# Operationalizing Symptom Distress in Adults With Cancer: A Literature Synthesis

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**Purpose/Objectives:** To address inconsistencies in the definition and operationalization of symptom distress by synthesizing the literature on cancer-related symptom distress in adults.

**Data Sources:** Electronic nursing, psychology, and medicine databases; online meeting abstracts; and various print sources.

**Data Synthesis:** Eight distinct methods of operationalizing the concept were identified. Gender, ethnic, developmental, cultural, and individual differences in symptom distress have not been identified. Relationships among symptom frequency, intensity, and distress are unclear.

**Conclusions:** Lack of clarity and consensus in defining and operationalizing symptom distress hinder meta-analysis, research synthesis, and research utilization. Symptom distress may be emerging as a component of the multidimensional symptom experience.

**Implications for Nursing:** Defining and operationalizing symptom distress consistently will enhance research synthesis and assist clinicians with more effectively meeting the needs of people with cancer. Research is needed to identify the meanings of symptom distress to patients with cancer and to differentiate symptom distress from symptom frequency and intensity.

## Key Points . . .

- The concept of symptom distress often is mentioned in the cancer literature but is operationalized and defined inconsistently.
- A literature synthesis revealed eight distinct operationalizations of symptom distress in published cancer studies, aside from equating symtom distress with symptom intensity.
- A view of symptom distress as a dimension of the symptom experience distinct from symptom intensity and frequency may be emerging but requires examination and validation.
- Consistently operationalizing symptom distress in a manner congruent with patients' interpretations of symptom distress is recommended to enhance symptom management research.

Symptom distress often is used to describe the subjective experience of people in various states of health and illness. Multiple studies have shown that symptom distress is related to quality of life, treatment tolerance, and even survival in patients with cancer and other illnesses. The importance of symptom distress as a multidimensional concept in cancer has been demonstrated repeatedly and is supported by theory. Yet, despite or perhaps because of its ubiquity, symptom distress remains largely undefined and undeveloped conceptually (McClement, Woodgate, & Degner, 1997). The significance of symptom distress mandates the development of a uniform and valid definition, conceptualization, and operationalization.

This article summarizes and interprets the literature about symptom distress in adults with cancer, describes definitions and conceptualizations of symptom distress, differentiates symptom distress from related terms, and highlights issues raised by the lack of consensus regarding symptom distress. Gaps in the literature are identified, and future directions in concept development are suggested.

This literature synthesis was carried out according to the five-stage process described by Cooper (1998). In this model, the problem is formulated, data are collected, quality of the data is evaluated, data are analyzed and interpreted, and results are presented. In the first stage, problem formulation, the nature of the sources to be included and excluded is determined. Figure 1 summarizes the criteria used to identify sources to be included in this literature synthesis.

To include the many valuable sources in which implicit models of symptom distress are used, rather than clearly explicated ones, this review does not exclude articles that have left the concept undefined or failed to articulate implicit conceptual models of symptom distress. In cases where symptom distress remains undefined, the ways in which authors have

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- Source explicitly refers to symptom distress.
- Symptom distress is measured, not merely mentioned.
- Multiple physical and psychoemotional cancer-related symptoms are measured.
- Method of operationalizing the concept is explicit or can be inferred from the text.
- Symptom distress is not simply equated with symptom intensity or severity.
- Measurement is not restricted to one type of cancer or one setting.

**Figure 1. Criteria for Inclusion of Cancer Symptom Distress Studies**

operationalized the concept and the conclusions drawn can shed light on implicit conceptual models of symptom distress.

This review is restricted to cancer, although symptom distress also is relevant in other disease categories. The literature search produced a predominance of symptom distress sources pertaining to cancer. The nature of symptom distress may differ by disease, especially when an interaction occurs among multiple symptoms of varying frequency and intensity. Exploring differences and similarities across disease categories is important but lies outside the scope of this article.

## Search Strategy

Articles that included symptom distress in the key words, title, or abstract were identified through searches of MEDLINE®, the Cumulative Index to Nursing and Allied Health Literature, PsycINFO, the Cochrane Databases of Systematic Reviews and Abstracts of Reviews of Effectiveness, and Health and Psychosocial Instruments. An initial search of these databases, conducted in February 2004, revealed more than 800 unique articles. Limiting this list to English-language articles relevant to symptom distress and cancer or neoplasms reduced the number to 323. Limiting the search further to exclude articles about children and adolescents eliminated just 39 studies, leaving 284 for the final review.

After the initial electronic database searches, hand searches were done of the citations in the reference lists of relevant articles. Electronically searchable meeting abstracts (e.g., American Society of Clinical Oncology, Oncology Nursing Society, World Congress of Psycho-Oncology) and printed proceedings (e.g., University of California, San Francisco, Symptom Management Symposia; Western Institute of Nursing Assemblies) also were examined. Book chapters, editorials, and presentations that did not report research were excluded. Because of the significance of symptom clusters (Dodd, Miaskowski, & Paul, 2001), the predominance of multiple concurrent symptoms of a physical and psychoemotional nature in patients with cancer, and the potential for multiple symptoms to exacerbate one another, the authors focused on symptom distress from multiple cancer-related symptoms. For this reason, articles focusing strictly on symptom distress in relation to psychoemotional symptoms alone were excluded from the review.

Sources that did not include a measurement of symptom distress, used only part of a validated symptom distress instrument, or focused on distress from a single symptom were omitted. Eliminating dissertations and theses in which the operationalization of symptom distress or the findings related to symptom distress could not be determined from the abstract further reduced the list. Abstracts, dissertations, theses, journal articles, conference proceedings, and research monographs were among the final list of relevant sources. The research articles included instrument validation, descriptive and exploratory, intervention, and evaluation studies.

## Definitions of Symptom Distress

Symptom distress has been equated with symptom intensity, a combination of symptom intensity and frequency, quality of life, and health-related quality of life (McClement et al., 1997). Tishelman, Degner, and Mueller (2000) noted that even the word "symptom" rarely is defined. Measurements of symptom distress often have been combined with other measures to evaluate clinical trial end points (Dutcher et al., 2000; Ingham, Seidman, Yao, Lepore, & Portenoy, 1996; Robert, Soong, & Wheeler, 1997). One recent review of symptoms in patients with lung cancer (Cooley, Short, & Moriarty, 2002) noted that few researchers have delineated the dimensions of the symptom experience being studied. Table 1 lists symptom distress operationalizations uncovered in this literature review aside from the many sources in which symptom distress simply was equated with symptom intensity or severity. These operationalizations will be discussed in chronologic order.

Johnson (1973) was one of the first to explore the term "symptom distress" in her work on pain sensations. She conceptualized symptoms as consisting of physiologic (sensory) and reactive (distress) components and tested the independence of both using a quasi-experimental design. A standard pain stimulus and repeated measures of single-item, investigator-designed sensory and distress scales were used

**Table 1. Operationalizations of Symptom Distress in Different Studies**

| Operationalization of Symptom Distress | Source |
|---|---|
| Bother is equal to distress and distinct from pain intensity. | Johnson, 1973; Johnson & Rice, 1974 |
| Distress is synonymous with discomfort. Distress from treatment and disease are similar. Distress is equal to the intensity and frequency of symptoms. | McCorkle, 1987; McCorkle & Young, 1978 |
| Distress is physical or mental upset, anguish, or suffering. Distress and frequency of occurrence are two fundamental symptom attributes. | Rhodes et al., 2000; Rhodes & Watson, 1987 |
| Distress, intensity, and frequency are three fundamental symptom attributes. | Portenoy et al., 1994 |
| Distress is equal to bother and one of four symptom attributes (the others are quality, timing, and intensity). | Lenz et al., 1997 |
| Distress equals symptom interference with life activities or emotional upset. | Cleeland et al., 2000 |
| Distress is psychological, emotional, social, or spiritual concern caused by physical symptoms or other sources. | National Comprehensive Cancer Network, 2004 |

to examine the sensory and distress components of pain in healthy volunteers. In two studies, subjects were asked to mark a sensory scale to reflect the physical intensity of the pain stimulus and a separate distress scale to reflect "the amount of distress the sensations caused" (Johnson, p. 263) or "how much the sensations bother[ed]" them (Johnson & Rice, 1974, p. 206). Both studies identified variations in sensory and distress ratings among subjects given different preparatory information prior to the same painful stimulus.

Johnson's (1973) study is significant because its findings supported a two-factor conceptualization of pain and were the first to show empirical evidence that symptom distress is not synonymous with symptom intensity. Subsequent studies of symptom distress in people with cancer used "distress" and "bother" interchangeably. Although Johnson's initial work was conducted with healthy volunteers, her findings subsequently have been applied in many clinical oncology studies.

In a 1987 issue of *Seminars in Oncology Nursing* dedicated to symptoms, distress is defined as "pressure that is applied to produce or restrain action" (Rhodes & Watson, p. 243). This definition is reflected in more recent symptom management models in which perception and evaluation of a symptom precede and direct actions intended to relieve the symptom (Dodd, Janson, et al., 2001; Teel, Meek, McNamara, & Watson, 1997). Rhodes and Watson defined symptom distress as "the degree or amount of physical or mental upset, anguish, or suffering experienced from a specific symptom" (p. 243). More recently, Rhodes, McDaniel, Homan, Johnson, and Madsen (2000) distinguished between the frequency of a symptom's occurrence and the distress caused by it. The combination of these two dimensions was termed "symptom experience," and a symptom assessment tool, the Adapted Symptom Distress Scale-2, was developed using these definitions.

In the same issue of *Seminars in Oncology Nursing,* McCorkle (1987) defined symptom distress as "the person's level of distress from a specific symptom being experienced" (p. 248) and was the first to determine that symptom distress did not need to be differentiated according to whether it resulted from the disease itself or from the treatment. Symptom distress was defined earlier by McCorkle and Young (1978) as "the degree of discomfort from the specific symptom as reported by the patient" (p. 374). This definition was applied in the development of the Symptom Distress Scale (SDS), perhaps the most widely used cancer symptom scale. Distress and discomfort, therefore, are treated as synonymous in the SDS. Symptom distress is operationalized as the sum of responses to symptom intensity and frequency items. Not all symptoms in the SDS are rated in terms of both intensity and frequency, and none is rated in terms of distress or bother. Because the SDS item stems are not consistent across symptoms, different symptoms contribute conceptually diverse information to the global symptom description.

The Memorial Symptom Assessment Scale (MSAS) (Portenoy et al., 1994) measures a set of symptoms in terms of frequency, intensity, and distress (bother). The authors described these attributes as the fundamental properties of symptoms, although the properties themselves are not explicitly defined. Portenoy et al. offered evidence of this assertion by showing that the three subscales are moderately, but not highly, intercorrelated. Similar to other researchers (Johnson, 1973; Lenz, Pugh, Milligan, Gift, & Suppe, 1997; Rhodes et al., 2000; Rhodes & Watson, 1987), the authors of the MSAS considered distress to be one distinct aspect of the symptom experience to be examined along with other symptom dimensions, not as a summation of the entire symptom experience.

Lenz et al. (1997) formulated the Theory of Unpleasant Symptoms. According to this theory, distress is one of four dimensions of a symptom and reflects "the degree to which the person is bothered by" the symptom (p. 16). The other three dimensions of a symptom are quality, timing, and intensity. The original theory (Lenz, Suppe, Gift, Pugh, & Milligan, 1995) was modified to encompass the coexistence of multiple symptoms. The authors asserted that multiple symptoms occurring simultaneously were likely to have a multiplicative, not an additive, effect on the person experiencing them. This premise, if borne out in subsequent research, casts doubt on the common practice of measuring symptom distress by summing several items on a scale.

In the M.D. Anderson Symptom Inventory (Cleeland et al., 2000), symptom distress is operationalized as the mean of six items in which subjects rate how much their symptoms interfere with relationships, mood, enjoyment of life, and physical activity. The first half of the tool asks subjects to rate the highest recent intensity of 13 symptoms on a scale from 1–10. In this section, one item asks subjects to rate emotional distress in terms of the intensity of "being distressed (upset)" (Cleeland et al.). The dual meaning of distress used in this tool, as both synonymous with symptom interference and emotional upset, illustrates the variation in interpretation of the term in research on symptoms.

The National Comprehensive Cancer Network (NCCN, 2004) developed a distress thermometer consisting of a vertical scale resembling a mercury thermometer on which respondents rate their global distress. A companion scale asks respondents to indicate which of five categories of problems (i.e., practical, family, physical, spiritual or religious, and emotional) has caused the distress. The thermometer and its companion scale are meant to be used as a screening tool for distress in clinical practice.

NCCN (2004) defined distress as

> A multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis (p. DIS-2).

This conceptualization emphasizes the emotional aspects of distress, and symptoms are seen as one of several possible causes of distress, which also include coping with family members, financial problems, and existential issues. The NCCN conceptualization is unique in that distress, not the symptom(s) alone, is the stimulus to action and that the ability to cope with symptoms is an outcome of distress.

## Related Terms

Many terms similar to symptom distress have been used in describing and measuring symptom experiences. "Symptom

burden" is one of the more common. In the large, hospital-based SUPPORT study (Desbiens, Mueller-Rizner, Connors, Wenger, & Lynn, 1999), symptom intensity and frequency were measured with investigator-designed tools. Symptom burden was operationalized as the total number of patients per hospital reporting one or more symptoms of moderate to intense severity present half or more of the time or one or more symptoms of extreme severity, regardless of frequency. Among seven disease categories, the number of people exceeding these investigator-defined symptom thresholds was highest in the lung cancer population (Desbiens & Wu, 2000).

In a hospice study, Kutner, Kassner, and Nowels (2001) modified the MSAS, originally a self-report scale, to allow providers to rate patients' symptom burden. In the modification, the distress dimension of the scale was omitted and providers evaluated symptom intensity and frequency alone. These two dimensions, combined with the prevalence of symptoms in the sample population, were termed "symptom burden."

Both of these studies used symptom burden to describe population or sample characteristics, not individual symptom experiences. Symptom burden may be used to refer to the collective symptom experiences of a group, but its use in this manner is not universal. In addition, no concept development has occurred with respect to symptom burden.

"Bother" is another term closely associated with symptom distress. Johnson and Rice (1974) evaluated symptom distress by asking subjects how much a symptom (i.e., pain) bothered them. Similarly, the MSAS measures distress by asking patients how much a symptom bothers or distresses them (Portenoy et al., 1994). Nesbitt and Heidrich (2000) used a symptom bother scale to study older women's functional health, symptom bother, quality of life, illness appraisal, and sense of coherence. The symptom bother scale rates 13 symptoms on a scale of 0 (not bothered) to 3 (bothered a great deal).

Patients understand the terms used to measure their symptoms from a lay viewpoint. Therefore, vernacular definitions of these terms may be useful in understanding their meaning to research subjects and patients. Bother, which is synonymous with irk and pester, is defined by Merriam-Webster, Incorporated (2005), as "to annoy, especially by petty provocation." However, distress, which is synonymous with being upset, is defined as "the state of being in great trouble" (Merriam-Webster, Incorporated). These two definitions suggest that distress and bother may be qualitatively different. Whether patients distinguish bother from distress and whether that distinction affects the validity of measurements of symptom distress are not known.

Symptom experience has been used to describe symptoms of patients with cancer (Knobf, 2001; Rhodes et al. 2000; Samarel et al., 1996). Samarel et al. operationalized symptom experience as the sum of 24 items querying the intensity, frequency, and distress of eight symptoms. The Symptom Experience Scale, like Rhodes et al.'s Adapted Symptom Distress Scale-2, began as a modification of the McCorkle SDS. In the Symptom Experience Scale, distress, frequency, and intensity ratings are summed to produce a symptom experience score. Unlike the SDS, these dimensions are measured separately for each symptom in both the Symptom Experience Scale and the Adapted Symptom Distress Scale-2.

Knobf (2001) also used symptom experience to describe the findings of a qualitative study of women experiencing premature menopause related to breast cancer treatment. In a concept analysis, symptom experience was described broadly as encompassing symptom intensity, frequency, distress, and meaning (Armstrong, 2003). These articles suggest that symptom experience encompasses symptom distress, signifying an emerging view of symptom experience as a broader concept than symptom distress.

## Relationships Among Symptom Distress, Intensity, and Frequency

Some symptoms likely are more distressing than others. For example, pain, nausea, fatigue, and shortness of breath often are observed in clinical practice as distressing, even if they are moderate in intensity and frequency. In contrast, other symptoms, such as a change in personal appearance or dry mouth, may not cause distress, even if they are frequent and intense.

The values of the patient may influence the relationships among symptom intensity, frequency, and distress. An example from the primary author's clinical practice illustrates this assertion. Mr. L, a 70-year-old entrepreneur with stage IV esophageal cancer, was considering endoscopic treatment for malignant dysphagia. Although his dysphagia was only grade I on the 0–5 dysphagia scale, he described intense distress from the social effects of this symptom, which kept him from attending important business and social events at the city's top steak houses.

The importance of Mr. L's business and social engagements, centered around sharing a steak dinner, transformed a symptom that was mild in intensity (according to a standard measure) to one that represented significant distress. For another individual, grade I dysphagia (dysphagia for only some solid foods) may not be distressing, but Mr. L was distressed enough to seek palliative treatment.

If Mr. L's case is representative, the meaning assigned to a symptom by the individual and not its intensity or frequency may be a predictor of distress. For Mr. L, symptom distress seemed linked to the social significance of the symptom, but for others, distress may be associated with the degree of functional impairment, a change in personal appearance, or interference with usual activities caused by the symptom.

With few exceptions, patients' views of the factors that contribute to symptom distress have not been reported. One of the few studies that examined this issue (Knobf, 2001) showed that the symptom experience is context-bound among women experiencing chemotherapy-induced menopause. Although the quality of menopausal symptom distress described by the study participants was similar to that described by women experiencing natural menopause, the study participants' young age and the abrupt onset of menopausal symptoms within the context of a breast cancer diagnosis influenced their appraisal of symptoms and decision making about symptom relief strategies. These findings are consistent with conceptual models such as the University of California, San Francisco, Symptom Management Model (Dodd, Janson, et al., 2001) and the Symptom Interpretation Model (Teel et al., 1997) that take into account the meaning of symptoms to the individual and give further support to the possibility that symptom meaning may play a role in the degree of symptom distress reported by patients.

Only a few investigators have measured the relationships among symptom intensity, frequency, and distress. In a validation study of the MSAS in patients with various cancers

(Portenoy et al., 1994), distress consistently was rated lower than frequency or severity, suggesting that patients may not evaluate distress as a function of frequency and intensity. Correlations of frequency (r = 0.43) and intensity (r = 0.70) with symptom distress supported the conceptualization of distress, frequency, and intensity as distinct but interrelated dimensions of the symptom experience.

Further support for conceptualizing symptom frequency, intensity, and distress as separate dimensions of the symptom experience is found in Samarel, Fawcett, and Tulman (1993), who studied the effect of a support group on symptom distress in women with breast cancer. Women reported no change in symptom frequency or intensity as measured by the SDS, but participants reported decreased distress in the qualitative portion of the study. Samarel et al. (1996) subsequently developed the Symptom Experience Scale, evaluating symptoms in terms of distress, intensity, and frequency. Distress, frequency, and intensity ratings pertaining to a given symptom consistently loaded together in the final rotated factor matrix, but factor loadings did not achieve unity, which supported the idea that the three separate symptom dimensions were independent.

In contrast, Nail (1993), in a longitudinal study of women with gynecologic cancer, found high correlations between severity and upset (r = 0.89–0.97), suggesting that they were not distinct dimensions. This finding appears to contradict those of Portenoy et al. (1994) and Samarel et al. (1996). Nail's findings may be attributable to the meaning of the word "upset" (as opposed to distress or bother), the characteristics of the population under study, or the nature of their symptoms.

## Implications

This literature synthesis has reinforced the relevance of symptom distress and the need for further explication of its definition, contributing factors, and the outcomes associated with it. Most of the literature regarding symptom distress is concerned with cancer; nearly half of the references initially retrieved concerned cancer or neoplasms. The number of references to symptom distress in the cancer literature has increased dramatically since 2000. Of the more than 200 sources reviewed for this article, approximately 30% were published after January 1, 2000.

Despite increasing support for a multidimensional conceptualization of symptom distress, operational definitions of symptom distress as a simple function of intensity remain common in recent literature. For example, Mercadante et al. (2001) measured the effectiveness of methadone versus morphine for pain in palliative care by summing a set of symptom intensity items to produce a distress score. In another study, Kuo and Ma (2002) examined symptom distress in a sample of 73 Taiwanese patients with lung cancer. This study employed a 47-item author-designed tool measuring physical and psychological symptoms on a scale of 0 (never experienced) to 3 (severe). Although the quality of these two examples, and many similar studies, is not in dispute, the use of the phrase "symptom intensity" or "symptom severity" may be a clearer representation of the concept.

Whether patients with cancer equate symptom distress with related terms such as discomfort, burden, trouble, upset, or anguish is not known. An appreciation of how patients understand and describe the various terms used to capture the impact of their symptoms would contribute a great deal to symptom measurement and enhance clinicians' understanding of the experiences of patients who live with multiple symptoms.

The meaning of symptom distress may differ by race, ethnicity, socioeconomic status, education, disease, or other demographic or clinical variables. The initial search results revealed that most of the literature about symptom distress in cancer applies to adults, although in recent years, more attention has been paid to symptom distress in children with cancer (Woodgate, Degner, & Yanofsky, 2003). In 2002, a National Institutes of Health consensus panel concluded that too few established symptom assessment tools for children, adolescents, older adults, individuals with cognitive impairments, and individuals of various ethnic and cultural groups exist.

Tishelman, Taube, and Sachs (1991) provided empirical evidence for the contribution of clinical and demographic factors to symptom distress by measuring psychological and clinical characteristics, perceptions of care, and demographic variables of patients with cancer. Combining these sets of explanatory variables produced a regression model that explained more of the variance in symptom distress as measured by the SDS than any single category.

## Conclusions

This literature synthesis highlights the many issues associated with defining and conceptualizing symptom distress in people with cancer. Inconsistent or assumed definitions, incomplete descriptions of conceptualization and operationalization, and insufficient research on the nature of the concept itself inhibit comparisons across studies and may cause confusion with related issues, such as quality of life and symptom intensity.

Future research should explore symptom distress from the patient's perspective. Delineating cultural, disease-related, and individual differences in symptom distress may assist clinicians and researchers with better meeting the needs of people living with cancer symptoms. Moreover, it may help clinicians and researchers understand the overlap of symptom frequency and intensity with symptom distress and identify priorities for research and individual symptom management.

The outcomes associated with symptom distress should be explored more thoroughly. McCorkle et al. (2000) suggested that symptom distress independently influences survival. Symptom distress may be a powerful tool for outcomes prediction if proven to be an indicator of individual differences in disease states not accounted for by objective disease severity indicators such as cancer staging.

Further concept development would permit comparison across studies and facilitate meta-analysis. The ability to describe relationships among symptom intensity, frequency, and distress and the influences on the nature of these relationships may advance the science of symptom management and help clinicians set priorities for symptom management interventions, which are crucial for improving the treatment of people with cancer symptoms.

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