

Original Article

Symptom Burden Clusters: A Challenge for Targeted Symptom Management. A Longitudinal Study Examining Symptom Burden Clusters in Breast Cancer

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Abstract

Context. Although there has been a growing interest in cancer symptom clusters, less is known about symptom burden clusters.

Objectives. To explore clusters of burdensome symptoms over time, the impact on health status and quality of life, and coping capacity in patients with breast cancer.

Methods. In this longitudinal study, a sample of 206 patients completed the Memorial Symptom Assessment Scale, the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire, and the Sense of Coherence scale, at diagnosis of primary or recurrent breast cancer, and at one-, three-, and six-month follow-ups.

Results. Three clusters of burdensome symptoms were identified: emotional symptom burden, gastrointestinal symptom burden, and unwellness symptom burden. Most burdensome were emotional symptoms, with worrying, feeling sad, and feeling nervous as the core or defining symptoms. Over time, additional symptoms escalated the emotional symptom burden. The gastrointestinal symptom burden, with “change in the way food tastes” as a core symptom, was more often associated with chemotherapy. Less stable over time, the unwellness symptom burden could be interpreted as short- and long-term side effects of hormonal therapy. Of these clusters, only the emotional symptom burden cluster significantly diminished health status and quality of life. Patients reporting lower coping capacity experienced higher levels of symptom burden.

Conclusion. This study provides insights into symptom burden clusters over time. A challenging approach toward symptom management in clinical oncology

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is to target the burden of a symptom cluster and to recognize the need for individually designed interventions to ameliorate symptom burden in cancer patients. *J Pain Symptom Manage* 2014;47:731–741. © 2014 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Breast cancer, sense of coherence, symptom burden, symptom burden clusters, quality of life, health status

Introduction

Pioneering research by Dodd et al.¹ and Miaskowski et al.² has put forward substantial evidence that cancer and cancer treatment lead to multiple symptoms that frequently occur in clusters. Although there is agreement that symptoms in a cluster are correlated with each other and coexist,^{1,3,4} there are conceptual disagreements. Based on a study of symptom clusters over time, Molassiotis et al.³ define a symptom cluster “to be two or more symptoms that are clinically meaningful together, relate to each other at a given time, and share a significant variance with their cluster. The cluster should be stable across time, at least with respect to the core or defining symptom(s).” Not only do symptom clusters have clinical outcomes different from individual symptoms,^{1,4,5} but the total impact of a cluster also may be greater than the sum of the impact of the individual symptoms;⁶ this collective impact of multiple symptoms could be described as a symptom burden.^{7,8} Symptom burden is defined as the subjective, quantifiable prevalence, frequency, and severity of symptoms, placing a physiological burden on patients and producing multiple negative, physical, and emotional patient responses.⁹ Although there has been rapidly growing interest in the occurrence of cancer symptom clusters over the past few years,¹⁰ less is known about how burdensome these clusters are.¹¹

Patients with breast cancer experience multiple concurrent symptoms associated with stage of disease or with treatment side effects, and evidence suggests that there are a number of different symptom clusters^{12–14} associated with a decline in functional status and quality of life (QoL).^{12,14} However, there is a paucity of data concerning which symptoms are the most burdensome over time and their impact on health status and QoL. Although various

antecedents of symptom clusters are related to the cancer disease and treatment, it is important to note that physiological, psychological, or situational factors may be prerequisites to the presence of symptom clusters.⁴ Less is known about the personal factors that could interfere with the capacity to cope with a variety of burdensome symptoms that challenge a patient from the moment of a cancer diagnosis through the treatment and its aftermath.

According to Antonovsky,^{15,16} a personal factor is the sense of coherence (SOC), conceptualized as a global orientation that views the world and one’s life as comprehensible, manageable, and meaningful. Individuals with a strong SOC are able to mobilize their resources to cope, and explains why some individuals cope successfully and maintain psychological health in spite of stressors and others do not. Hence, there is a significant need to gain insight into a symptom burden cluster, its stability over time and impact on health status and QoL, and the relationship between coping capacity and symptom burden cluster. Such insights may provide new strategies for symptom management in clinical oncology. The purpose of this prospective and longitudinal study was to explore clusters of burdensome symptoms over time, their impact on health status and QoL over time, and coping capacity in women with breast cancer.

Methods

Settings and Sample

In this study, data were extracted from a larger descriptive longitudinal project involving studies on postmenopausal women with primary or recurrent breast cancer, with the aim of capturing the symptom experience of these patients. Patients were consecutively recruited from two surgical and two oncology

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