignant melanoma. Subjects had been diagnosed with either myocardial infarction or malignant melanoma within one year of the interview. Age range for the subjects was 31 to 70 years with a mean age of 53 years. Most of the sample was Caucasian, married and middle to upper socioeconomic status.
Measures: Quality of Life Index, Graham Global Well-being Scale, Current Quality of Life Scale, Satisfaction with Current Quality of Life Scale, The Coherence Scale, Rosenberg Self Esteem Scale, Symptoms of Stress Inventory, SDS, Psychosocial Adjustment to Illness Scale, Functional Status Questionnaire, Enforced Social Dependency Scale.
Findings: Manifest symptom distress (composite of three instruments used to measure manifest symptom distress) is inversely related to functional alterations, cognitive adaptation and perceived quality of life. Functional alterations are inversely related to cognitive adaptation and perceived quality of life. Cognitive adaptation is directly related to perceived quality of life. There were no statistical differences between the myocardial infarction and the malignant melanoma subjects. The authors conclude that the model of quality of life may be generalizable to both patients with malignant melanoma and myocardial infarction.

2. Dean, G.E., Spears, L., Ferrell, B. R., Quan, W. D., Groshon, S. & Mitchell, M. S. (1995). Fatigue in patients receiving interferon alpha. *Cancer Practice*, 3, 164-172.
Purpose: Describe the experience of fatigue over time in patients receiving treatment with interferon alpha.
Design: Longitudinal. Patients were assessed before therapy and at the end of each two weeks of treatment for two consecutive months.
Sample:Thirty patients with malignant melanoma receiving treatment with alpha interferon. The majority of subjects were male, white, married, and had a mean age of 53 years.

Measures: SDS, Piper Fatigue Scale
Findings: The pattern of fatigue was consistent over time for patients receiving treatment with interferon alpha. The most extreme fatigue scores were in the affective domain, followed by the sensory, temporal, total fatigue and fatigue severity scores. The authors suggest that the patterns and dimensions of fatigue provide implications for planning future care of patients receiving interferon alpha. The SDS was used in this study to test the concurrent validity of the Piper Fatigue Scale. Results of the study showed a strong positive correlation between the SDS and the Piper Fatigue Scale, thus leading support for the validity of the Piper Fatigue Scale.

3. Degner, L. F., Henteleff, P. D. & Ringer, C. (1987). The relationship between theory and measurement in evaluations of palliative care services. *Journal of Palliative Care*, 3, 8-13.
Purpose: Tested a method for measuring the effectiveness of an established palliative care service.
Design: Pre test- Post test. The first testing occurred within 48 hours of admission to the palliative care service and the second testing occurred seven days after the first test.
Sample: Twenty nine patients with advanced cancer admitted to an inpatient palliative care service. The subjects' age ranged from 33 to 89 years with a mean of 65.5 years. There was a near even distribution of males and females.
Measures: SDS, Enforced Social Dependency Scale, Quality of Life Index.
Findings: The mean SDS scores of subjects decreased from 33.8 at time of admission to 25.7 seven days later. Improvement in symptoms were noted in pain frequency and intensity, and bowel patterns. The SDS was reliable and proved to be the most sensitive of the measures to detect changes within this sample.

4. Degner, L. F. & Sloan, J. A. (1992). Decision making during serious illness: What role do patients really want to play? *Journal of Clinical Epidemiology*, 45, 941-950.
Purpose: Determine what roles people actually want to assume in selecting cancer treatments and identify which demographic and treatment variables were most important predictors of those preferences.
Design: Survey.
Sample: Four hundred thirty six newly diagnosed cancer patients and 482 members of the general public.
Measures: Card sort to elicit preferences about roles in treatment decision making, SDS, age, educational level, gender, residence (urban vs. rural), type and stage of disease, type of treatment, whether or not the patient agreed to enter an experimental treatment protocol.
Findings: Fifty-nine percent of patients with newly diagnosed cancer preferred to have physicians make treatment decisions on their behalf, whereas 12% preferred to make their own decisions and 29% preferred a collaborative decision-making role. In contrast, 64% of the public preferred to make their own treatment decisions if they were to develop cancer, whereas only 9% preferred to have physicians make treatment decisions on their behalf and 27% preferred a collaborative decision-making role. Fifty-one percent of patients and 49% of the general public indicated that they wanted the physician and the family to share decision making about treatment on their behalf if they were too ill to make the decision on their own. Only 15% of the variance in decision making preferences was accounted for by the sociodemographic variables. Clinical

variables, symptom distress and stage of disease, were not related to patients' role preferences. The authors conclude that the impact of being diagnosed with a life threatening illness may influence preferences for decision making and that sociodemographic variables are not particularly helpful in making predictions about which groups want more or less active roles in decision making.

5. Degner, L. F. & Sloan, J. (1995). Symptom distress in newly diagnosed cancer patients and as a predictor of survival in lung cancer. *Journal of Pain and Symptom Management*, 10, 423-431.
Purpose: Describe the levels of symptom distress in a general ambulatory population of patients with newly diagnosed cancer, describe the factors associated with this distress and assess the prognostic value of symptom distress in patients with lung cancer.
Design: Cross-sectional for general ambulatory population of patients with newly diagnosed cancer and longitudinal for patients with lung cancer.
Sample: Four hundred thirty four patients with newly diagnosed cancer and 82 patients with lung cancer. The mean age of patients with newly diagnosed cancer was 59 years. The subjects were evenly split between males and females. The mean age of patients with lung cancer was 64 years and most of subjects were men.
Measures: SDS
Findings: The overall level of symptom distress in the general ambulatory population was low. The mean score for symptom distress was 23 with a range of 13 to 50. The most common symptoms were fatigue, insomnia, pain and distressing outlook. Women reported more symptom distress than men and patients with advanced disease had more distress than those with early stage disease. Significant differences in symptom distress by disease site were identified with patients with lung cancer having the most distress and patients with genitourinary cancer having the least distress. Older subjects appeared to have less distress than their younger counterparts. The survival analysis for patients with lung cancer showed that symptom distress at diagnosis and for six months after the diagnosis is strongly related to subsequent survival.

6. Donaldson, G., McCorkle, R., Georgiadou, F. & Quint Benoliel, J. (1986). Distress, dependency and threat in newly diagnosed cancer and heart disease patients. *Multivariate Behavioral Research*, 21, 267-298.
Purpose: Test a model of threat assimilation in patients with one of two newly diagnosed life threatening illnesses, either lung cancer or myocardial infarction, by examining both group differences and individual differences.
Design: A short term longitudinal study design was used to interview subjects at one and two months post diagnosis.
Sample: Fifty-six patients with newly diagnosed lung cancer and 65 patients with a recent myocardial infarction. The subjects' ages ranged from 32 to 89 years with a mean age of 62 years for patients with cancer and a mean age of 61 years for patients with myocardial infarction.
Measures: SDS, Enforced Social Dependency Scale, Inventory of Current Concerns, Profile of Mood States, Self Evaluation Scale, Sixteen Personality Factor Questionnaire, Eysenek Personality Questionnaire.
Findings: Lung cancer patients had more symptom distress and concerns, and evaluated themselves more harshly than myocardial infarction patients. Though symptom distress remained

unchanged between time one and time two, both lung cancer and myocardial infarction patients reported significantly improved mood and fewer concerns at time two, thus lending support for the threat assimilation model. Structural equation models of individual differences suggested that, though the two groups were characterized by mean differences, the causal processes within the two groups were similar, with symptom distress the most persuasive and powerful influence on emotional cognitive distress, social dependency and self evaluation. Symptom distress directly affected emotional-cognitive distress, social dependency, and self evaluation at the second occasion and indirectly influenced self evaluation at the first occasion.

7. Ehlke, G. (1988). Symptom distress in breast cancer patients receiving chemotherapy in the outpatient setting. *Oncology Nursing Forum*, 15, 343-346.
Purpose: Determine what variables were significantly related to symptom distress in breast cancer patients receiving chemotherapy in the outpatient setting.
Design: Cross sectional. Subjects were recruited from outpatient settings.
Sample: One hundred and seven women with breast cancer who were receiving chemotherapy in an outpatient setting. The age range for the sample was 28 to 78 years with a mean of 53 years. Subjects were primarily white, middle income, college educated, and receiving cyclophosphamide, methotrexate sodium and 5 fluorouracil combination chemotherapy drugs. There was heterogeneity regarding the stage of the disease; 47% had stage I or II and 53% had stage III or IV.
Measures: Multidimensional Health Locus of Control Scale, Norbeck Social Support Questionnaire, SDS, stage of disease, number and types of chemotherapy agents.
Findings: Overall level of symptom distress in this population was low. There was a significant relationship between symptom distress and perception of illness, internal locus of control, and external locus of control: negative perception of illness was related to increased symptom distress, whereas individuals with an internal locus of control experienced less symptom distress. Social support, powerful others health locus of control, stage of disease and aggressiveness of chemotherapy were not significantly related to symptom distress.

8. Frederickson, K., Jackson, B. S., Strauman, T. & Strauman, J. (1991). Testing hypotheses derived from the Roy adaptation model. *Nursing Science Quarterly*, 4, 168-174.
Purpose: Examine the relationship between the perception of physiologic symptoms and psychosocial well-being in patients with cancer entering an aggressive cancer treatment program.
Design: Cross-sectional. The first 45 adults who participated in a National Cancer Institute sponsored clinical trial at a university medical center were recruited for this study.
Sample: Forty-five patients with advanced, unresectable cancers who received treatment with IL-2 LAK cell therapy. The sample consisted of 25 men and 20 women who were between the ages of 19 and 61 years with a mean age of 45 years. Most of the sample was white and had greater than a high school education.
Measures: APACHE II, SDS, Sickness Impact Profile.
Findings: Perception of symptoms was positively correlated with psychosocial adaptation but not with actual physiological status. The baseline scores of subjects who survived for six months were compared with those who died before six months. The results showed that actual physiological status as measured by the Apache II was not linked to survival. However, patients who were still alive at six months had lower scores at baseline for SDS and SIP.

9. Germino, B. & McCorkle, R. (1985). Acknowledged awareness of life threatening illness. *International Journal of Nursing Studies*, 22, 33-44.
Purpose: Describe acknowledged awareness of diagnosis, prognosis, treatment and treatment goals in persons who have been recently diagnosed with lung cancer or a first myocardial infarction and explore the relationships of acknowledged awareness to the particular disease, to the time elapsed since diagnosis and to symptom distress.
Design: A short term longitudinal study design was used to interview subjects at one and two months post diagnosis.
Sample: Fifty-six patients with newly diagnosed lung cancer and 65 patients with a recent myocardial infarction. The subjects' ages ranged from 32 to 89 years with a mean age of 62 years for patients with cancer and a mean age of 61 years for patients with myocardial infarction.
Measures: Acknowledged Awareness Structured Interview Scale, SDS.
Findings: Mean scores of acknowledged awareness did not differ significantly between the subjects with lung cancer and those with myocardial infarction. Cancer patients reported significantly more symptom distress than myocardial infarction patients at both points in time. Among the cancer patients, those with high levels of symptom distress displayed significantly higher levels of acknowledged awareness than those reporting low symptom distress. This relationship was not evident for the coronary patients. Pain was the only variable that contributed to the explanation of acknowledged awareness and only in patients with cancer. The authors suggest that perhaps cancer patients who have a high level of symptom distress are constantly reminded of the potential meaning of those symptoms in relationship to their illness and its future course.

10. Given, B. & Given, C. W. (1992). Patient and family caregiver reaction to new and recurrent breast cancer. *Journal of the American Medical Women Association*, 47, 201-206.
Purpose: Assess the psychosocial status of patients with recurrent breast cancer and their families and compare it with the experiences of patients and families with newly diagnosed breast cancer.
Design: Longitudinal. Data were collected at entry into the study and six months later.
Sample: Forty-nine breast cancer patient-caregiver dyads; twenty-one women had newly diagnosed breast cancer and 28 women had recurrent disease. All women were receiving adjuvant therapy, primarily chemotherapy. Eighty percent of caregivers were married to their patients.
Measures: Center for Epidemiologic Studies Depression Scale, SDS, Caregiving Reactions Inventory, hours per day for the past two weeks the caregiver was directly involved with care, Family Assistance Scale, objective measure of impaired patient mobility activities.
Findings: Newly diagnosed patients were more depressed than those with recurrent disease at intake. At six months, however, depression scores for both patient groups declined but remained at a higher level for the patient with recurrent disease. Patients with recurrent disease had higher levels of symptom distress and dependency at baseline. Although symptom distress decreased for both groups of patients at six months, patients with recurrent disease experienced an increase in dependency at six months. Family members, no matter whether they were caring for patients with newly diagnosed or recurrent disease, became more depressed six months later. The authors conclude that psychological distress may be more marked in the family member than in the patient and that care givers can be distressed by the care experience even when the patient

improves.

11. Given, C. W., Stommel, M., Given, B., Osuch, J., Kurtz, M. & Kurtz, J. C. (1993). The influence of cancer patients' symptoms and functional status on patients' depression and family caregivers' reaction and depression. *Health Psychology*, 12, 277-285.
Purpose: Examine how patients' reported symptoms and losses in functioning affect patients' level of depression and influence caregivers' burden and caregivers' level of depression and how caregivers' optimism affects caregivers' level of depression and caregivers' reactions to the burden of caring.
Design: Cross sectional. Subjects were recruited through six community based cancer treatment centers.
Sample: One hundred and ninety-six patient-caregiver dyads. The most common cancer sites were breast, lung and lymphatic system. Most of the patients were receiving chemotherapy. There were some patients, however, that were receiving radiation therapy and hormonal treatments. Approximately two-thirds of the caregivers were women. The patients were almost equally divided according to gender. Fifty-three percent of patients were newly diagnosed with cancer and 47% had recurrent disease. Most caregivers were married to their patients.
Measures: Center for Epidemiologic Studies Depression Scale, Caregiver Reaction Assessment, SDS, OARS Multidimensional Functional Assessment Questionnaire, Life Orientation Test.
Findings: Patients' depression was largely explained by their symptom distress and to a lesser degree their loss of mobility and dependency in activities of daily living. Patients' physical limitations including symptom distress, immobility and dependency in activities of daily living influenced caregivers' daily schedules but not the caregivers' physical health. Patients' levels of depression were related to those of their caregivers. Caregiver optimism was identified as an important influence on caregiver depression. Caregivers who scored high on optimism were less depressed and tended to view caring as having a smaller impact on their health and daily schedule.

12. Jackson, B. S., Strauman, J., Frederickson, K. & Strauman, T. J. (1991). Long-term biopsychosocial effects of interleukin-2 therapy. *Oncology Nursing Forum*, 18, 683-690.
Purpose: Evaluate the biopsychosocial effects of interleukin-2 therapy in patients with advanced cancer.
Design: Longitudinal. Data were collected during the treatment period and one, six and 12 months after the completion of therapy.
Sample: Forty-five patients with a variety of advanced cancers who were receiving treatment with interleukin-2. The sample consisted of 25 men and 20 women who were between the ages of 19 and 61 years with a mean age of 45 years. Most of the sample was white and had greater than a high school education.
Measures: Sickness Impact Profile, Inventory of Current Concerns, SDS, APACHE II, Therapeutic Intervention Scoring System.
Findings: Disease progression and an unexpectedly poor survival rate resulted in a steady decrease in the number of respondents over time. Thirty-four patients were treated with only one course of interleukin-2 therapy. Patients who responded to treatment or had stable disease were offered additional courses of therapy. Eight patients had a second course of treatment and three patients had a third course. The treatment caused severe and, at times, life threatening toxicity.

The treatment negatively affected patients' emotional well being besides the physical toxicity. Scores from the symptom distress and emotional concerns reflected the severity of toxicity from treatment as perceived by the patient. However, both SDS and Inventory of Current Concerns scores returned to baseline one month after the treatment, representing recovery from the treatment effects. Patients who failed to survive six months were noted to have significantly higher baseline SDS scores than those who survived.

13. Kukull, W. A., McCorkle, R. & Driver, M. (1986). Symptom distress, psychosocial variables and survival from lung cancer. *Journal of Psychosocial Oncology*, 4, 91-104.
Purpose: Identify patients' perceptions of their symptoms and examine psychosocial variables that may be associated with survival.
Design: Longitudinal study design. Patients were followed for three and one-half years after the initial diagnosis and treatment.
Sample: Fifty-three patients with inoperable lung cancer treated with radiation therapy. Characteristics of the sample included a mean age of 62 years, primarily Caucasian, and primarily male.
Measures: SDS, McGill Pain Questionnaire, Inventory of Current Concerns, Enforced Social Dependency Scale, Profile of Mood States, Acknowledged Awareness, Personality Factor Questionnaire, Eysenck Personality Inventory, amount of time elapsed from the day the patient noted symptoms to when they sought health care.
Findings: Forty-five subjects had died, four were alive, two were lost to follow up and two had died of other causes at the end of three and one half years. The patient's SDS score shortly after their diagnosis was the most important predictor of survival after adjusting for age, functional status and personality traits.

14. Kurtz, M. E., Kurtz, J. C., Given, C. W. & Given, B. (1995). Relationship of caregiver reactions and depression to cancer patients' symptoms, functional states and depression- A longitudinal view. *Social Science in Medicine*, 40, 837-846.
Purpose: Examine how patients' physical and psychological characteristics are related to caregivers' reactions to providing care over time.
Design: Longitudinal. Data collected at entry into the study and at six months later.
Sample: One hundred fifty patients with various cancers and their caregivers. Patients were equally divided according to gender and the majority were undergoing active treatment with chemotherapy. The mean age of patients was 58.3 years. The majority of caregivers were female and the mean age was 55.1 years.
Measures: Center for Epidemiologic Studies Depression Scale, Caregiver Reactions Inventory, Life Orientation Test, SDS, OARS Multidimensional Assessment Questionnaire.
Findings: Caregiver optimism was a strong predictor of caregiver reactions to the burden of caring. Levels of patient symptoms and their change over time were both strongly linked to change in patient immobility over time. Patient symptoms and to a lesser degree patient immobility were strong predictors of patient depression, which in turn predicted caregiver depression. Overall, as patients' needs subsided, caregivers perceived fewer reactions to the burden of caring. The authors underscored the importance of the characteristic of caregiver optimism in the development of interventions to help patients and their care givers.

15. Lev, E. L. (1995). Triangulation reveals theoretical linkages and outcomes in a nursing intervention study. *Clinical Nurse Specialist*, 9, 300-305.
Purpose: Test effects of an efficacy-enhancing intervention compared with usual preparation in patients receiving outpatient chemotherapy.
Design: Random assignment to efficacy-enhancing or usual care treatment.
Sample: Forty nine patients were entered into the study; 25 in the self-efficacy enhancing intervention and 24 in the usual care group. Subjects ranged in age from 36 to 84 years.
Measures: SDS, Profile of Mood States, Functional Assessment of Cancer Treatment Scale, Strategies Used by Patients to Promote Health Scale, Tape recorded interviews.
Findings: Although multivariate analysis of variance found no significant differences between the groups for the outcome variables of quality of life, mood distress, self-efficacy, and symptom distress, analysis of data from the taped interviews revealed outcomes not apparent in the hypothesis testing study. Analysis of the taped interviews revealed that efficacy-enhancing interventions may have been responsible for positive responses demonstrated by subjects in both groups. Intervenors and interviewers may have inadvertently functioned as competent role models, given positive reinforcement regarding effective strategies for self-care and provided benefits to subjects in both groups by reinforcing subjects' self-care efficacy.

16. Lovejoy, N. C., Morgenroth, B. N., Paul, S., Freeman, E. & Christianson, B. (1992). Potential predictors of information-seeking behavior by homosexual/bisexual (gay) men with a human immunodeficiency virus seropositive health status. *Cancer Nursing*, 15, 116-124.
Purpose: Examine patterns and potential predictors of information-seeking activity in HIV seropositive men.
Design: Repeated measure, cross-sectional. Data collection occurred during three consecutive visits to the clinic (once every two or three weeks).
Sample: One hundred sixty-two men who received outpatient care for HIV infection, 60 of whom provided complete data sets. Most of the sample was white, well educated and the mean age was 38 years.
Measures: Profile of Mood States, HIV Self-Care Inventory (revised), HIV Information-Seeking Questionnaire, SDS, HIV Symptom Distress Scale, Karnofsky Performance Scale.
Findings: Once aware of being HIV +, men significantly increased use of self-care behaviors such as stress reduction, cognitive strategies and symptom surveillance behaviors. Overall, study participants experienced low levels of symptom and affective distress. The men consulted an average of 5.8 resources. The most frequent resources included friends, physicians, professional journals, new age churches, centers for attitudinal healing, social security personnel and health food centers. Aid acquired from these networks and the frequency of consultation was positively related to patterns of HIV self-care behaviors and feeling calm.

17. Lovejoy, N. C., Paul, S., Freeman, E. & Christianson, B. (1991). Potential correlates of self-care and symptom distress in homosexual/bisexual men who are HIV seropositive. *Oncology Nursing Forum*, 18, 1175-1185.
Purpose: Identify patterns of HIV self care and symptom distress among men attending HIV outpatient clinics in San Francisco, identify potential correlates of frequent use of HIV self-care, and establish selected psychometric properties of standardized and unstandardized instruments used in data collection.

Design: Nonrandomized modified, repeated measures. Data collection occurred during three consecutive visits to the clinic (once every two or three weeks).
Sample: One hundred sixty-two men who received outpatient care for HIV infection. Most of the sample was white, well educated and the mean age was 38 years.
Measures: Profile of Mood States, HIV Self-Care Inventory (revised), HIV Information-Seeking Questionnaire, SDS, HIV Symptom Distress Scale.
Findings: Men increased their use of HIV self-care behaviors once they became aware of their HIV diagnosis. Frequent use of HIV self-care behaviors was related to several variables, including past use of self-care behaviors, an AIDS diagnosis, feeling close to friends and external locus of control. Overall, the men experienced a low level of symptom distress. Symptom distress was inversely related to several variables including: functional status, employment status, and external locus of control, whereas a positive relationship was noted between SDS, negative mood state and a recent diagnosis of HIV related conditions. The POMS and the SDS displayed adequate internal consistency reliability and the authors suggest that these tools may be considered useful in screening ambulatory patients to identify those needing close follow-up.

18. McCorkle, R., Benoliel, J. Q., Donaldson, G., Georgiadou, F., Moinpour, C. & Goodell, B. (1989). A randomized clinical trial of home nursing care for lung cancer patients. *Cancer*, 64, 199-206.
Purpose: Assess the effects of home nursing care for patients with progressive lung cancer.
Design: Longitudinal, randomized clinical trial. Patients were interviewed every six weeks for six months.
Sample: One hundred sixty-six patients with advanced lung cancer were assigned to either an oncology home care group, a standard home care group, or an office care group. Of these 166 patients, 105 were male and 61 were female. Most of the subjects were white and married.
Measures: SDS, McGill-Melzack Pain Questionnaire, Inventory of Current Concerns, Profile of Mood States, Enforced Social Dependency Scale, Health Perceptions Questionnaire.
Findings: The three groups did not differ in pain, mood disturbance, and concerns at the end of six months. There were significant differences in symptom distress, enforced social dependency, and health perceptions. The two nursing groups had less symptom distress and greater independence six weeks longer than the office care group. Despite the increase in distress and dependency, the office care group reported improved health perceptions over time.

19. McCorkle, R., Jepson, C., Malone, D., Lusk, E., Braitman, L., Buhler-Wilkerson, K. & Daly, J. (1994). The impact of posthospital home care on patients with cancer. *Research in Nursing and Health*, 17, 243-251.
Purpose: Explore the impact of home health care services on the psychosocial status of patients with cancer who had at least one complex need at hospital discharge.
Design: Longitudinal. Interviews were conducted at discharge from the hospital and at three and six months post discharge.
Sample: Sixty patients with solid tumor cancers. Of the sixty patients, 49 patients received home care services and 11 did not receive home care services after hospitalization. Most of the subjects were more than 50 years of age and had at least a high school education. Sixty two percent of the sample was female and 42% were married.

Measures: SDS, Enforced Social Dependency Scale, Health Perceptions Questionnaire, Mental Health Status Inventory.
Findings: Patients receiving home care had significantly more symptom distress at baseline than the patients who were not receiving home care. Although the patients receiving home care were also more dependent at baseline than the patients not receiving home care, the difference was not statistically significant. Home care patients experienced a significant improvement in mental health and dependency as compared with the no home care group. Symptom distress was improved in the home care group as compared with the no home care group but this result fell short of statistical significance. After controlling for the baseline differences in the psychosocial measures, the home care group had significantly higher mental health status at three months after discharge than the no home care group.

20. McCorkle, R. & Quint-Benoliel, J. (1983). Symptom distress, current concerns and mood disturbance after diagnosis of life threatening disease. *Social Science and Medicine*, 17, 431-438.
Purpose: Describe the level of symptom distress, current concerns and mood disturbance in persons newly diagnosed with lung cancer and myocardial infarction.
Design: A short term longitudinal study design was used to interview subjects at one and two months post diagnosis.
Sample: Fifty-six patients with newly diagnosed lung cancer and 65 patients with a recent myocardial infarction. The subjects' ages ranged from 32 to 89 years with a mean age of 62 years for patients with cancer and a mean age of 61 years for patients with myocardial infarction. Most of the subjects were Caucasian.
Measures: SDS, Inventory of Current Concerns and Profile of Mood States.
Findings: Patients with lung cancer experienced significantly more symptom distress than patients with myocardial infarction. Symptom distress affected current concerns and mood disturbance for both groups at both occasions. An increase in symptom distress was associated with more concerns and greater mood disturbance. Patients with cancer also reported more mood disturbance and health and existential concerns than myocardial infarction patients. An interesting finding of the study was that although symptom distress remained the same between groups on both occasions, both groups of patients reported fewer concerns and less mood disturbance at the second interview. The reduction in concerns and mood disturbance between interviews suggests that patients assimilate to their situation.

21. McCorkle, R., Yost, L. S., Jepson, C., Malone, D., Baird, S. & Lusk, E. (1993). A cancer experience: Relationship of patient psychosocial responses to caregiver burden over time. *Psycho-Oncology*, 2, 21-32.
Purpose: Describe the relationship of cancer patient psychosocial responses to caregiver burden over time.
Design: Longitudinal. Interviews were conducted at discharge from the hospital and at three and six months post discharge.
Sample: Seventeen patient-caregiver dyads. Patients were newly diagnosed with cancer. The patient sample consisted of 10 men and seven women with a mean age of 63 years. Most of the subjects were white, married and had completed high school. The caregiver sample consisted of 14 women and three men with a mean age of 61 years.

Measures: SDS, Enforced Social Dependency, Mental Health Inventory 5, Center for Epidemiologic Studies Depression Scale, Caregiver Reaction Assessment, Experience of Caregiving Inventory.
Findings: Patients reported high levels of psychosocial distress at hospital discharge. Although most of their conditions improved three and six months later, caregivers continued to report similar levels of burden. Patients' symptoms, functional ability, mental health status and depression were significantly related to caregivers' physical caregiving responsibilities and their reported impact on schedules and finances. The authors suggest that the results underscore the importance of including the needs of family members when planning for posthospitalization care.

22. Moinpour, C. M. (1994). Measuring quality of life: An emerging science. *Seminars in Oncology*, 21 (supplement 10), 48-63.
Purpose: Evaluate the palliative effect of chemotherapy on symptom relief in patients with non-small cell lung cancer.
Design: Randomized clinical trial. Data were collected at randomization, every two weeks for two months and then monthly for two additional months.
Sample: Two hundred and eleven patients with stage IV non-small cell lung cancer were randomized to receive vinorelbine or 5 Flurouracil and leucovorin. Of the 211 patients, 143 received vinorelbine and 68 received 5 fluorouracil and leucovorin. Complete data were obtained on 42 of the vinorelbine patients and 10 of the 5 fluorouracil and leucovorin patients.
Measures: Medical Outcomes Study Short Form-20, Medical Outcomes Study Short Form-36, SDS, Global Quality of Life Linear Analog Scale, Patient Perceived Change in Symptom Status.
Findings: The vinorelbine treated patients showed more improvement over time in symptom distress scores than the 5 flurouracil plus leucovorin group.
Purpose: Evaluate the palliative effect of chemotherapy on symptom relief in patients with non-small cell lung cancer.
Design: SWOG single arm trial. Data were collected at randomization, every two weeks for two months and then monthly for two months.
Sample: One hundred sixty-two patients with stage IV non-small cell lung cancer received treatment with oral vinorelbine.
Measures: Medical Outcomes Study Short Form-20, Medical Outcomes Study Short Form 36, SDS, Global Quality of Life Linear Analog Scale, Patient Perceived Change in Symptom Status.
Findings: Only 43% of the patients could complete data beyond course two/week one. The major reason for attrition was death or a deterioration in patients status related to progressive disease. Results suggested that better symptom distress and physical functioning scores at entry into the study were associated with longer time in the study. For patients with complete data, symptom distress seemed stable over time, showing neither improvement nor deterioration.

23. Molassiotis, A., Van Den Akker, O. B., Milligan, D. W., Goldman, J. M. & Boughton, B. J. (1996). Psychological adaptation and symptom distress in bone marrow transplant recipients. *Psycho-Oncology*, 5, 9-22.
Purpose: Measure changes in the psychological status, self esteem, dependence on other people, physical symptom distress and coping during isolation for bone marrow transplantation, identify common coping mechanisms during isolation for bone marrow transplant, evaluate symptom distress and its association with mood disturbance, and compare psychological morbidity of

patients treated with various types of isolation for bone marrow transplant.
Design: Longitudinal. Patients were interviewed a day before transplant, at approximately day 21, prior to discharge from the hospital and one month after discharge.
Sample: Twenty six patients undergoing treatment with bone marrow transplant. Subjects were recruited from three different centers. Age of subjects ranged from 18 to 50 years with a mean of 33.0 years. The majority of subjects were male, married and white.
Measures: Profile of Mood States, Rosenberg Scales of Adult Self Image, SDS, Coping Style Checklist.
Findings: Psychological morbidity was high in the pre-transplant period and continued at high levels throughout the study. Change in bowel patterns, fatigue, insomnia, poor appetite and poor concentration were the most distressing symptoms. Activity levels declined over time. Coping mechanisms identified during isolation were hope, directing attention, maintaining control over the situation and acceptance. Higher symptom distress was associated with higher mood disturbance. The type of isolation experienced by the patient was not related to psychological morbidity. The patients who received professional psychological support during bone marrow transplant demonstrated significantly lower mood disturbance compared to those patients who did not receive psychological support.

24. Northouse, L., Dorris, G. & Charron-Moore, C. (1995). Factors affecting couples' adjustment to recurrent breast cancer. *Social Science and Medicine*, 41, 69-76.
Purpose: Identify factors that affect the adjustment of women and their husbands to recurrent breast cancer and to examine the mutual effect that partners have on one another.
Design: Cross sectional. Subjects were recruited from medical oncology offices in the Midwest region of the United States.
Sample: Women with recurrent breast cancer and their husbands. Eighty-one were women with a first recurrence of breast cancer and 74 were husbands of these women. The average age for the women was 54 years and the average age for men was 57 years.
Measures: Social Support Questionnaire, Mishel Uncertainty in Illness Scale, SDS, Beck Hopelessness Scale, Brief Symptom Inventory and Psychosocial Adjustment to Illness Scale.
Findings: Women who had less uncertainty, less symptom distress and less hopelessness reported less emotional distress and fewer psychosocial role adjustments. More emotional support was related to less emotional distress but not to better role adjustment. Husbands' perceived health problems, amount of social support, level of hopelessness and their wives' levels of symptom distress each made significant contributions to husbands' abilities to carry out their social roles. There was a significant positive relationship between wives' and husbands' scores on both measures of adjustment. Wives' who reported higher levels of emotional distress also had husbands who reported higher levels of emotional distress. Similarly, wives' who reported more role adjustment problems had husbands who also reported more role adjustment problems. Symptom distress accounted for the largest degree of variance in both the women's and husbands' levels of adjustment. The authors suggest that the findings of the study support that the adjustments of partners to recurrent cancer are related to each other.

25. Northouse, L. L., Laten, D. & Reddy, P. (1995). Adjustment of women and their husbands to recurrent breast cancer. *Research in Nursing and Health*, 18, 515-524.
Purpose: Examine the differences in the levels of adjustment, support, symptom distress, hopelessness and uncertainty reported by patients and spouses during the phase of recurrent breast cancer and to identify whether differences exist in their perceptions of the recurrence and their degree of surprise that the cancer recurred.
Design: Cross sectional. Subjects were recruited from medical oncology offices in the Midwest region of the United States.
Sample: Women with recurrent breast cancer and their husbands. Eighty-one were women with a first recurrence of breast cancer and 74 were husbands of these women. The average age for the women was 54 years and the average age for men was 57 years.
Measures: Social Support Questionnaire, Mishel Uncertainty in Illness Scale, SDS, Beck Hopelessness Scale, Brief Symptom Inventory and Psychosocial Adjustment to Illness Scale.
Findings: Although both women and their husbands experienced significant emotional distress as compared with the normal population, women with recurrent breast cancer reported more emotional distress than their husbands. Women and their husbands both experienced significant psychosocial role problems. Women were more surprised by the recurrent cancer and found the recurrent phase of illness more distressing than their husbands. No significant differences were found between womens' and their husbands' levels of hopelessness and overall symptom distress. There were significant differences, however, between the amount of social report they received and their levels of uncertainty. Women reported higher levels of social support received from family and friends than their husbands. Conversely, husbands' reported significantly more uncertainty about the illness than their wives.

26. O'Hare, P. A., Malone, D., Lusk, E. & McCorkle, R. (1993). Unmet needs of black patients with cancer posthospitalization: A descriptive study. *Oncology Nursing Forum*, 20, 659-664.
Purpose: Describe the self-reported posthospitalization unmet needs of black patients with cancer and identify patients at greatest risk for unmet needs.
Design: Secondary analysis of a larger longitudinal study. Data collected from the first interview were analyzed.
Sample: Sixty-three black patients with a diagnosis of cancer. Most of the subjects had advanced cancer and were unmarried, low income and urban dwelling.
Measures: Enforced Social Dependency Scale, Unmet Needs Checklist, SDS, audits of home health care agency referral form.
Findings: The most common unmet needs were eating, walking, bathing and personal care activities. Patients who lived alone reported more personal care needs than those who lived with others. Frequency of nausea, intensity of pain and difficulty breathing were the most common symptoms. The greatest levels of symptom distress were reported by patients with breast and gynecologic malignancies. Women who were elderly, black, alone, poor and chronically ill were more likely to have unmet needs and higher levels of symptom distress. Patients in this study had complex needs and limited financial and social resources. The authors suggest that lack of knowledge about community resources may prevent low income black patients from effectively using these services.

27. Pasacreta, J. V. (1997). Depressive phenomena, physical symptom distress, and functional status among women with breast cancer. *Nursing Research,* 46, 214-221.
Purpose: Examine the nature and scope of depression and its relationship to physical symptom distress and functional status.
Design: Cross sectional. Subjects were recruited from surgical oncology offices at a large urban medical center.
Sample: Seventy nine women three to seven months following the initial diagnosis of breast cancer. The age of the sample ranged from 25 to 85 years with a mean age of 54.9 years. The majority of the sample had early stage breast cancer and were white, married and well educated.
Measures: Diagnostic Interview Schedule, Center for Epidemiological Studies of Depression, SDS, Enforced Social Dependency Scale, Cognitive Capacity Screening Test.
Findings: Nine percent of the sample had depressive disorder, 24% had elevated depressive symptoms. Women with elevated depressive symptoms had more physical symptom distress and more impaired functioning than subjects with depressive disorders and without depression. Symptom distress and depressive symptoms explained 35% of the variance in functional status. The author suggests that depressive symptoms of lesser magnitude than those associated with stringent psychiatric diagnoses are associated with unfavorable outcomes in medically ill patients and may warrant the expansion of clinically significant depression in this population.

28. Peruselli, C., Camporesi, E., Colombo, A. M., Cucci, M., Mazzoni, G. & Paci, E. (1993). Quality of life assessment in a home care program for advanced cancer patients: A study using the Symptom Distress Scale. *Journal of Pain and Symptom Management*, 8, 306-311.
Purpose: Examine the variations over time in the degree of symptom distress in patients with advanced cancer receiving home care and to identify those symptoms that are most responsive to home care.
Design: Longitudinal. Patients completed the SDS weekly and at least twice.
Sample: Forty-three patients with advanced cancer who were receiving home nursing care. The mean age of subjects was 67 years.
Measures: SDS-Italian Version
Findings: The numbers of patients who experienced serious distress decreased over time with the use of the SDS. The symptoms most responsive to interventions were pain, nausea and bowel pattern. Concentration was the symptom identified to be least affected by home care interventions.

29. Peruselli, C., Camporesi, E., Colombo, A. M., Cucci, M., Sironi, P. G., Bellodi, M., Cirillo, R., Love, E. & Mariano, R. (1992). Nursing care planning for terminally ill cancer patients receiving home care. *Journal of Palliative Care*, 8, 4-7.
Purpose: Identify the prevalence of physical, psychological and social problems in patients receiving palliative home care, verify whether the nursing diagnosis is a sufficient tool for identifying the health needs of a patient during palliative home care and identify discrepancies between nurses' diagnostic statements and patients' reports.
Design: Longitudinal. Patients completed the SDS weekly and at least twice.
Sample: Forty patients with advanced stages of cancer receiving home nursing care. Subjects ranged in age from 34 to 84 years with a mean age of 66 years.
Measures: Nursing charts, SDS-Italian Version.

Findings: Six hundred and ninety-seven nursing diagnoses were identified for 40 patients. The most frequently reported nursing diagnoses were anxiety, constipation, diminished food intake, noncompliance with physical activity and coping potential of the family. Fifteen of the forty patients completed a weekly self report of their symptoms. There was congruence between patient self report and the nursing documentation in 63% of reported instances. Agreement was more frequently found for somatic symptoms than with psychological ones. The authors conclude that there are significant advantages for using nursing diagnoses. They suggest, however, that the use of assessment tools, such as using the SDS, be incorporated into clinical practice to reduce discrepancies between patients' self reports and nurses' assessments.

30. Pickett, M. (1991). Determinants of anticipatory nausea and anticipatory vomiting in adults receiving cancer chemotherapy. *Cancer Nursing*, 14, 334-343.
Purpose: Examine the relationship of anticipatory nausea and anticipatory vomiting in adults receiving an initial course of cancer chemotherapy in an outpatient setting with the following set of variables: symptom distress, mood disturbance, stage of disease, sensitivity to conditioning cues, emetic potential of antineoplastic drugs, age, psychosocial distress and ability to cope.
Design: Longitudinal. Data were collected before administration of the initial chemotherapy cycle and then before the forth and fifth cycle of chemotherapy.
Sample: Sixty adults who were receiving an initial course of cancer chemotherapy in an outpatient setting. The mean age of the sample was 55 years.
Measures: Modified versions of Morrow Assessment of Nausea and Emesis and Morrow Assessment of Nausea and Emesis Follow Up, SDS, Profile of Mood States, stage of disease, Pretreatment Assessment of Sensitivity to Conditioning Cues, Craig and Powell's Rating Scale of Antineoplastic Agents, Psychosocial Distress Scale, Ability to Cope Assessment Scale.
Findings: Thirty two percent (n=16) of the sample developed anticipatory nausea; no subjects reported the development of anticipatory vomiting. Subjects who subsequently developed anticipatory nausea differed significantly from the subjects who did not develop anticipatory nausea on three variables of interest. The group who developed anticipatory nausea was receiving a drug regimen higher in emetogenic potential, were younger, and had an earlier stage of disease than those who did not develop anticipatory nausea. Emetic potential of drugs, symptom distress, psychosocial distress, ability to cope and mood disturbances were identified as predictors for anticipatory nausea and accounted for 53% of the variance. Eighty-eight percent of cases were correctly classified based on the data gathered before administration of chemotherapy. This combination of variables correctly classified 100% of patients who did experience anticipatory nausea and 82% of patients who did not experience anticipatory nausea.

31. Portenoy, R. K., Thaler, H. T., Kornblith, A. B., Lepore, J. M., Friedlander-Klar, H., Coyle, N., Smart-Curley, T., Kemeny, L., Norton, L., Hoskins, W. & Scher, H. (1994). Symptom prevalence, characteristics and distress in a cancer population. *Quality of Life Research*, 3, 183-189.
Purpose: Describe the characteristics and impact of symptoms in patients with cancer and clarify relationships among patients characteristics, symptom distress and other aspects of health related quality of life.
Design: Cross sectional. Subjects were recruited from four inpatient units and three outpatient clinics at a large cancer center.

Sample: Two hundred forty three patients with colon, prostate, breast or ovarian cancer. Subjects were evenly distributed between inpatients and outpatients. The mean age of subjects was 56 years with a range from 23 to 86 years. Most of the subjects were women and had advanced disease.
Measures: Memorial Symptom Assessment Scale, Memorial Pain Assessment Card, Rand Mental Health Inventory, Functional Living Index- Cancer, SDS, Karnofsky Performance Scale.
Findings: Forty to eighty percent of subjects within each cancer group experienced lack of energy, pain, feeling drowsy, dry mouth, insomnia, or symptoms indicative of psychological distress (worrying, feeling sad, feeling nervous or feeling irritable). The mean number of symptoms per patient was 11.5. There were no significant differences in this overall symptom prevalence by age or gender, type of tumor or extent of disease. There was a significant difference in the mean number of symptoms experienced by inpatients versus outpatients (13.5 compared with 9.7) and those with a performance status less than 80 and those with a performance status greater than 80 (14.8 compared with 9.2). The number of symptoms, as measured by the Memorial Symptom Assessment Scale and the SDS, per patient was strongly associated with greater psychological distress and poorer quality of life.

32. Portenoy, R. K., Thaler, H. T., Kornblith, A. B., Lepore, J. M.M., Friedlander-Klar, H., Kiyasu, E., Sobel, S., Coyle, N., Kemeny, N., Norton, L. & Scher, H. (1994). The Memorial Symptom Assessment Scale: An instrument for the evaluation of symptom prevalence, characteristics and distress. *European Journal of Cancer*, 30A, 1326-1336,
Purpose: Evaluate the validity of the Memorial Symptom Assessment Scale
Design: Cross sectional. Subjects were recruited from four inpatient units and three outpatient clinics at a large cancer center.
Sample: Two hundred eighteen patients with prostate, colon, breast or ovarian cancer. Subjects were evenly distributed between inpatients and outpatients. The mean age of subjects was 56 years with a range from 23 to 86 years. Most of the subjects were women and had advanced disease.
Measures: Memorial Symptom Assessment Scale, Memorial Pain Assessment Card, Rand Mental Health Inventory, Functional Living Index- Cancer, SDS, Karnofsky Performance Scale.
Findings: Symptom prevalence on the Memorial Symptom Assessment Scale ranged from 73.4 % for lack of energy to 10.6 % for difficulty swallowing. Based on content analysis of the items, three symptoms were deleted and two were added to provide a total of 32 physical and psychological symptoms. Factor analysis was done and revealed two factors that distinguished three major symptom groups: psychological symptoms, high prevalence physical symptoms and low prevalence physical symptoms. Cronbach internal reliability coefficients ranged from 0.58 to 0.88 for the three subscales. Dimensionality of the instrument (frequency, severity and distress) was assessed and results suggested that the distress measurement provided the most information about quality of life and the frequency but not the severity measure added significant information. High correlations with clinical measures and quality of life instruments including the SDS support the validity of the Memorial Symptom Assessment Scale. The authors conclude that the Memorial Symptom Assessment Scale is a reliable and valid instrument for the assessment of symptom prevalence characteristics and distress in patients with cancer.

33. Ragsdale, D. & Morrow, J. R. (1990). Quality of life as a function of HIV classification. *Nursing Research*, 39, 355-359.
Purpose: Identify variables related to quality of life for persons with Human Immunodeficiency Virus Infection (HIV) and to ascertain if quality of life differs according to the classification of a positive serologic test for HIV antibodies, AIDS- related complex (ARC), and Acquired Immunodeficiency Syndrome (AIDS).
Design: Cross-sectional. Subjects were recruited from AIDS support groups and affiliated agencies in a major southwest urban area.
Sample: Ninety-five patients infected with HIV. Most of the subjects (59%) were diagnosed with AIDS, followed by HIV + only (25%) and ARC (16%). Subjects were between the ages of 20 and 52 years with a mean age of 35 years and were primarily male.
Measures: Sickness Impact Profile, SDS.
Findings: Mean scores from the Sickness Impact Profile and the SDS suggested HIV infection significantly affected subjects' quality of life. The quality of life indicators varied according to the disease classification: subjects who were HIV + had the best quality of life whereas those with ARC had the poorest. HIV infection had the greatest disruption on the psychosocial aspects of life.

34. Samarel, N., Fawcett, J. & Tulman, L. (1993). The effects of coaching in breast cancer support groups: A pilot study. *Oncology Nursing Forum*, 20, 795-798.
Purpose: Determine the feasibility of a large scale study testing how cancer support groups with coaching affect adaptation to newly diagnosed, early stage breast cancer.
Design: Randomized clinical trial. Data for the control group were collected at time of entry into the study and then eight weeks later. Data for the cancer support groups were collected at the beginning of the first cancer support group and then at the end of the support group (eight weeks later).
Sample: Seventy-seven women diagnosed with either stage I or II breast cancer within four months of entry into the study were randomly assigned to one of three groups; a cancer support group with coaching (include partners who acted as coaches to support the woman during diagnosis and treatment for breast cancer), a cancer support group without coaching or no cancer support group. Sixty-four subjects completed the pilot study. Most of the subjects were white, married and had a mean educational level of 14 years. Mean age of the women in the three groups ranged between 51 and 54 years.
Measures: SDS, Profile of Mood states, Linear Analog Self Assessment, Inventory of Functional Status- Cancer, Relationship Change Scale.
Findings: Results of the study suggested that the cancer support group with coaching significantly affected symptom distress, emotional distress and functional status. Further analyses revealed that subjects in the cancer support group with coaching experienced less symptom distress than subjects in the other two groups. Subjects who were not in a cancer support group experienced the highest levels of functional status. There was no evidence that the type of group made a difference in the quality of relationship with the significant other.

35. Sarna, L. (1993a). Women with lung cancer: Impact on quality of life. *Quality of Life Research*, 2, 13-22.
Purpose: Describe disruptions in quality of life in women with lung cancer.
Design: Cross-sectional. Subjects were recruited from a university medical center and private medical offices in Southern California.
Sample: Sixty-nine women with lung cancer. Women ranged in age from 32-86 years with a mean age of 61 years. Most of the women were married, had at least a partial college education and had limited stage non-small cell lung for more than 12 months.
Measures: SDS, CARES-SF, Karnofsky Performance Scale
Findings: Women with lung cancer experienced greater overall disruption in quality of life than other normative groups of women with cancer. The most common areas of disruption were reduction in energy, worry about ability to provide self care, difficulty with household chores and worry about recurrence. Women younger than 65 years of age, those with recurrent disease and those with low income experienced the greatest disruptions in quality of life. Overall quality of life was correlated with functional status and symptom distress. Increased disruption in quality of life was related to decreased functional status and increased symptom distress. The SDS was found to have a strong positive relationship with the physical subscale of the CARES-SF.

36. Sarna, L. (1993b). Correlates of symptom distress in women with lung cancer. *Cancer Practice*, 1, 21-28.
Purpose: Describe the symptom distress and its correlates in women with lung cancer
Design: Cross-sectional. Subjects were recruited through a university medical center and private physician offices.
Sample: Sixty-nine women with lung cancer. Women ranged in age from 32-86 years with a mean age of 61 years. Most of the women were married, had at least a partial college education and had limited stage non-small cell lung for more than 12 months.
Measures: SDS, CARES-SF, Karnofsky Performance Scale.
Findings: The most distressing symptoms in this study included fatigue, frequent pain, poor outlook, dyspnea and insomnia. Most of the women experienced more than one symptom. Individuals with recurrent disease had the highest levels of symptom distress. Concurrent respiratory disease, previous chemotherapy, no surgical treatment, and low income were also associated with a high level of symptom distress. Quality of life and functional status were strongly correlated with symptom distress.

37. Sarna, L. (1995). Smoking behaviors of women after diagnosis with lung cancer. *Image*, 27, 35-41.
Purpose: Describe the smoking behavior of women with a recent diagnosis or recurrence of lung cancer.
Design: Cross sectional. Subjects were recruited from a university medical center, physician offices and health maintenance facilities.
Sample: Sixty-five women with lung cancer. The mean age of the women was 62 years. Most of the subjects had non-small cell lung cancer and were white, married and had more than a high school education.

Measures: Interview questions related to smoking history, current smoking status and perception of the effect of the diagnosis on the smoking behavior of family members, SDS, Karnofsky Performance Status, Rand Physical Function Scale.
Findings: Five of the women were currently smoking, 51 were former smokers and nine never smoked. Smoking status was significantly different by age with current smokers in the youngest group. Symptom distress and physical function were not significantly different by smoking status. The diagnosis of lung cancer affected the smoking behaviors of family and friends.

38. Sarna, L. (1997). Dimensions of symptom distress in women with advanced lung cancer: A factor analysis. *Heart and Lung,* 26, 23-30.
Purpose: Explore the underlying constellation of distressing symptoms in women with lung cancer and investigate the differences in symptoms among clinical and demographic variables.
Design: Secondary analysis of two data sets. One data set consisted of women with advanced lung cancer and the second data set was from a longitudinal study focused on women with advanced lung cancer.
Sample: Sixty women with advanced lung cancer. The mean ages of the subjects were 58 years with a range between 33 and 80 years. Most of the women had advanced stage non-small cell lung cancer and were white, married and educated above the high school level.
Measures: SDS, Karnofsky Performance Scale
Findings: Symptom distress scores ranged from 14 to 44 with an average number of 3.2 symptoms. The most common symptoms were fatigue, disruptions in outlook, frequent pain and insomnia. A four factor solution for low symptom distress (symptoms rated as 1-2) explained 63.3% of the variance: emotional and physical suffering (five items), gastrointestinal distress (3 items), respiratory distress (3 items), and malaise (2 items). A five-factor solution explaining 65% of the variance was identified for high symptom distress (symptoms rated as 3-5): gastrointestinal distress (three items), respiratory distress (three items), malaise (two items), physical distress (three items), and emotional distress (two items). The overall symptom distress score was negatively related to functional status.

39. Sarna, L. (1998). Effectiveness of structured nursing assessment of symptom distress in advanced lung cancer. *Oncology Nursing Forum,* 25, 1041- 1048.
Purpose: Explore the efficacy of a structured assessment protocol in reducing symptom distress in patients with advanced lung cancer.
Design: Longitudinal randomized clinical trial. Subjects were randomized to either the structured assessment with the SDS or usual care. Both groups completed the SDS monthly for six months.
Sample: Forty-eight adults with advanced stage non-small cell lung cancer. The mean age of the sample was 62 years. Most of the subjects were white, married, and had at least a partial college education.
Measures: SDS, Karnofsky Performance Status, Physical Functional Status, Hospital Anxiety Depression Scale.
Findings: Fatigue was the most common symptom reported. Although both chemotherapy and structured assessment with the SDS were associated with less distress over time, the impact of chemotherapy on decreasing symptom distress lessened over time. Subjects with higher levels of depression and more functional limitations experienced higher levels of symptom distress. The

author concludes that a structured assessment of symptoms using the SDS made a significant difference in controlling distress.

40. Sarna, L., Lindsey, A. M., Brecht, M. L. & McCorkle, R. (1993). Nutritional intake, weight change, symptom distress and functional status over time in adults with lung cancer. *Oncology Nursing Forum*, 20, 481-489.
Purpose: Describe nutritional intake and weight changes over a six-month period in adults with progressive lung cancer, examine the relationships among 1) weight changes, food intake and functional status, 2) symptom distress, hunger, appetite, nausea, functional status and food intake and 3) differences in food intake and weight changes and among demographic and clinical variables.
Design: Secondary analysis of a larger longitudinal study. Patients were interviewed every six weeks for six months.
Sample: Twenty-eight patients who were a subsample of a larger study. The mean age of subjects was 62 years. Most of the subjects were male, white and had stage III non-small cell lung cancer and were receiving treatment.
Measures: scale to measure weight in pounds, a self-recorded dietary intake, Hunger Linear Analog Scale, SDS, Enforced Social Dependency Scale.
Findings: Average weight change and nutritional intake varied little over time. A decrease in the amount of kilocalories was related to a subsequent decrease in functional status. Kilocalorie status was not directly related to change in weight. Symptom distress and symptoms of hunger, nausea, and appetite disturbance showed little variation over time and had inconsistent relationships with food intake over time. This study did not support a relationship between decreased nutritional intake and increased symptom distress. Subjects younger than 65 years of age, those with small cell lung cancer and those who received chemotherapy experienced the greatest amount of weight loss over time.

41. Sarna, L., Lindsey, A. M., Dean, H., Brecht, M. L. & McCorkle, R. (1994). Weight change and lung cancer: Relationships with symptom distress, functional status and smoking. *Research in Nursing and Health*, 17, 371-379.
Purpose: Describe weight change in adults with progressive lung cancer over a six month period, investigate the relationship of symptom distress, functional status and smoking status with weight change over time, and explore differences in patterns of weight change by demographic and clinical subgroups.
Design: Secondary analysis of a larger longitudinal study. Patients were interviewed every six weeks for six months.
Subjects: Sixty patients with lung cancer. The mean age of subjects was 62 years with a range from 38 to 84 years. Most of the subjects were white males who had non-small cell lung cancer, stage III disease, and received some form of treatment.
Measures: scale to measure weight in pounds, SDS, Enforced Social Dependency Scale, self report of smoking behavior.
Findings: Changes from pre-illness body weight ranged from a 31% loss to a 32% gain. Weight loss of 10% or more at study entry occurred in 35% of subjects. Almost half the sample (46.9%) lost weight over six months, 15.6% had no change and 37.5% had a weight gain. The majority of those who lost weight over time received palliative treatment and were currently smoking. Pre-

illness weight loss was moderately correlated with subsequent decreased functional status. Weight loss correlated with subsequent increased symptom distress. Chemotherapy and smoking predicted weight loss over time, explaining 28% of the variance.

42. Sims, S. (1986). Slow stroke back massage for cancer patients. *Nursing Times*, 82(13), 47-50.
Purpose: Determine whether gentle back massage is associated with a perceived change in symptom distress and mood in women with breast cancer receiving radiation therapy.
Design: Pilot study using randomized assignment.
Sample: Six women who were receiving radiation therapy for breast cancer were randomly assigned to receive either slow stroke massage or a rest period. Subjects in the experimental group received the massage for three consecutive days and then received the rest periods for three days during the following week. Subjects in the control group received the experimental and control treatments in reverse order.
Measures: SDS, Mood Likert Scale.
Findings: Although the results of the pilot study were not statistically significant, the authors noted a trend toward less symptom distress, higher degrees of tranquility and vitality, and less tension and tiredness following the back massage as compared with the control intervention.

43. Strauman, J. J. (1986). Symptom distress in patients receiving phase one chemotherapy with taxol. *Oncology Nursing Forum*, 13, 40-43.
Purpose: Evaluate the degree of discomfort from specific subjective symptoms in patients receiving taxol in a phase one clinical trial.
Design: Short term longitudinal design. Subjects completed the symptom distress scale the day before, or the morning of their first taxol treatment. The SDS was then completed by the patient the day after treatment and then weekly until the next treatment. The SDS was completed with the first course of therapy only.
Sample: Twenty-nine patients, 10 males and 19 females, with a variety of solid tumors treated with taxol chemotherapy. The age range for the sample was 30-79 years with a median age of 60 years.
Measures: SDS.
Findings: No statistically significant change was noted in the mean SDS after taxol therapy when compared with baseline scores. Each item of the SDS was also analyzed for change over the treatment period. Outlook was the only item to change significantly ($p < 0.001$). The mean score for outlook improved during treatment. The authors conclude that taxol appears to be well tolerated in this population, that baseline assessment of symptom distress before therapy is important, and that treatment had a positive effect upon outlook.

44. Strauman, J. J., Frederickson, K. & Jackson, B. S. (1987). Preliminary report on the biopsychosocial effects of interleukin-2 cancer therapy. *Journal of the New York State Nurses' Association*, 18(2), 50-61.
Purpose: Reports the preliminary results of a larger clinical trial designed to evaluate the biopsychosocial effects of interleukin-2 therapy in patients with advanced cancer.
Design: Longitudinal data were collected during the treatment period and one, six and 12 months after the completion of therapy. This study reports the results of data collected during the

treatment and one month after the completion of therapy.
Sample: Twenty patients with a variety of advanced cancers who were receiving treatment with interleukin-2. The sample consisted of 13 men and 7 women who were between the ages of 19 and 58 years with a mean age of 47 years. The sample was white and on average, had greater than a high school education.
Measures: Sickness Impact Profile, Inventory of Current Concerns, SDS, APACHE II, Therapeutic Intervention Scoring System.
Findings: Multiple physical toxicities were noted during the treatment. The SDS, Therapeutic Intervention Scoring System, and the APACHE II scores were sensitive in capturing the toxicities as experienced by the patients. The Sickness Impact Profile and the Inventory of Current Concerns scores showed little change during the treatment and at one month. Establishing the statistical significance of the changes noted in the Sickness Impact Profile and Inventory of Current Concerns was not possible, however, due to the preliminary nature of the results.

45. Taylor, E. J. (1993). Factors associated with meaning in life among people with recurrent cancer. *Oncology Nursing Forum*, 20, 1399-1407.
Purpose: Determine what factors were associated with the sense of meaning in life among individuals with recurrent disease.
Design: Cross-sectional. Subjects were recruited from two oncology outpatient departments in a large university medical center.
Sample: Seventy-four adults with a diagnosis of recurrent cancer within the past year. Subjects ranged in age from 20-89 years with a mean age of 54 years. The majority of subjects were white, female, married and had a high socioeconomic status.
Measures: Psychosocial Adjustment to Illness Scale, SDS, Enforced Social Dependency Scale, Search for Meaning Survey, Purpose in Life Test.
Findings: Subjects with recurrent cancer experienced a moderate amount of symptom distress and social dependency. Symptom distress, social dependency and time since diagnosis of recurrence were negatively correlated with an individual's sense of meaning. Positive psychosocial adjustment and being married were associated with a greater sense of meaning. The results suggest that an individual's sense of meaning is closely related to the physical and psychosocial effects of illness.

46. Taylor, E. J., Baird, S. B., Malone, D. & McCorkle, R. (1993). Factors associated with anger in cancer patients and their care givers. *Cancer Practice*, 1, 101-109.
Purpose: Determine the presence of anger among a heterogeneous group of patients with cancer and their caregivers, explore the relationship between anger and the phase of the cancer trajectory, and measure relationships among anger and symptom distress, functional status, physical caregiver responsibilities, depression and selected demographic data.
Design: Secondary analysis of a larger longitudinal study. Interviews were conducted at discharge from the hospital and at three and six months post discharge.
Sample: One hundred sixty-five adult patients with cancer who had a solid tumor and 73 primary caregivers. Fifty-two of the patients and 12 of the caregivers completed all three interviews. Most of the patients were older than 65 years of age, white, married and high school educated. Most of caregivers were older than 65 years of age, female, and married.

Measures: Multidimensional Anger Inventory, SDS, Enforced Social Dependency Scale, Physical Caregiving Responsibility Inventory, and the Center for Epidemiologic Studies Depression Scale.
Findings: Anger scores were low over time for both patients and their caregivers. Patients' age, symptom distress, depression and church attendance were associated with anger: patients' less than 50 years of age were more angry than their older counterparts, patients with increased symptom distress, increased depression and those who never attended church reported higher levels of anger. Caregivers who reported more anger tended to be those who reported more physical illness, reported feeling stressed about their caregiving role, and never attended church.

47. Yost, L. S., McCorkle, R., Buhler-Wilkerson, K., Schultz, D. & Lusk, E. (1993). Determinants of subsequent home health care nursing service use by hospitalized patients with cancer. *Cancer*, 72, 3304-3312.
Purpose: Examine the extent to which specific patient characteristics and length of hospitalization were capable of independently explaining the use of home health care nursing services by patients with cancer after discharge from the hospital.
Design: Secondary data analysis of a larger descriptive study. Interviews were conducted at discharge from the hospital and at three and six months post discharge.
Sample: One hundred thirty adults with various solid tumor cancers. Of these patients, 87 received home health care and 43 did not receive home health care. Most of the subjects were older than 50 years of age, married, white and had health insurance.
Measures: SDS, Enforced Social Dependency Scale, Center for Epidemiologic Studies Depression Scale, Risk Index, Health Perceptions Questionnaire.
Findings: Age, length of hospital stay and level of symptom distress were significant explanatory variables for home health care use. Subjects older than 50 years of age, hospitalized for longer than seven days and those with moderate levels of symptom distress (31-65) were more likely to receive home health care services.

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Appendix A
Symptom Distress Scale -English Version

Over the years, the administration of the scale has taken several formats. The developer of the scale has been consistent in using a 5 X 7 card format. Many of the studies discussed in this manual, however, have administered the SDS as consecutive items on several pages. For ease of presentation, the SDS is presented in this appendix as consecutive items.

SYMPTOM DISTRESS SCALE

Instructions
Below are 5 different numbered statements. Think about what each statement says, then place a circle around the one statement that most closely indicates how you have been feeling lately. The statements are ranked from 1 to 5, where number one indicates no problems and number five indicates the maximum amount of problems. Numbers two through four indicate you feel somewhere in between these two extremes. Please circle one number on each card.

Degrees of Distress

Nausea (1)

1	2	3	4	5
I seldom if ever have nausea	I have nausea once in a while	I have nausea fairly often	I have nausea half the time at least	I have nausea continually

Nausea (2)

1	2	3	4	5
When I do have nausea, it is very mild	When I do have nausea, it is mildly distressing	When I have nausea, I feel pretty sick	When I have nausea, I usually feel very sick	When I have nausea, I am as sick as I could possibly be

Appetite

1	2	3	4	5
I have my normal appetite and enjoy good food	My appetite is usually, but not always, pretty good	I don't really enjoy my food	I have to force myself to eat my food	I cannot stand the thought of food

Degrees of Distress

Insomnia

1	2	3	4	5
I sleep as well as I always have	I occasionally have trouble getting to sleep and staying asleep	I frequently have trouble getting to sleep	I have difficulty getting to sleep and staying asleep almost every night	It is almost impossible for me to get a decent night's sleep

Pain (1)

1	2	3	4	5
I almost never have pain	I have pain once in a while	I have pain several times a week	I am usually in some degree of pain	I am in some degree of pain almost constantly

Pain (2)

1	2	3	4	5
When I do have pain, it is very mild	When I do have pain, it is mildly distressing	When I do have pain, it is usually fairly intense	The pain I have is very intense	The pain I have is almost unbearable

Fatigue

1	2	3	4	5
I seldom feel tired or fatigued	There are periods when I am rather tired or fatigued	There are periods when I am quite tired and fatigued	I am usually very tired and fatigued	Most of the time, I feel exhausted

Bowel

1	2	3	4	5
I have my normal bowel pattern	My bowel pattern occasionally causes me some discomfort	My present bowel pattern occasionally causes me considerable discomfort	I am usually in considerable discomfort because of my present bowel pattern	I am in almost constant discomfort because of my bowel pattern

Concentration

1	2	3	4	5
I have my normal ability to concentrate	I occasionally have trouble concentrating	I occasionally have considerable trouble concentrating	I usually have considerable difficulty concentrating	I just can't seem to concentrate at all

Degrees of Distress

Appearance

1	2	3	4	5
My appearance has basically not changed	Occasionally I am concerned about the worsening of my physical appearance	I am not often concerned that my appearance is worsening	Most of the time I am concerned that my physical appearance is worsening	The worsening of my physical appearance is a constant, preoccupying concern

Breathing

1	2	3	4	5
I usually breathe normally	I occasionally have trouble breathing	I often have trouble breathing	I can hardly ever breathe as easily as I want	I almost always have severe trouble with my breathing

Outlook

1	2	3	4	5
I am not worried or frightened about the future	I am slightly worried but not frightened about things	I am worried and frightened about things	I am very worried and frightened about things	I am terrified by thoughts of the future

Cough

1	2	3	4	5
I seldom cough	I have an occasional cough	I often cough	I often cough, and occasionally have severe coughing spells	I often have persistent and severe coughing spells

Appendix B
Symptom Distress Scale – French Canadian Version
Échelle de la nature des symptômes

Instructions:
Vous trouverez ci-dessous une liste de symptômes et une série de cinq énoncés pour chaque symptôme. Lisez-les attentivement et entourez le numéro de l'énoncé qui correspond le plus à ce que vous avez ressenti dernièrement. Chaque énoncé est numéroté de 1 a 5, le numéro 1 indique que vous n'éprouvez peu ou pas de difficulté et le numéro 5 indique que vous en éprouvez beaucoup. Les numéro 2 à 4 indiquent que vous vous situez entre ces deux extrêmes. Veillez encercler un chiffre pour chaqun des énoncés sur la carte.

NIVEAUX DE DETRESSE

NAUSÉE 1				
1	2	3	4	5
J'ai très rarement la nausée.	J'ai parfois la nausée.	J'ai souvent la nausée.	J'ai généralement la nausée.	J'ai presque toujours la nausée.

NAUSÉE 2				
1	2	3	4	5
Lorsque j'ai la nausée, c'est trés supportable.	Lorsque j'ai la nausée, c'est un peu pénible.	Lorsque j'ai la nausée, je me sens bien malade.	Lorsque j'ai la nausée, je me sens très malade.	Lorsque j'ai la nausée, je suis extrêmement malade.

APPÉTIT				
1	2	3	4	5
Mon appétit est normal.	Mon appétit est généralement assez bon, mais pas toujours.	Je n'apprécie plus la nourriture comme avant.	Je dois me forcer pour manger.	Je ne peux pas supporter l'idée de manger.

INSOMNIE				
1	2	3	4	5
Je dors aussi bien qu'avant.	J'ai parfois la difficulté à dormir.	J'ai fréquemment du mal à m'endormir et à rester endormi(e).	J'ai de la difficulté à dormir presque toutes les nuits.	Il m'est presqu'impossible d'avoir une nuit de sommeil convenable.

NIVEAUX DE DETRESSE

DOULEUR (1)

1	2	3	4	5
Je ne ressens presque jamais de douleur.	Je ressens de la douleur à l'occasion.	Je ressens de la douleur plusieurs fois par semaine.	Je ressens de la douleur plusieurs fois par jour.	Je ressens de la douleur presque tout le temps.

DOULEUR (2)

1	2	3	4	5
Lorsque je ressens de la douleur, elle est très supportable.	Lorsque je ressens de la douleur, elle est un peu pénible.	Lorsque je ressens de la douleur, elle est moyennement intense.	Lorsque je ressens de la douleur, elle est généralement très intense.	Lorsque je ressens de la douleur, elle est presqu' insupportable.

FATIGUE

1	2	3	4	5
Généralement, je ne suis pas fatigué(e).	Je suis parfois assez fatigué(e).	Il m'arrive souvent d'être très fatigué(e).	Je suis généralement très fatigué(e).	La plupart du temps, je me sens épuisé(e).

ÉLIMINATION FÉCALES

1	2	3	4	5
Mon élimination fécale est normale.	Mon élimination fécale me cause un certain inconfort.	Mon élimination fécale me cause fréquemment de l'inconfort.	Mon élimination fécale me cause généralement de l'inconfort.	Mon élimination fécale actuelle est radicalement différente comparativement à ce qu'elle était normalement.

CONCENTRATION

1	2	3	4	5
J'ai la même capacité de concentration qu'auparavant.	J'ai parfois de la difficulté à me concentrer.	J'ai souvent de la difficulté à me concentrer.	J'ai généralement de la difficulté à me concentrer.	Je ne parviens pas à me concentrer.

NIVEAUX DE DETRESSE

APPARENCE

1	2	3	4	5
Mon apparence n'a pas changé	Mon apparence s'est un peu détérioré(e).	Mon apparence s'est détérioré (e) mais je ne m'en préoccupe pas beaucoup.	Mon apparence s'est considérablement détérioré (e) et ça me préoccupe.	Mon apparence a radicalement changé comparativement à ce qu'elle était auparavant.

RESPIRATION

1	2	3	4	5
Habituellement, je respire normalement.	J'ai parfois de la difficulté à respirer.	J'ai souvent de la difficulté à respirer.	Il est rare que je puisse respirer aussi bien que je veux.	J'ai presque toujours de graves difficultés à respirer.

PERSPECTIVES DE L'AVENIR

1	2	3	4	5
Je n'ai pas peur et je ne m'inquiète pas.	Je m'inquiète un peu.	Je suis assez inquiet(e) mais je n'ai pas peur.	Je suis inquiet(e) et j'ai un peu peur.	Je suis inquiet(e) et j'ai peur.

TOUX

1	2	3	4	5
Je tousse rarement.	Je tousse parfois.	Je tousse souvent.	Je tousse souvent et j'ai parfois de mauvaises quintes de toux.	J'ai souvent des quintes de toux graves et persistantes.

Appendix C
Symptom Distress Scale – Southwest Oncology Group Spanish Version

FECHA:_____ PACIENTE #: _____

NOMBRE DEL PACIENTE: _____ EDAD:_____

INSTITUTO: _____ DOCTOR:_____

ESCALA DE LOS SÍNTOMAS

Cada una de las siguientes preguntas presenta 5 situaciones diferentes. Piense en lo que cada situación significa y haga un círculo alrededor de una de las respuestas que mejor representa como se ha sentido durante la semana pasada incluyendo el día de hoy. Las respuestas están numeradas del 1 al 5, el número 1 significa que no hay problema el número 5 indica la cantidad máxima de problemas. Los números 2, 3 y 4 indican que usted se siente entre ambos extremos. Por favor marque un círculo alrededor de una de las respuestas. Si usted no ha tenido nausea o dolor durante la semana pasada, por favor escoja el número 1 de la pregunta 2 y 6.

1. **NÁUSEA (1)**
   1 Raras veces tengo náusea
   2 De vez en cuando tengo náusea
   3 Frecuentemente tengo náusea
   4 Al menos la mitad del tiempo tengo náusea
   5 Casi continuamente tengo náusea

2. **NÁUSEA (2)**
   1 Cuando tengo náusea, es muy leve
   2 Cuando tengo náusea, es una molestia leve
   3 Cuando tengo náusea, me siento muy enfermo
   4 Cuando tengo náusea, generalmente me siento bastante enfermo
   5 Cuando tengo náusea, me siento extremadamente enfermo

3. **APETITO**
   1 Mi apetito es normal y me agrada la buena comida
   2 Usualmente mi apetito es bueno pero no siempre
   3 En realidad no me agrada la comida
   4 Tengo que forzarme para comer
   5 No puedo soportar el pensar en la comida

4. **INSOMNIO** (Dificultad para Dormir)
   1 Duermo tan bien como siempre
   2 Ocasionalmente tengo problemas para dormir y permanecer dormido
   3 Frecuentemente tengo problemas para dormir
   4 Tengo problemas para dormir y permanecer dormido casi todas las noches
   5 Es casi imposible que yo duerma una buena noche

5. **DOLOR (1)**
   1 Casi nunca tengo dolor
   2 Tengo dolor de vez en cuando
   3 Tengo dolor varias veces a la semana
   4 Generalmente tengo algo de dolor
   5 Me siento con dolor casi constantemente

6. **DOLOR (2)**
   1 Cuando tengo dolor no me molesta casi nada
   2 Cudando tengo dolor me molesta un poco
   3 Cuando tengo dolor es moderadamente intenso
   4 El dolor que tengo es muy intenso
   5 El dolor que tengo es casi insoportable

7. **FATIGA**
   1 Raramente me siento cansado o fatigado
   2 Hay veces que me siento algo cansado o fatigado
   3 Hay veces que me siento muy cansado y fatigad
   4 Usualmente estoy muy cansado y fatigado
   5 La mayor parte del tiempo estoy exhausto

8. **REGULARIDAD INTESTINAL** (Problemas con la Frecuencia o Dolor Durante los Movimientos Intstinales
   1 Mis movimientos intestinales son normales
   2 Mis movimientos intestinales ocasionalmente me causan algo de incomodidad
   3 Mis movimientos intestinales ocasionalmente me causan bastante molestia o incomodidad
   4 Con frecuencia estoy muy molesto o incómodo por mis movimientos intestinales
   5 Casi siempre estoy molesto e incómodo por mis movimientos intestinales

9. **CONCENTRACION**

1 Tengo habilidad normal para concentrarme
2 Ocasionalmente tengo problemas para concentrarme
3 Ocasionalmente tengo bastante problemas para concentrarme
4 Usualmente tengo bastante problemas para concentrarme
5 Parece que no me puedo concentrar en nada

10. **APARIENCIA**

1 Básicamente mi apariencia no ha cambiado
2 Ocasionalmente me preocupa que empeore mi apariencia física
3 Frecuentemente me preocupa el que mi apariencia este empeorando
4 La mayor parte del tiempo me preocupa que mi apariencia física este empeorando
5 El deterioro de mi apariencia física me preocupa constantemente

11 **RESPIRACION**

1 Usualmente respiro normal
2 Ocasionalmente tengo problemas para respirar
3 Frecuentemente tengo problemas para respirar
4 Casi nunca puedo respirar con la facilidad que quiero
5 Casi siempre tengo severos problemas con mi respiración

12. **PERCEPCÍON/PERSPECTIVA**

1 No estoy (me siento) temeroso o preocupado
2 Estoy un poco preocupado de las cosas
3 Estoy muy preocupado pero no tengo miedo
4 Estoy preocupado y un poco temeroso de las cosas
5 Estoy preocupado y temeroso de las cosas

13. **TOS**

1 Nunca o casi nunca toso
2 Toso ocasionalmente
3 Toso con frecuencia
4 Toso con frecuencia y a veces tengo severos ataques de tos
5 Con frecuencia tengo severos y persistentes ataques de tos

Appendix D
Symptom Distress Scale – Swedish Version (First Version)

McCorkle and Young, översatt till svenska: Tishelman och Andersson, 1987

OBS: I intervjusituation presenteras varje symtom på ett eget A4 ark

Illamånde, frekvens						
Jag mår nästan aldrig illa	1	2	3	4	5	Jag mår nästan alltid illa
Illamående, svårighetsgrad						
När jag mår illa, är det mycket lindrigt	1	2	3	4	5	När jag mår illa, mår jag så illa som man någonsin kan
Aptiten						
Aptiten är mycket god	1	2	3	4	5	Aptiten är mycket dålig
Sömnen						
Sömnen är mycket god	1	2	3	4	5	Sömnen är mycket dålig
Trötthet						
Jag är aldrig speciellt trött	1	2	3	4	5	Jag är alltid utmattad
Smärta, frekvens						
Jag har aldrig ont	1	2	3	4	5	Jag har alltid ont
Smärta, svårighetsgrad						
Ingen smärta	1	2	3	4	5	Värsta tänkbara smärta
Andning						
Helt utan problem	1	2	3	4	5	Stora problem att andas
Hosta						
Inget besvär med hosta	1	2	3	4	5	Värsta tänkbara besvär med hosta

Rörlighet						
Jag kan röra mig fritt	1	2	3	4	5	Jag kan inte ta mig fram alls
Tarmfunktion						
Fungerar alltid bra	1	2	3	4	5	Fungerar aldrig bra
Humör						
Humöret kan inte vara bättre	1	2	3	4	5	Humöret kan inte vara sämre
Koncentration						
Kan alltid koncentrera mig	1	2	3	4	5	Lyckas inte koncentrera mig
Utseende						
Oförändrat	1	2	3	4	5	Mycket förändrat
Framtidsperpektiv						
Jag känner mig inte alls rädd eller orolig för framtiden	1	2	3	4	5	Jag känner mig mycket rädd och orolig för framtiden