

Symptom Burden: A Concept Analysis and Implications for Oncology Nurses

Roxanna L. Gapstur, MS, APRN-BC, AOCN®

Purpose/Objectives: To analyze the concept of symptom burden and discuss implications for symptom research and symptom management.

Data Sources: MEDLINE®, CINAHL®, PsycINFO, Cochrane Reviews, and published literature.

Data Synthesis: Through Rodgers's evolutionary method of concept analysis, attributes of symptom burden were identified as dynamic, multidimensional, quantifiable, subjective, and physiologic. The major antecedent was multiple symptoms related to worsening disease status. Consequences of symptom burden included decreased survival, poor prognosis, delay or termination of treatment, increased hospitalizations and medical costs, decreased functional status, and lowered self-reported quality of life. Symptom burden is defined as the subjective, quantifiable prevalence, frequency, and severity of symptoms placing a physiologic burden on patients and producing multiple negative, physical, and emotional patient responses.

Conclusions: Symptom burden is an important concept in the symptoms experience, separate from symptom distress and other related terms. The continued differentiation of symptom concepts is important for sound methodologic research and meaningful interventions that affect and improve patient experiences.

Implications for Nursing: Clarifying multiple symptom concepts in the symptoms experience, determining appropriate measurement methodologies for the concepts, and identifying appropriate strategies will lessen the burden of symptoms and contribute to improved quality of life and better patient outcomes.

The concept of symptom burden commonly is used in medical and psychological literature, especially in reference to patients with chronic or terminal illnesses (Desbiens, Mueller-Rizner, Connors, Wenger, & Lynn, 1999; Klinkenberg, Willems, van der Wal, & Deeg, 2004; Kutner, Kassner, & Nowels, 2001; Nelson et al., 2004; Rose, Koshman, Spreng, & Sheldon, 2000; Ruo et al., 2003; Silveira, Kabeto, & Langa, 2005; Walke, Gallo, Tinetti, & Fried, 2004; Weisbord et al., 2003). Few research investigations concerning symptom burden have appeared in the nursing literature (Longman, Braden, & Mishel, 1997; Zambroski, Moser, Bhat, & Ziegler, 2005); however, multiple related concepts, such as symptom distress, commonly are explored (McCormick, Naimark, & Tate, 2002; Schneider, 1999). The recent concept analyses of symptom clusters (Kim, McGuire, Tulman, & Barsevick, 2005) and symptoms experience (Armstrong, 2003) bring into question inter-relationships among various symptom concepts, including symptom burden. A clear definitional concept of symptom burden is required for continued advancement of scientific knowledge about the symptom experience (Beck, 2004).

Several self-report instruments are available that measure particular concepts in the symptom experience, including symptom burden and symptom distress (Barresi, Shadbolt,

Key Points . . .

- ▶ Patients with cancer experience multiple symptoms related to the disease and its treatment.
- ▶ Identifying key concepts in symptom experiences guides measurement and methodologies for nursing research.
- ▶ Symptom burden is a distinct concept in symptom experience that contributes to the understanding of patients' physiologic and psychological functioning during the diagnosis and treatment of cancer.
- ▶ Oncology nurses must understand symptom concepts and appropriate assessment of multiple symptoms in the illness trajectory to select management strategies that positively affect patient outcomes.

Byrne, & Stuart-Harris, 2003; Chiou, 1998; Cleeland et al., 2000; Cooley, 2000; de Haes, van Knippenberg, & Neijt, 1990; McCorkle & Young, 1978; Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Kiyasu, et al., 1994). The instruments are used in multiple disease states, including cancer. Medical and nursing researchers often use the same symptom identification instruments, with portions of the tools excluded, depending on the symptom concept being measured. Given the inconsistencies, a specific definition of symptom burden clearly is required for continued advancement of scientific knowledge about the symptom experience.

Methods

Rodgers' (2000) evolutionary method of concept analysis allows for a dynamic reality with overlapping and inter-related elements in a multitude of contexts and disciplines. The technique requires a multidisciplinary literature review to identify attributes, antecedents, surrogate and related concepts, consequences, and contextual variations of the concept. This literature analysis will address the following questions.

Roxanna L. Gapstur, MS, APRN-BC, AOCN®, is the director of nursing at Methodist Hospital, Park Nicollet Health Services, in St. Louis Park, MN, and a doctoral student in the School of Nursing at the University of Minnesota in Minneapolis. (Submitted July 2006. Accepted for publication October 19, 2006.)

Digital Object Identifier: 10.1188/07.ONF.673-680

- How is symptom burden in any disease state conceptualized by psychology and psychiatry, nursing, and medicine? What contextual variations are used?
- What are the attributes, antecedents, and consequences? What are the surrogate terms and related concepts?
- What is the definition of symptom burden and the implications for oncology nursing research?

Literature Review

An adequate sampling of the literature, according to Rodgers's (2000) method, was completed using a random selection of at least 30 articles from each discipline or 20% of the total population of articles, whichever was greater. The analysis included a search of medical, psychological, and nursing literature from 1982–2005. The key words symptom burden and symptom load were used to identify and retrieve literature written in English with human subjects from CINAHL®, MEDLINE®, PsycINFO, and Cochrane Reviews. The initial search identified 3 articles from CINAHL, 780 from MEDLINE, and 5 from PsycINFO. Because of a low volume of articles in nursing, the search was refined in all databases to include related terms of symptom distress, symptom clusters, symptom experience, tumor burden, patient burden, and symptom burden or load in the title of the article. The search yielded 441 articles from CINAHL for symptom distress and 3 for symptom burden; 159 articles from MEDLINE for tumor burden and 414 for symptoms, symptom burden, and chronic illness; and 56 articles from PsycINFO for symptom and symptom burden or load in article titles. After the abstracts were reviewed for overlapping content, the final random and hand-selected sample for the analysis consisted of 39 articles from CINAHL on symptom burden and related concepts of symptom distress, symptom clusters, and symptoms experience and 39 articles from MEDLINE and 18 from PsycINFO for symptom burden.

Results of the Review

The multidisciplinary literature review provided context for clarification of the concept, using an inductive approach. Major themes were identified, and areas of agreement and disagreement in the disciplines provided insight for a possible definition of the concept.

Psychological and Psychiatric Literature

In the psychological literature, medical diagnoses, such as diabetes, heart disease, cancer, gastrointestinal disorders, chronic obstructive pulmonary disease (COPD), and renal failure correlated with physical symptomatology amplification (i.e. increased symptom burden) and psychological distress. Authors recognized that the prevalence of symptoms is dependent on antecedents of disease progression, treatment regimen, and adherence to medical treatments, as well as possible psychological disorders. Patients who report a higher symptom burden than others with similar disease severity may have untreated depression or other mental illnesses (Chen, 2004).

Symptom burden in the psychological literature is identified as the quantifiable number of symptoms experienced at any time or mean number of symptoms per patient as measured by a symptom checklist specific to the medical illness (Ludman et al., 2004). In medically ill patients, a positive symptom is

experienced at least “several days” in the prior month. More medical symptoms and lowered quality of life affect psychological adaptation and physiologic measures, such as glycemic control (Christensen et al., 2004; Francoeur, 2005; Ludman et al.; Morasso et al., 1999).

Other physiologic dimensions noted the recognition of an underlying shared etiology of multiple symptoms in patients with cancer. Francoeur (2005) studied 268 patients with recurrent disease, initiating palliative radiation for bone pain. Patients self-reported symptom severity and depressive symptoms. The results suggested a paradigm of sickness behavior, and the malaise theory of depression was a potential explanation for physiologic changes, such as fever, fatigue, and weakness. Francoeur hypothesized that crossover effects from symptom interventions could reduce several symptoms in a cluster.

The psychological and psychiatric literature identified a quantifiable, subjective number of symptoms in a population; related symptom burden to psychological distress, depression, and severity of illness; described the potential for a shared underlying etiology of multiple symptoms in patients with cancer; and identified negative consequences of symptom burden on quality of life and mental health. Depression or other psychological symptoms may be a consequence and an antecedent of symptom burden.

Medicine

In medical literature, the concept of symptom burden was used as a quantifiable term to describe the number of symptoms a person experienced at any time (Cleeland & Reyes-Gibby, 2002; Mercadante, Casuccio, & Fulfaro, 2000; Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Coyle, et al., 1994; Potter, Hami, Bryan, & Quigley, 2003; Silveira et al., 2005; Vainio, Auvinen, & Symptom Prevalence Group, 1996). Cleeland and Reyes-Gibby described symptom burden in patients with cancer as the subjective counterpart of tumor burden (i.e., a measurement of tumor volume). Potter et al. and Silveira et al. identified symptom burden as the mean number of symptoms per patient. Other diseases in which attempts to quantify symptom burden have been made include diabetes (Ludman et al., 2004; Weijman et al., 2003), heart disease (Paquette et al., 2000; Ruo et al., 2003), ulcerative colitis (Hjortswang et al., 2003), COPD (Klinkenberg et al., 2004), HIV and AIDS (Holzemer, 2002; Hudson, Lee, & Portillo, 2003; Vogl et al., 1999), renal failure (Jablonski, 2004; Weisbord et al., 2004), hemodialysis (Weisbord et al., 2003), and chronic critical illness (Nelson et al., 2004).

Symptoms are known to be the subjective evidence of illness or disease that signify a change in normal cellular function (Cleeland, 2000; Given, Given, Azzouz, Stommel, & Kozachik, 2000; Kurtz, Kurtz, Stommel, Given, & Given, 2000; Mercadante et al., 2000; Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Coyle, et al., 1994; Vainio et al., 1996; Walsh, Donnelly, & Rybicki, 2000; Zhukovsky, Abdullah, Richardson, & Walsh, 2000). In animal studies, changes in cytokine serum concentrations have been implicated in symptoms, such as malaise, anxiety, and sleep disturbances (Cleeland et al., 2003; Wood, Nail, Gilster, Winters, & Elsea, 2006). As noted in psychological literature, general medicine suggests a shared underlying etiology of multiple symptoms in patients with cancer (Wood et al.) because the role of pro-inflammatory cytokines may form the biologic basis for tumor

progression and cancer-related symptoms (Lee et al., 2004). Researchers, including Donnelly and Walsh (1995), have studied patients with advanced cancer to determine prevalence and severity of symptoms. The number of symptoms reported ranged from 1–27, with a median of 11. Pain, fatigue, and anorexia were cited frequently among the 10 most prevalent symptoms for all tumor types. The finding supports current research about multiple symptoms with shared mechanisms in patients with cancer and demonstrates a direct relationship between more symptoms and higher symptom burden. Despite the consistent report of multiple symptoms in the literature, consensus does not exist on the number of symptoms that constitutes a particular level of symptom burden. However, all studies clearly describe the negative effect of symptoms on quality of life, including role performance; physical, social, and psychological functioning; and treatment-related costs and hospitalizations.

Researchers suggest that, in addition to symptom prevalence, severity and frequency of symptoms are important multidimensional characteristics of symptom burden (Chang, Hwang, Feuerman, & Kasimis, 2000; Kutner et al., 2001; Lutz et al., 2001; Mercadante et al., 2000). Symptoms that are continuous, unrelieved, and pervasive cause a higher symptom burden, which was demonstrated by Desbiens et al. (1999) in a study that enrolled 1,582 seriously ill hospitalized patients with multiple diagnoses. The criteria used to sort frequency of symptom occurrence were symptoms of moderate severity that occurred half the time or were extremely severe at any level of frequency. Kutner et al. discovered a significant burden of unrelieved symptom prevalence, frequency, and severity among patients enrolled in hospice. Similar results have been reported previously by other researchers (Desbiens & Wu, 2000; Nelson et al., 2004) and support the multidimensional nature of symptom burden, including demographic differences, such as age and gender.

Symptom burden is viewed as dynamic, changing over time as patients experience exacerbations or remissions of their illnesses or undergo treatment (Vig & Pearlman, 2003). Patients with cancer undergoing active treatment with chemotherapy, radiation, or biologic response modifiers experience an increase in symptom burden for a period of time that relents after treatment is finished or during treatment breaks (Cooley, Short, & Moriarty, 2003; Wood et al., 2006). The same phenomenon has been reported in patients with AIDS, ulcerative colitis, multiple sclerosis, and other diseases (Holzemer, 2002; Hjortswang et al., 2003; Nelson et al., 2004).

Symptom burden correlates with survival in patients with cancer. Donnelly and Walsh (1995) discovered that patients with advanced cancer who experienced anorexia, hallucinations, bloating, and mucositis were more likely to die than patients without those symptoms. In a National Hospice Study, five symptoms (i.e., anorexia, dyspnea, weight loss, dysphagia, and dry mouth) were predictive of reduced survival (Krech & Walsh, 1991). Lutz et al. (2001) identified decreased survival with increased symptom frequency and severity in 69 patients with metastatic or locally recurrent lung cancer undergoing radiation treatments.

The medical literature identifies symptom burden in multiple disease states; focuses on quantification, severity, and frequency of symptoms; recognizes a potential underlying etiology related to sickness behavior and cytokine release; explores the attribute of multidimensionality; and indicates

that symptom burden is a predictor of survival in patients with cancer. Medicine, psychology, and psychiatry have noted poor quality of life resulting from high symptom burden.

Nursing

The concept of symptom burden rarely is mentioned in nursing literature despite a search that included several related and surrogate terms. Goodell and Nail (2005) noted that no concept development has occurred with respect to symptom burden and acknowledged that the term symptom burden has been used in medical literature to describe the prevalence of symptoms in a sample population, but rarely in individual patients. Beck (2004) reviewed the lack of science to guide management of symptom clusters, including lack of clarity around the term symptom burden.

In one nursing study, Zambroski et al. (2005) explored symptom prevalence, overall symptom burden, and the effects on quality of life in patients with heart failure. Symptoms were measured using the Memorial Symptom Assessment Scale–Heart Failure. Patients experienced a mean of 15.1 symptoms, with shortness of breath and lack of energy being most prevalent. The authors concluded that patients with heart failure experience a high level of symptoms and total symptom burden.

The concept of symptom burden is used infrequently in nursing, with no concept definition or recommendation for methodologic issues in research. Concept clarity, including instrumentation for measurement and delineation from other symptom concepts, is lacking.

Symptom Burden, Attributes, Antecedents, and Consequences

Attributes

Research supporting the attributes of symptom burden is summarized in Table 1.

Dynamic: Symptom burden is dynamic throughout the disease trajectory with exacerbations and remissions commonly occurring in many illnesses, including cancer. Symptoms occur more or less frequently and with lesser or greater severity depending on multiple factors, including stage or progression of disease, treatments, activity level, and awareness. Across disease states, including cancer, symptom burden increases as disease worsens (Brandt et al., 2005; Klinkenberg et al., 2004; Kutner et al., 2001; Sarna, 1998; Silveira et al., 2005).

Multidimensional: As a multidimensional concept, symptom burden is conceptualized in the literature with the following dimensions: symptom prevalence, frequency, and intensity (Chang et al., 2000; Desbiens et al., 1999; Walke et al., 2004). Research varied widely, and some authors only counted the number of symptoms (Vainio et al., 1996); other authors included measurements of prevalence, frequency, severity, and distress associated with symptoms (Chen, 2004; Cooley et al., 2003).

Quantifiable: The measurement of symptom burden commonly was performed with the aid of disease-specific symptom checklists (Barresi et al., 2003; Cleeland et al., 2000; McCorkle & Young, 1978; Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Kiyasu, et al., 1994), requesting that patients self-report symptoms they experienced as well as their severity. The literature describes the presence of

Table 1. Attributes of Symptom Burden and Findings in the Literature

Attribute	Findings
Dynamic	Identified different severities and frequencies of symptoms in terminally ill patients at the end of life (Kutner et al., 2001) Symptom burden differed in the last week of life depending on comorbidities and factors such as cognitive decline (Klinkenberg et al., 2004). Discovered varying symptom prevalence and distress over time in adults receiving treatment for lung cancer (Cooley et al., 2003)
Multidimensional	Identified prevalence and severity of symptoms in patients with congestive heart failure, chronic obstructive pulmonary disease, and cancer (Chang et al., 2000) Found a high prevalence and adverse effect of physical and psychological symptoms in patients with cancer (Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Coyle, et al., 1994)
Quantifiable	Identified the most prevalent symptoms in patients with cancer by primary site (Vainio et al., 1996) Identified median number of symptoms per patient and the relationship to age, gender, and performance status (Walsh et al., 2000)
Physiologic	Reviewed literature related to pro-inflammatory cytokines released during cancer development and treatment (Miller, 2003) Reviewed evidence for a cytokine-immunologic model of symptom expression in cancer (Cleeland et al., 2003)
Subjective	Self-reported information from patients on symptom prevalence, distress, and change over time (Cooley et al., 2003) Self-reported information from patients with advanced lung cancer on frequent and severe symptoms that worsen in the final months of life (Lutz et al., 2001)

multiple symptoms in reference to symptom burden (Nelson et al., 2004; Walsh et al., 2000); however, it fails to confirm the number or severity of symptoms that correlates with the amount of symptom burden. Researchers recognize that one severe symptom, such as pain, could be the source of a significant symptom burden (Cleeland & Reyes-Gibby, 2002).

Physiologic burden: Symptoms signify a change in normal physical functioning of the human body. Cancer research is beginning to illuminate the underlying signaling and cellular changes that create symptoms (Cleeland et al., 2003; Lee et al., 2004; Miller, 2003; Wood et al., 2006). Multiple symptoms that increase patients' symptom burden and occur simultaneously potentially share an underlying etiology (Parker, Kimble, Dunbar, & Clark, 2005). Symptoms can be manifested as physical, psychosocial, or cognitive.

Although occasional studies incorporated symptom distress in symptom burden, the two concepts usually were measured separately. The amount of emotional distress that patients experience is variable and may not correlate with the degree of physiologic symptom burden. Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Coyle, et al. (1994) noted that distress ratings in patients with cancer were consistently lower than the

frequency or severity of symptoms, which suggests that patients do not assign meaning or emotional distress to a symptom merely because of its prevalence or severity. For instance, patients who experience moderate nausea and vomiting from chemotherapy may express hope and decreased emotional distress if they believe the symptoms signify that the treatment is working. In addition, researchers cite the importance of complicating factors, such as depression, on the reporting of physical symptomatology (Chen, 2004; Kuo & Ma, 2002; Ludman et al., 2004; Pirraglia, Sanyal, Singer, & Ferris, 2004).

Subjective: A symptom is a subjective awareness of disease or illness, as opposed to a sign, which is the objective and observable manifestation of disease (Dodd, Janson, et al., 2001). Symptom burden is measured subjectively by self-reports from patients. Although studies have used proxies to measure symptom burden experienced by terminally ill patients, these proxy ratings have proven to be less accurate (Klinkenberg et al., 2003).

Antecedents

All three disciplines considered controlled, severe symptoms that cause changes in normal physiologic functioning of the human body related to illness, disease, or treatment to be antecedents of symptom burden. The concept of cytokine release in patients with cancer suggests that physiologic changes occur, resulting in symptom clusters or complexes (Miller, 2003; Wood et al., 2006), thereby increasing symptom burden. Disease characteristics, including stage of disease, were antecedents because the highest burden was in patients with more advanced disease states who experienced more changes in physiologic functioning (Degner & Sloan, 1995; Sarna & Brecht, 1997).

Patient characteristics are an antecedent to symptom burden. Symptom amplification related to psychological disorders, such as depression, creates the impression of higher symptom burden in some patients, unrelated to disease severity. Researchers have demonstrated differences in symptom burden correlating to gender and age in patients with heart disease, cancer, and other disorders (Hjortswang et al., 2003; Paquette et al., 2000).

Consequences

Studies in the medical literature have described the effect of cancer symptom burden on quality of life and functional status (Bernhard et al., 2002; Dodd, Miaskowski, & Paul, 2001; Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Coyle, et al., 1994). Consequences of elevated symptom burden may include decreased survival and poor prognosis (Chang et al., 2000); Degner & Sloan, 1995); decreased quality of life (Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Coyle, et al.); depression (Ludman et al., 2004); lowered functional status (Given, Given, Azzouz, & Stommel, 2001; Sarna & Brecht, 1997); delay or termination of treatment; increased hospitalizations, emergency room visits, or medical costs; and loss of employment (Cleeland, 2000). In general, the higher the symptom burden, the lower the self-reported quality of life and functional status. However, a "response shift" may affect patients' perceptions of symptoms. The phenomenon results from changing patient conceptualizations and adjustment to illness. As patients adjust to their limited capacity, their perception of the illness and their limitations change and adaptation occurs (Cleeland & Reyes-Gibby, 2002).

Downloaded on 05-07-2024. Single-user license only. Copyright 2024 by the Oncology Nursing Society. For permission to post online, reprint, adapt, or reuse, please email pubpermissions@ons.org. ONS reserves all rights.

Variations and Consensus

In medical literature, quantification of symptom burden was accomplished with the use of symptom scales. Symptom measurement scales are available for use in various populations (Borgaro, Prigatano, Alcott, Kwasnica, & Cutter, 2003; Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Kiyasu, et al., 1994; Tranmer et al., 2003). All disciplines measured symptom burden as a quantifiable number of symptoms, and the definitions offered were related to the average number of symptoms experienced. In cancer-related medical literature, eliminating the distress portion of the scale and focusing on the number and severity of symptoms were common. Oncology nurse researchers often measured the concept of symptom distress using symptom scales similar to those used to measure symptom burden (Cleeland et al., 2000; McCorkle & Young, 1978; Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Kiyasu, et al.; Stein et al., 2003). Proxy ratings of symptom burden in patients with cancer are common in the medical literature but were not identified in the nursing literature.

Nursing, medical, and psychological literature suggest that the concept of symptom clusters or multiple symptoms is a factor in the burden of symptoms and distress in patients with cancer (Armstrong, Cohen, Eriksen, & Hickey, 2004; Gift, Jablonski, Stommel, & Given, 2004; Gift, Stommel, Jablonski, & Given, 2003; Wilmoth, Coleman, Smith, & Davis, 2004). Clear agreement exists regarding the notion of symptom clusters occurring at various times in the disease trajectory, either related to disease or side effects of treatment.

Clarifying and Defining the Concept

Definition of Symptom Burden

As a result of understanding the available literature, a working definition of symptom burden gradually developed as the subjective, quantifiable prevalence, frequency, and severity of symptoms that place a physiologic burden on patients and may produce multiple negative physical, psychological, and emotional patient responses. The term “burden” is defined in Webster’s (1997) dictionary as, “to load oppressively, that which is carried, that which is borne with difficulty;” and symptom is described as, “subjective evidence of disease or physical disturbance; broadly something that indicates the presence of bodily disorder.” Combining the two dictionary definitions captures the attributes of physiologic changes in normal functioning that place a burden on the human body. However, the dictionary definition is incomplete because it does not address the multidimensionality of symptom burden, the quantifiable nature of the concept, or the effect on quality of life.

Related Concepts and Surrogate Terms

Multiple terms relate to symptoms experienced by patients. Figure 1 summarizes the definitions of the symptom terms identified in the literature of all three disciplines.

Symptom distress is defined as the physical or mental anguish or suffering that results from experiencing symptoms or the perception of feeling states (Rhodes & Watson, 1987). Symptom distress is conceptualized as ability of individuals to perceive or be cognizant of the amount of upset, strain, or physical or mental anguish experienced (Rhodes, McDaniel, Homan, Johnson, & Madsen, 2000). Measurement of symptom distress is accomplished with the use of symptom

Patient burden: patients’ perceptions of the amount of burden the disease and treatment processes have placed on them (Sloan, 2002)

Side-effects burden or treatment burden: the perceived level of physical and psychological problems in terms of severity and problematic burden (Longman et al., 1997)

Symptom clusters: two or more symptoms that are related to each other and that occur together; composed of stable groups of symptoms that are relatively independent of other clusters and may reveal specific underlying dimensions of symptoms; relationships among symptoms within a cluster should be stronger than relationships across different clusters (Sloan, 2002).

Symptom distress: the need to alter (i.e., restrain or produce) actions in response to a subjective indication of disease or illness; also, the physical or mental anguish or suffering that results from the experience of symptom occurrence or the perception of feeling states (Rhodes & Watson, 1987)

Symptom load: the number of symptoms experienced at any given time (Christensen et al., 2004)

Symptoms experience: the perception of the frequency, intensity, distress, and meaning, occurring as symptoms are produced and expressed (Armstrong, 2003)

Tumor burden: a measure of the total volume of tumor lesions (Gobbi et al., 2004)

Figure 1. Symptom Terms and Definitions

scales such as the Symptom Distress Scale (McCorkle & Young, 1978), which defines symptom distress as the degree of discomfort from the symptom being experienced as perceived by the patient. The focus is less on the number of symptoms and more on the distress faced by patients.

Symptoms experience is a concept defined as the perception of the frequency, intensity, distress, and meaning, occurring as symptoms are produced and expressed. The conceptual model of the symptoms experience suggests a broader context and includes the concept of symptom distress (Armstrong, 2003). Rhodes et al. (2000) developed the Symptom Experience Scale, which measures symptom occurrence and symptom distress and was adapted from the Symptom Distress Scale.

Patient burden is patients’ perceptions of the amount of burden the disease and treatment processes have placed on them (Sloan, 2002). Treatment burden, a similar term, entails patient and physician estimation of overall symptom burden during a course of treatment (Bernhard, et al., 2002).

Tumor burden is a term in the medical literature that has been defined as the measure of the total volume of tumor lesions in cm^3/m^2 as determined by radiologic imaging (Gobbi et al., 2004). Tumor burden is a mathematical factor used in the prognosis and staging of hematologic cancers such as lymphoma (Evans, 1996; Schmid, Bird, Dummer, Kempf, & Burg, 1999; Specht, 1992). A high tumor burden is correlated with decreased survival and treatment failures (Gobbi et al., 2004; Hehlmann & Heimpel, 1996).

Side-effects burden is used to describe the burden of treatment-related symptoms. Measurement scales list common side effects of a particular tumor treatment, such as for breast cancer, and patients rate the number and severity of side effects on a Likert scale (Longman et al., 1997).

Symptom load is an infrequently used surrogate term for symptom burden in the psychological literature; the concept is used similarly and is measured by symptom checklists (Christensen et al., 2004).

Nursing Implications

Assessment

Cancer symptom assessment scales focus on the frequency, severity, and distress that patients experience during illness. More recent scales attempt to incorporate the meaning that patients assign to their symptom experiences. To accurately measure the concept of symptom burden, instruments must measure the prevalence, severity, and frequency of disease-specific symptoms during periods in the illness and treatment trajectory (Zhukovsky et al., 2000). According to Cleeland and Reyes-Gibby (2002); the ideal tool for measuring symptom burden would focus on the most prevalent and distressing symptoms for a particular group of patients. Correlating symptom burden with survival, symptom distress, and symptom patterns over time will help target appropriate and timely interventions (Teel, Meek, McNamara, & Watson, 1997).

Interventions

Literature supports the concept of an increasing symptom burden in most diseases as patients progress through the disease trajectory. In cancer research, a growing body of evidence demonstrates the possibility of an underlying shared etiology for symptom clusters. The evidence has implications for nursing interventions that relieve several symptoms at once, potentially saving time, decreasing cost, and improving patient quality of life (Dodd, Miaskowski, & Paul, 2001; Fu, LeMone, & McDaniel, 2004).

Research studies with patient populations who are experiencing varying amounts of symptom burden at different points in their illness are important. At which stage or amount of burden an intervention successfully will affect patient outcomes is unknown. According to strong evidence in the

pain literature, treating symptoms before they become severe is more effective.

Outcomes

Symptom burden affects multiple patient outcomes, including survival, functional status, quality of life, activities of daily living, wound healing, and economic outcomes (Kutner et al., 2001; McClement, Woodgate, & Degner, 1997; Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Coyle, et al., 1994; Tishelman, Degner, & Mueller, 2000). Studies in patients with cancer describe the symptoms associated with the highest frequency and severity. The identification of the symptoms allows nurses to target most symptom burdens with strategies that have greater effect, which may improve patient outcomes and survival.

Conclusion

In this concept analysis, literature related to the concept of symptom burden in psychology and psychiatry, medicine, and nursing was reviewed, and a beginning definition of the concept of symptom burden was offered in the symptoms experience, which includes multiple related concepts. Measurement of symptom burden and other symptom concepts can occur only after understanding the inter-relationships and differences in each concept. The continued development of symptom burden as a concept may spur development of improved symptom assessment and timely interventions that could result in improved patient outcomes. Further investigation into the effect of symptom clusters on symptom burden and the underlying interactions among symptoms (Parker et al., 2005) is imperative.

Author Contact: Roxanna L. Gapstur, MS, APRN-BC, AOCN®, can be reached at roxanna.gapstur@parknicollet.com, with copy to editor at ONFEditor@ons.org.

References

- Armstrong, T.S. (2003). Symptoms experience: A concept analysis. *Oncology Nursing Forum*, 30, 601–606.
- Armstrong, T.S., Cohen, M.Z., Eriksen, L.R., & Hickey, J.V. (2004). Symptom clusters in oncology patients and implications for symptom research in people with primary brain tumors. *Journal of Nursing Scholarship*, 36, 197–206.
- Barresi, M.J., Shadbolt, B., Byrne, D., & Stuart-Harris, R. (2003). The development of the Canberra symptom scorecard: A tool to monitor the physical symptoms of patients with advanced tumours. *BMC Cancer*, 3, 32.
- Beck, S.L. (2004). Symptom clusters: Impediments and suggestions for solutions. *Journal of the National Cancer Institute Monographs*, 32, 137–138.
- Bernhard, J., Maibach, R., Thurlimann, B., Sessa, C., Aapro, M.S., & Swiss Group for Clinical Cancer Research. (2002). Patients' estimation of overall treatment burden: Why not ask the obvious? *Journal of Clinical Oncology*, 20, 65–72.
- Borgaro, S.R., Prigatano, G.P., Alcott, S., Kwasnica, C., & Cutter, N. (2003). The Patient Distress Scale Questionnaire: Factor structure and internal consistency. *Brain Injury*, 17, 545–551.
- Brandt, H.E., Deliens, L., Ooms, M.E., van der Steen, J.T., van der Wal, G., & Ribbe, M.W. (2005). Symptoms, signs, problems, and diseases of terminally ill nursing home patients. *Archives of Internal Medicine*, 165, 314–320.
- Chang, V.T., Hwang, S.S., Feuerman, M., & Kasimis, B.S. (2000). Symptom and quality-of-life survey of medical oncology patients at a Veterans Affairs medical center: A role for symptom assessment. *Cancer*, 88, 1175–1183.
- Chen, M.L. (2004). Physical symptom profiles of depressed and nondepressed patients with cancer. *Palliative Medicine*, 18, 712–718.
- Chiou, C. (1998). Development and psychometric assessment of the Physical Symptom Distress Scale. *Journal of Pain and Symptom Management*, 16, 87–95.
- Christensen, U., Lund, R., Damsgaard, M.T., Holstein, B.E., Ditlevsen, S., Diderichsen, F., et al. (2004). Cynical hostility, socioeconomic position, health behaviors, and symptom load: A cross-sectional analysis in a Danish population-based study. *Psychosomatic Medicine*, 66, 572–577.
- Cleeland, C.S. (2000). Cancer-related symptoms. *Seminars in Radiation Oncology*, 10, 175–190.
- Cleeland, C.S., Bennett, G.J., Dantzer, R., Dougherty, P.M., Dunn, A.J., Meyers, C.A., et al. (2003). Are the symptoms of cancer and cancer treatment due to a shared biologic mechanism? *Cancer*, 97, 2919–2925.
- Cleeland, C.S., Mendoza, T.R., Wang, X.S., Chou, C., Harle, M.T., Morrissey, M., et al. (2000). Assessing symptom distress in cancer patients: The M.D. Anderson Symptom Inventory. *Cancer*, 89, 1634–1646.
- Cleeland, C.S., & Reyes-Gibby, C.C. (2002). When is it justified to treat symptoms? Measuring symptom burden. *Oncology*, 16(9), 64–70.
- Cooley, M.E. (2000). Symptoms in adults with lung cancer: A systematic research review. *Journal of Pain and Symptom Management*, 19, 137–153.
- Cooley, M.E., Short, T.H., & Moriarty, H.J. (2003). Symptom prevalence, distress, and change over time in adults receiving treatment for lung cancer. *Psycho-Oncology*, 12, 694–708.
- Degner, L.F., & Sloan, J.A. (1995). Symptom distress in newly diagnosed

- ambulatory cancer patients and as a predictor of survival in lung cancer. *Journal of Pain and Symptom Management*, 10, 423–431.
- de Haes, J.C., van Knippenberg, F.C., & Neijt, J.P. (1990). Measuring psychological and physical distress in cancer patients: Structure and application of the Rotterdam Symptom Checklist. *British Journal of Cancer*, 62, 1034–1038.
- Desbiens, N.A., Mueller-Rizner, N., Connors, A.F.J., Wenger, N.S., & Lynn, J. (1999). The symptom burden of seriously ill hospitalized patients. *Journal of Pain and Symptom Management*, 17, 248–255.
- Desbiens, N.A., & Wu, A.W. (2000). Pain and suffering in seriously ill hospitalized patients. *Journal of the American Geriatrics Society*, 48, 5183–5186.
- Dodd, M.J., Janson, S., Facione, N., Faucett, J., Froelicher, E.S., Humphreys, J., et al. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing*, 33, 668–676.
- Dodd, M.J., Miaskowski, C., & Paul, S.M. (2001). Symptom clusters and their effect on the functional status of patients with cancer. *Oncology Nursing Forum*, 28, 465–470.
- Donnelly, S., & Walsh, D. (1995). The symptoms of advanced cancer. *Seminars in Oncology*, 22(S3), 67–72.
- Evans, R.A. (1996). The tumor burden of locally recurrent breast cancer is a neglected prognostic factor. *American Journal of Surgery*, 171, 445–448.
- Francoeur, R.B. (2005). The relationship of cancer symptom clusters to depressive affect in the initial phase of palliative radiation. *Journal of Pain and Symptom Management*, 29, 130–155.
- Fu, M.R., LeMone, P., & McDaniel, R.W. (2004). An integrated approach to an analysis of symptom management in patients with cancer. *Oncology Nursing Forum*, 31, 65–70.
- Gift, A.G., Jablonski, A., Stommel, M., & Given, C.W. (2004). Symptom clusters in elderly patients with lung cancer. *Oncology Nursing Forum*, 31, 202–212.
- Gift, A.G., Stommel, M., Jablonski, A., & Given, W. (2003). A cluster of symptoms over time in patients with lung cancer. *Nursing Research*, 52, 393–400.
- Given, B., Given, W., Azzouz, F., & Stommel, M. (2001). Physical functioning of elderly cancer patients prior to diagnosis and following initial treatment. *Nursing Research*, 50, 222–232.
- Given, C.W., Given, B., Azzouz, F., Stommel, M., & Kozachik, S. (2000). Comparison of changes in physical functioning of elderly patients with new diagnoses of cancer. *Medical Care*, 38, 482–493.
- Gobbi, P.G., Broglia, C., Di Giulio, G., Mantelli, M., Anselmo, P., Merli, F., et al. (2004). The clinical value of tumor burden at diagnosis in Hodgkin lymphoma. *Cancer*, 101, 1824–1834.
- Gobbi, P.G., Ghirardelli, M.L., Solcia, M., Di Giulio, G., Merli, F., Tavecchia, L., et al. (2001). Image-aided estimate of tumor burden in Hodgkin disease: Evidence of its primary prognostic importance. *Journal of Clinical Oncology*, 19, 1388–1394.
- Goodell, T.T., & Nail, L.M. (2005). Operationalizing symptom distress in adults with cancer: A literature synthesis. *Oncology Nursing Forum*, 32, E42–E47. Retrieved April 3, 2007, from <http://www.ons.org/publications/journals/ONF/Volume32/Issue2/pdf/320242.pdf>
- Hehlmann, R., & Heimpel, H. (1996). Current aspects of drug therapy in Philadelphia-positive CML: Correlation of tumor burden with survival. *Leukemia and Lymphoma*, 22(Suppl. 1), 161–167.
- Hjortswang, H., Jarnerot, G., Curman, B., Sandberg-Gertzen, H., Tyst, C., Blomberg, B., et al. (2003). The influence of demographic and disease-related factors on health-related quality of life in patients with ulcerative colitis. *European Journal of Gastroenterology and Hepatology*, 15, 1011–1020.
- Holzemer, W.L. (2002). HIV and AIDS: The symptom experience. *American Journal of Nursing*, 102(4), 48–52.
- Hudson, A.L., Lee, K.A., & Portillo, C.J. (2003). Symptom experience and functional status among HIV-infected women. *AIDS Care: Psychological and Socio-Medical Aspects of AIDS/HIV*, 15, 483–492.
- Jablonski, A.M. (2004). The symptom experience of patients with end stage renal disease on hemodialysis. Doctoral dissertation, Michigan State University.
- Kim, H.J., McGuire, D.B., Tulman, L., & Barsevick, A.M. (2005). Symptom clusters: Concept analysis and clinical implications for cancer nursing. *Cancer Nursing*, 28, 270–282.
- Klinkenberg, M., Smit, J.H., Deeg, D.J.H., Willems, D.L., Onwuteaka-Philipsen, B.D., & van der Wal, G. (2003). Proxy reporting in after-death interviews: The use of proxy respondents in retrospective assessment of chronic diseases and symptom burden in the terminal phase of life. *Palliative Medicine*, 17, 191–201.
- Klinkenberg, M., Willems, D.L., van der Wal, G., & Deeg, D.J.H. (2004). Symptom burden in the last week of life. *Journal of Pain and Symptom Management*, 27, 5–13.
- Krech, R., & Walsh, D. (1991). Symptoms of pancreatic cancer. *Journal of Pain and Symptom Management*, 6, 360–367.
- Kuo, T.T., & Ma, F.C. (2002). Symptom distresses and coping strategies in patients with non-small cell lung cancer. *Cancer Nursing*, 25, 309–317.
- Kurtz, M.E., Kurtz, J.C., Stommel, M., Given, C.W., & Given, B.A. (2000). Symptomatology and loss of physical functioning among geriatric patients with lung cancer. *Journal of Pain and Symptom Management*, 19, 249–256.
- Kutner, J.S., Kassner, C.T., & Nowels, D.E. (2001). Symptom burden at the end of life: Hospice providers' perceptions. *Journal of Pain and Symptom Management*, 21, 473–480.
- Lee, B.N., Dantzer, R., Langley, K.E., Bennett, G.J., Dougherty, P.M., Dunn, A.J., et al. (2004). A cytokine-based neuroimmunologic mechanism of cancer-related symptoms. *Neuroimmunomodulation*, 11, 279–292.
- Longman, A.J., Braden, C.J., & Mishel, M.H. (1997). Pattern of association over time of side-effects burden, self-help, and self-care in women with breast cancer. *Oncology Nursing Forum*, 24, 1555–1560.
- Ludman, E.J., Katon, W., Russo, J., Von Korff, M., Simon, G., Ciechanowski, P., et al. (2004). Depression and diabetes symptom burden. *General Hospital Psychiatry*, 26, 430–436.
- Lutz, S., Norrell, R., Bertuccio, C., Kachnic, L., Johnson, C., Arthur, D., et al. (2001). Symptom frequency and severity in patients with metastatic or locally recurrent lung cancer: A prospective study using the Lung Cancer Symptom Scale in a community hospital. *Journal of Palliative Medicine*, 4, 157–165.
- McClement, S.E., Woodgate, R.L., & Degner, L. (1997). Symptom distress in adult patients with cancer. *Cancer Nursing*, 20, 236–243.
- McCorkle, R., & Young, K. (1978). Development of a symptom distress scale. *Cancer Nursing*, 1, 373–378.
- McCormick, K.M., Naimark, B.J., & Tate, R.B. (2002). Symptoms and distress in patients awaiting coronary artery bypass surgery. *Canadian Journal of Nursing Research*, 34(5), 95–105.
- Mercadante, S., Casuccio, A., & Fulfaro, F. (2000). The course of symptom frequency and intensity in advanced cancer patients followed at home. *Journal of Pain and Symptom Management*, 20, 104–112.
- Miller, A.H. (2003). Cytokines and sickness behavior: Implications for cancer care and control. *Brain, Behavior, and Immunity*, 17, S132–S134.
- Morasso, G., Capelli, M., Viterbori, P., Di Leo, S., Alberisio, A., Costantini, M., et al. (1999). Psychological and symptom distress in terminal cancer patients with met and unmet needs. *Journal of Pain and Symptom Management*, 17, 402–409.
- Nelson, J.E., Meier, D.E., Litke, A., Natale, D.A., Siegel, R.E., & Morrison, R.S. (2004). The symptom burden of chronic critical illness. *Critical Care Medicine*, 32, 1527–1534.
- Paquette, M., Roy, D., Talajic, M., Newman, D., Couturier, A., Yang, C., et al. (2000). Role of gender and personality on quality-of-life impairment in intermittent atrial fibrillation. *American Journal of Cardiology*, 86, 764–768.
- Parker, K.P., Kimble, L.P., Dunbar, S.B., & Clark, P.C. (2005). Symptom interactions as mechanisms underlying symptom pairs and clusters. *Journal of Nursing Scholarship*, 37, 209–215.
- Pirraglia, P.A., Sanyal, P., Singer, D.E., & Ferris, T.G. (2004). Depressive symptom burden as a barrier to screening for breast and cervical cancers. *Journal of Women's Health*, 13, 731–738.
- Portenoy, R.K., Thaler, H.T., Kornblith, A.B., Lepore, J.M., Friedlander-Klar, H., Coyle, N., et al. (1994). Symptom prevalence, characteristics, and distress in a cancer population. *Quality of Life Research*, 3, 183–189.
- Portenoy, R.K., Thaler, H.T., Kornblith, A.B., Lepore, J.M., Friedlander-Klar,

- H., Kiyasu, E., et al. (1994). The Memorial Symptom Assessment Scale: An instrument for the evaluation of symptom prevalence, characteristics, and distress. *European Journal of Cancer*, 30A, 1326–1336.
- Potter, J., Hami, F., Bryan, T., & Quigley, C. (2003). Symptoms in 400 patients referred to palliative care services: Prevalence and patterns. *Palliative Medicine*, 17, 310–314.
- Rhodes, V.A., McDaniel, R.W., Homan, S.S., Johnson, M., & Madsen, R. (2000). An instrument to measure symptom experience: Symptom occurrence and symptom distress. *Cancer Nursing*, 23, 49–54.
- Rhodes, V.A., & Watson, P.M. (1987). Symptom distress—The concept: Past and present. *Seminars in Oncology Nursing*, 3, 242–247.
- Rodgers, B.L. (2000). Concept analysis: An evolutionary view. In B.L. Rodgers & K.A. Knafl (Eds.), *Concept development in nursing: Foundation, technique, and applications* (pp. 77–102). Philadelphia: Saunders.
- Rose, M.S., Koshman, M.L., Spreng, S., & Sheldon, R. (2000). The relationship between health-related quality of life and frequency of spells in patients with syncope. *Journal of Clinical Epidemiology*, 53, 1209–1216.
- Ruo, B., Rumsfeld, J.S., Hlatky, M.A., Liu, H., Browner, W.S., & Whooley, M.A. (2003). Depressive symptoms and health-related quality of life: The Heart and Soul Study. *JAMA*, 290, 215–221.
- Sarna, L. (1998). Effectiveness of structured nursing assessment of symptom distress in advanced lung cancer. *Oncology Nursing Forum*, 25, 1041–1048.
- Sarna, L., & Brecht, M.L. (1997). Dimensions of symptom distress in women with advanced lung cancer: A factor analysis. *Heart and Lung*, 26, 23–30.
- Schmid, M.H., Bird, P., Dummer, R., Kempf, W., & Burg, G. (1999). Tumor burden index as a prognostic tool for cutaneous T-cell lymphoma: A new concept. *Archives of Dermatology*, 135, 1204–1208.
- Schneider, S.M. (1999). I look funny and I feel bad. Measurement of symptom distress. *Journal of Child and Family Nursing*, 2, 380–384.
- Silveira, M.J., Kabeto, M.U., & Langa, K.M. (2005). Net worth predicts symptom burden at the end of life. *Journal of Palliative Medicine*, 8, 827–837.
- Sloan, J. (2002). Asking the obvious questions regarding patient burden. *Journal of Clinical Oncology*, 20, 4–6.
- Specht, L. (1992). Tumour burden as the main indicator of prognosis in Hodgkin disease. *European Journal of Cancer*, 28A, 1982–1985.
- Stein, K.D., Denniston, M., Baker, F., Dent, M., Hann, D.M., Bushhouse, S., et al. (2003). Validation of a modified Rotterdam Symptom Checklist for use with cancer patients in the United States. *Journal of Pain and Symptom Management*, 26, 975–989.
- Teel, C.S., Meek, P., McNamara, A.M., & Watson, L. (1997). Perspectives unifying symptom interpretation. *Image: Journal of Nursing Scholarship*, 29, 175–181.
- Tishelman, C., Degner, L.F., & Mueller, B. (2000). Measuring symptom distress in patients with lung cancer: A pilot study of experienced intensity and importance of symptoms. *Cancer Nursing*, 23, 82–90.
- Tranmer, J.E., Heyland, D., Dudgeon, D., Groll, D., Squires-Graham, M., & Coulson, K. (2003). Measuring the symptom experience of seriously ill cancer and noncancer hospitalized patients near the end of life with the Memorial Symptom Assessment Scale. *Journal of Pain and Symptom Management*, 25, 420–429.
- Vainio, A., Auvinen, A., and Symptom Prevalence Group. (1996). Prevalence of symptoms among patients with advanced cancer: An international collaborative study. *Journal of Pain and Symptom Management*, 12, 3–10.
- Vig, E.K., & Pearlman, R.A. (2003). Quality of life while dying: A qualitative study of terminally ill older men. *Journal of the American Geriatric Society*, 51, 1595–1601.
- Vogl, D., Rosenfeld, B., Breitbart, W., Thaler, H., Passik, S., McDonald, M., et al. (1999). Symptom prevalence, characteristics, and distress in AIDS outpatients. *Journal of Pain and Symptom Management*, 18, 253–262.
- Walke, L.M., Gallo, W.T., Tinetti, M.E., & Fried, T.R. (2004). The burden of symptoms among community-dwelling older persons with advanced chronic disease. *Archives of Internal Medicine*, 164, 2321–2324.
- Walsh, D., Donnelly, S., & Rybicki, L. (2000). The symptoms of advanced cancer: Relationship to age, gender, and performance status in 1,000 patients. *Supportive Care in Cancer*, 8, 175–179.
- Webster's International Dictionary*. (1997).
- Weijman, I., Ros, W.J., Rutten, G.E., Schaefeli, W.B., Schabracq, M.J., & Winnubst, J.A.M. (2003). Fatigue in employees with diabetes: Its relation with work characteristics and diabetes-related burden. *Occupational and Environmental Medicine*, 60(Suppl. 1), 93–98.
- Weisbord, S.D., Carmody, S.S., Bruns, F.J., Rotondi, A.J., Cohen, L.M., Zeidel, M.L., et al. (2003). Symptom burden, quality of life, advance care planning, and the potential value of palliative care in severely ill haemodialysis patients. *Nephrology, Dialysis, Transplantation*, 18, 1345–1352.
- Weisbord, S.D., Fried, L.F., Arnold, R.M., Rotondi, A.J., Fine, M.J., Levenson, D.J., et al. (2004). Development of a symptom assessment instrument for chronic hemodialysis patients: The Dialysis Symptom Index. *Journal of Pain and Symptom Management*, 27, 226–240.
- Wilmoth, M.C., Coleman, E.A., Smith, S.C., & Davis, C. (2004). Fatigue, weight gain, and altered sexuality in patients with breast cancer: Exploration of a symptom cluster. *Oncology Nursing Forum*, 31, 1069–1075.
- Wood, L.J., Nail, L.M., Gilster, A., Winters, K.A., & Elsea, C.R. (2006). Cancer chemotherapy-related symptoms: Evidence to suggest a role for pro-inflammatory cytokines. *Oncology Nursing Forum*, 33, 535–542.
- Zambroski, C.H., Moser, D.K., Bhat, G., & Ziegler, C. (2005). Impact of symptom prevalence and symptom burden on quality of life in patients with heart failure. *European Journal of Cardiovascular Nursing*, 4, 198–206.
- Zhukovsky, D.S., Abdullah, O., Richardson, M., & Walsh, D. (2000). Clinical evaluation in advanced cancer. *Seminars in Oncology*, 27, 14–23.