

ABSTRACT

Symptom Clusters: Impediments and Suggestions for Solutions

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The human experience of cancer is marked by the occurrence of multiple symptoms that influence one's ability to continue usual activities and enjoy life. Although the symptom experience is complex and multifaceted, knowledge of it has been limited by a paradigm that has been singular in scope, even when multiple symptoms have been studied. This approach, focused on one symptom at a time, holds true not only for descriptive and intervention research, but also for studies and published treatise on the barriers to management of specific symptoms. Thus, published research related to impediments to the management of symptom clusters is scant. This presentation considers the impediments that exist from two views: the first is from the broader view of impediments to palliative care; the second is from the view of impediments that exist due to the gaps in the current research related to symptom clusters.

The goal of palliative care is to provide comprehensive symptom management and psychological, educational, social, and spiritual support. Barriers to palliative care may be categorized into three main types: the patient/family, professional, and system barriers. Patient/family barriers include lack of awareness of services and possible benefits, societal views of death, views of potential users influenced by cultural and religious differences, and barriers to effective communication. For example, language barriers may lead to less optimal palliative care. Barriers related to health care providers include misconceptions and attitudes about how people perceive and behave in response to symptoms. In addition, many providers lack the skills and knowledge needed to manage multiple symptoms. Palliative care is only

minimally incorporated into the education of health care professionals. Many problems in the current health care system also impede management of symptom clusters. Palliative care is not well integrated into service delivery, and a systematic approach to assessment of multiple symptoms is lacking. The majority of cancer patients are not referred for palliative care services until they are close to death, limiting the time that symptom management can help. There are economic issues related to reimbursement for palliative care and certain drugs necessary to achieve that care. Health care system issues such as turf battles, lack of care coordination, and ineffective teamwork impede effective palliative care. Regulatory barriers persist, including a variety of laws and policies containing provisions that have the potential to discourage the use of opioid analgesics for the relief of pain. At the level of communities and countries, the issue of infrastructure and lack of resources to access quality care can also become a barrier. One additional notion crosses these categories. Patients and their families, professionals, and organizational systems may attach a higher relative value to one symptom over another. For example, how would an emergency room nurse or even a primary care provider respond if a patient's chief complaint was severe fatigue versus unrelied pain?

The second view considers the lack of science to guide our management of symptom clusters. This is the greatest impediment. At the substantive level, the published research on symptom clusters is descriptive and limited. There is significant published data on individual and multiple symptoms, but the symptoms were never conceptualized in a clustered fashion, making meta-analysis based on published reports impossible. No research on interventions targeting the symptom cluster of pain, fatigue, and depression nor on the barriers to this cluster exists.

The gaps in the science may be categorized into three levels: conceptual, methodological, and analytical. At the conceptual level, there is no agreed-upon definition or name for this symptom cluster. Are there symptom "pairs" and "clusters"? Is one symptom more dominant or important than another? Is there more than one type of cluster depending on which symptom predominates? For

example, is there a fatigue syndrome (that is associated with pain and depression) or a pain syndrome (that causes fatigue and depression) or both? What about other symptoms such as insomnia or anxiety? A clear understanding of how these symptoms "occur together" is lacking. In addition, new terms are emerging in the literature that are not clearly defined. What is the meaning of symptom burden, sentinel symptom, or worst symptom severity? Is there a need for a new language and taxonomy? The second level of knowledge gaps is methodological. What is the optimal way to measure a symptom cluster? Is it better to use multiple instruments or to use a consistent approach? What dimensions of the symptom experience should be used consistently to measure symptom clusters? There is no standard as to what "cutoff" score indicates that a symptom, symptom pair, or symptom cluster is present. In addition, research in the cancer population experiencing multiple symptoms is hindered by multiple methodological constraints: ill and weak patients, attrition, lack of adherence to time for reporting symptoms, and the need for help in completing the measures. Nonparticipants may be older and sicker, leading to an underestimation of the problem. The third and final gap is analytical. How is this symptom cluster analyzed? The application of multivariate approaches, including logistic regression, cluster analysis, mediation models, and innovative approaches, to both existing and new data sets can lead to analytic models that can be applied to understanding this complex human experience.

It will be impossible to advance the science without first addressing these gaps. However, in order to make a difference in improving the suffering from the symptom experience, there is a need

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to develop a scientific basis to support the management of the symptom cluster of pain, fatigue, and depression (and sleep). We need to include a diversity of populations, particularly those groups who are vulnerable and where disparities exist. Knowledge related to this symptom cluster in children, the elderly, the poor, and culturally diverse populations is minimal. Addressing these gaps can serve to direct future research.

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