Available online at www.sciencedirect.com
ScienceDirect
Nurs Outlook 63 (2015) 154–161
Nursing Outlook
www.nursingoutlook.org

Chronic disease self-management: A hybrid concept analysis

Wendy R. Miller, PhD, RN, CCRN[a,*], Sue Lasiter, PhD, RN[a], Rebecca Bartlett Ellis, PhD, RN[a], Janice M. Buelow, PhD, RN, FAAN[b]

[a] Indiana University School of Nursing, Bloomington, IN
[b] Epilepsy Foundation of America, Landover, MD

ARTICLE INFO

Article history:
Received 8 February 2014
Revised 14 May 2014
Accepted 21 July 2014
Available online 12 August 2014

Keywords:
Chronic disease
Concept analysis
Self-management

ABSTRACT

Background: Chronic diseases require chronic disease self-management (CDSM). Existing CDSM interventions, while improving outcomes, often do not lead to long-lasting effects. To render existing and new CDSM interventions more effective, an exploration of the concept of CDSM from both the literature and patient perspectives is needed. The purpose of this study was to describe the current conceptualization of CDSM in the literature, identify potential inadequacies in this conceptualization based on a comparison of literature- and patient-based CDSM descriptions, and to offer a more comprehensive definition of CDSM.

Methods: A hybrid concept analysis was completed.

Discussion: In the literature, CDSM is defined as behaviors influenced by individual characteristics. Patients in the fieldwork phase discussed aspects of CDSM not well represented in the literature.

Conclusions: CDSM is a complex process involving behaviors at multiple levels of a person's environment. Pilot work to develop and test CDSM interventions based on both individual and external characteristics is needed.

Cite this article: Miller, W. R., Lasiter, S., Bartlett Ellis, R., & Buelow, J. M. (2015, APRIL). Chronic disease self-management: A hybrid concept analysis. Nursing Outlook, 63(2), 154-161. http://dx.doi.org/10.1016/j.outlook.2014.07.005.

Introduction

Chronic disease is the central health care problem in the United States and beyond. Nearly one of two Americans suffers from at least one chronic disease, and chronic diseases contribute to the majority of U.S. health care costs. Furthermore, chronic diseases are responsible for downturns in quality of life (QOL) and are the leading cause of disability and death in the United States (Centers for Disease Control and Prevention, 2013).

Chronic diseases often require extensive lifestyle changes and consistent attention from both the person who has the disease and the care provider. Typically incurable and characterized by exacerbations and remissions, chronic diseases must be managed throughout a lifetime. Together, health care providers, patients, and families are charged with managing the day-to-day treatments, symptoms, and lifestyle modifications associated with chronic diseases, which impact all aspects of one's life, making the management of the disease complex. When patients and

Supported by National Institutes of Health F31NR012114 and KL2TR000163.
* *Corresponding author:* Wendy R. Miller, Indiana University School of Nursing, 1033 East Third Street, Bloomington, IN 47405.
E-mail address: wrtruebl@iu.edu (W.R. Miller).

http://dx.doi.org/10.1016/j.outlook.2014.07.005

families manage the complexity of disease characteristics and symptoms and restructure an acceptable lifestyle, patients and their families greatly contribute to better outcomes (Unger & Buelow, 2009).

Because of the ubiquity of chronic diseases and the costs associated with them, there has been a clear need for the development of interventions targeting chronic disease self-management (CDSM); many such interventions exist (Barlow, Sturt, & Hearnshaw, 2002) and are structured to prepare patients to manage diseases to improve outcomes. Although outcomes such as health status, QOL, and adherence have been improved by CDSM interventions based on behavior change theories, these changes are often short-lived. Although some interventions have shown effects on outcomes up to 4 years postintervention (Lorig, Mazonson, & Holman, 1993), these effects are generally smaller than at 6 months to 1 year postintervention (Barlow et al., 2008), and have been found to disappear after 5 years (Caplin & Creer, 2001). Clearly, for persons with chronic diseases that last a lifetime, achieving desired effects for only 4 years is insufficient.

Researchers must discover ways in which to achieve more comprehensive and longer-lasting effects of CDSM by building on existing interventions. Before such interventions can be devised, a more comprehensive conceptualization of CDSM is needed. Although prior research has shown that individual characteristics affect important outcomes and are amenable to intervention, because of fading effects of these interventions, other aspects important to CDSM may be missed. The purpose of this article was to describe the current conceptualization of CDSM in the literature, to identify potential inadequacies in the current conceptualization of the concept, and to offer a more comprehensive definition of CDSM. This definition will be derived via a hybrid concept analysis of CDSM. A hybrid concept analysis allows for the inclusion of actual patient experiences in defining a concept; thus, this method allows for a more patient-centered definition.

Background

As pointed out by Lorig (2003), CDSM has been conceptualized in a variety of ways over the past 4 decades. However, in nursing literature, CDSM has been represented primarily as a verb and refers to the behaviors that persons use to manage the disease and its associated effects (i.e., what people do constitutes their self-management; Lorig, 2003). These actions may be in the form of direct, observable behaviors; cognitive strategies; or decisions (Lorig, 2003). Similarly, Unger and Buelow (2009) found that the way in which CDSM has been conceptualized in nursing and medical literature can best be described as actions persons with chronic disease take concerning medication and treatment compliance, safety, event management, and lifestyle management.

Researchers have conducted investigations to specify and further explicate the self-management behaviors used by those with chronic diseases. For example, Corbin and Strauss (1988) found that CDSM behaviors occur within three realms: medical management, adopting new behaviors or life roles, and dealing with associated emotions. Later, based on 25 years of research with persons self-managing chronic diseases, Lorig et al. (2001) identified five core self-management behaviors that occur as features of the self-management of most chronic diseases: problem solving, decision making, resource utilization, forming of a relationship with a provider, and taking action. These five core behaviors are executed in the three realms outlined by Corbin and Strauss (1988). Lorig (2003) also noted that an additional core behavior of self-management is self-tailoring, which refers to persons with chronic disease using the aforementioned core behaviors based on personal evaluation of their own needs and not necessarily their health care providers' evaluation of their needs.

Self-management is also neither an end point nor an outcome but rather a process that affects and leads to outcomes (Holman & Lorig, 2004; Osborne, Wilson, Lorig, & McColl, 2007; Ryan & Sawin, 2009). However, as articulated by Clark (2003), changing self-management behaviors is useless if those behaviors do not improve outcomes such as QOL or perceived or actual health status. Although self-management affects important outcomes, self-management is not an outcome (Ryan & Sawin, 2009) in and of itself. Self-management, then, is a portion of the means to an end but not the end.

Internal, individual characteristics such as knowledge (Clark, 2003; Ryan & Sawin, 2009), self-efficacy (Lorig et al., 2001; Marks, Allegrante, & Lorig, 2005a, 2005b), and self-regulation (Clark, 2003; Ryan & Sawin, 2009) have been shown to affect CDSM. Thus, investigators have developed interventions aimed at altering these characteristics and, in so doing, alter CDSM outcomes. Some of these interventions have successfully improved CDSM outcomes, the most notable of which is Lorig et al. (2001) Chronic Disease Self-Management Program, which is based on social-cognitive theory (Bandura, 1986). In one study, this intervention was delivered to over 900 persons with arthritis, diabetes, chronic lung disease, and stroke. As part of the intervention, participants learned about cognitive symptom management, exercise program adoption, fatigue and sleep management, medication and community resource utilization, emotions (fear, anger, and depression) management, problem solving, and decision making; they also received training in how to effectively communicate with health care providers (Lorig et al., 2001). At 2 years postintervention, significant and desirable changes were noted in health care resource utilization (frequency of emergency room visits), health status (in the form of health distress), and experiences of symptom fatigue. Perceived functional disability was improved at 1 year,