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Processes of Self-Management in Chronic Illness

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Abstract

Purpose—Self-management is a dynamic process in which individuals actively manage a chronic illness. Self-management models are limited in their specification of the processes of self-management. The purpose of this article is to delineate processes of self-management in order to help direct interventions and improve health outcomes for individuals with a chronic illness.

Design—Qualitative metasynthesis techniques were used to analyze 101 studies published between January 2000 and April 2011 that described processes of self-management in chronic illness.

Methods—Self-management processes were extracted from each article and were coded. Similar codes were clustered into categories. The analysis continued until a final categorization was reached.

Findings—Three categories of self-management processes were identified: focusing on illness needs; activating resources; and living with a chronic illness. Tasks and skills were delineated for each category.

Conclusions—This metasynthesis expands on current descriptions of self-management processes by specifying a more complete spectrum of self-management processes.

Clinical Relevance—Healthcare providers can best facilitate self-management by coordinating self-management activities, by recognizing that different self-management processes vary in

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importance to patients over time, and by having ongoing communication with patients and providers to create appropriate self-management plans.

Keywords

Self-management; processes; chronic illness; metasynthesis; qualitative

Chronic illnesses, such as cardiovascular disease, cancer, and diabetes, are among the most prevalent and costly of all global health problems (World Health Organization, 2011). They are the primary reason adults seek health care and are the leading cause of death and disability in the United States (U.S. Centers for Disease Control and Prevention, 2011). Chronic illnesses are long term, uncertain, and can be very intrusive to individuals' everyday lives (Larsen, 2009). Often, chronic illnesses have a course that varies over time specific to the etiology and physiology of the particular illness. However, there are common challenges across chronic illnesses, which include recognizing symptoms and taking appropriate actions, using medications effectively, managing complex regimens, developing strategies to deal with the psychological consequences of the illness, and interacting with the healthcare system over time (Wagner et al., 2001; U.K. Department of Health, 2003). Chronic illness management has been recognized as an important component of health care, and there is increasing awareness that similar strategies can be effective across different types of chronic illnesses (Dowrick, Dixon-Woods, Holman, & Weinman, 2005; Harvey et al., 2008; Swendeman, Ingram, Rotheram-Borus, 2009).

Self-Management

Self-Management of Chronic Illness

Self-management is a dynamic, interactive, and daily process in which individuals engage to manage a chronic illness (Lorig & Holman, 2003). Self-management refers to “the ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions” (Richard & Shea, 2011, p. 261). Optimal self-management entails the ability to monitor the illness and to develop and use cognitive, behavioral, and emotional strategies to maintain a satisfactory quality of life (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Self-management has been distinguished from self-care, which more broadly delineates the healthy lifestyle behaviors undertaken by individuals for optimal growth and development, or the preventive strategies performed to promote or to maintain health (Richard & Shea, 2011; Riegel & Dickson, 2008).

Emerging Definition of Self-Management Processes

While several self-management frameworks have enhanced the understanding of self-management of chronic illness (Corbin & Strauss, 1988; Dunbar, Clark, Quinn, Gary, & Kaslow, 2008; Grey, Knafl, & McCorkle, 2006; Lorig & Holman, 2003; Ryan & Sawin, 2009), the specific processes or mechanisms of self-management have not been adequately defined, particularly from the perspective of individuals living with chronic illness. Corbin and Strauss (1988) first identified the processes of self-management by specifying the work of living with a chronic illness. They articulated three tasks of self-management: medical management, such as taking medications and attending medical appointments; behavioral management, such as adapting lifestyle or life roles; and emotional management, including processing emotions that arise from having a chronic illness. Lorig and Holman (2003) proposed several processes of self-management, including problem solving, decision making, utilizing resources, partnering with healthcare providers, taking action, and

improving self-efficacy. While these self-management tasks and processes are relevant across chronic illness, they are broadly stated.

Grey et al. (2006) depicted self and family management processes as being influenced by risk and protective factors and as contributing to outcomes, but did not specify these processes. Most recently, Ryan and Sawin (2009) described the self-management processes of enhancing knowledge and beliefs (i.e., self-efficacy, outcome expectancy, goal congruence), regulation of skills and abilities (i.e., goal-setting, self-monitoring, reflective thinking, decision making, planning and action, self-evaluation, emotional control), and social facilitation (i.e., influence, support, collaboration). These processes of self-management have greater specificity than previous conceptualizations; however, they do not address the emotional or existential challenges of living with a chronic illness. Other conceptualizations of adaptation to chronic illness and qualitative research on living with a chronic illness have highlighted the importance of emotional and existential processes, such as reconciling emotions and deriving meaning from the illness experience (deRidder, Geenen, Kuijer, & van Middendorp, 2008; Samson & Siam, 2008; Whittemore, Chase, Mandle, & Roy, 2002).

In sum, frameworks describing self-management have evolved to begin to capture important processes of self-management, but there has not been a comprehensive exploration of this experience from the perspective of individuals living with a chronic illness. Qualitative researchers have described the experience of living with a chronic illness and have identified self-management processes. Specification of the processes of self-management may guide intervention development, assure clinical assessment, and ultimately improve health outcomes. The purpose of this article is to delineate the processes of self-management by conducting a metasynthesis of the qualitative research on self-management in chronic illness.

Methods

Literature Review

This qualitative metasynthesis (Sandelowski & Barroso, 2003) began with a literature review to locate articles that used qualitative methodology to describe self-management processes from the perspective of individuals living with a chronic illness. Although quantitative research could include some description of self-management processes, the intent was to detail the processes of self-management rather than to examine correlations between processes and outcomes. The Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, PubMed, MEDLINE, and Academic Search Complete databases were searched using the terms “self-management” or “self-care” or “chronic illness” and “qualitative” and “process” or “task” or “strategy” or “strategies” between February and April 2011.

Inclusion/Exclusion Criteria

Included articles were those that discussed the processes of self-management in adults with chronic illness that were written in English and published between January 2000 and April 2011. Qualitative results of mixed methods studies were included when qualitative data were discernible from quantitative data. Excluded were studies that solely focused on mental illness; studies on substance abuse; studies that combined individuals with chronic illness along with children, caregivers, or healthcare providers in the same sample; as well as studies on individuals with disabilities who did not have a chronic illness, due to the potentially different self-management experiences among these populations. Also excluded

were metasyntheses, literature reviews, theory-based works, secondary analyses of data from pooled studies, evaluations of self-management interventions, and dissertations.

Article Review and Data Analysis

A review form was used to facilitate extraction of key information from each article, such as study design and sample characteristics. Three of the authors who were trained in qualitative research methods (R.W., S.J., D.S-G) independently extracted the processes of self-management from each article as a list, using the exact wording of the authors to create a descriptive phrase, or code, for each process (e.g., “managing medications”). Any theme, subtheme, participant quote, or phrase in an article that described a process of self-management was coded. A data display matrix was created to categorize extracted information and to guide comparison among articles (Miles & Huberman, 1994). Each article was assessed for quality based on various criteria, including appropriateness of study design and data saturation. Studies of any quality were included per qualitative metasynthesis methods, which recommend general, versus overly specific, quality criteria and inclusion of studies that offer important findings despite being methodologically imperfect (Sandelowski, Docherty, & Emden, 1997).

After 10 articles had been reviewed, the three coders met to discuss a coding scheme for the self-management processes. Initially, four broad categories of self-management processes were identified: medical or behavioral, role or identity, emotional, and other. These were then collapsed to medical/behavioral, emotional, and cognitive categories. These categories were added to the data display matrix to enable comparing and contrasting of each article across each category. Once all articles were reviewed and coded, codes were collapsed and clustered into categories according to similarity of meaning (Miles & Huberman, 1994) to further define sub-themes (i.e., tasks and skills) of the processes of self-management. In this categorization, codes that denoted self-management skills were placed where they seemed to fit best per the coding system; however, certain skills could fit into more than one category. The most appropriate fit for a particular skill may be regarded differently depending on the professional lens, patient population, or chronic illness. An iterative and consensual process of analysis and review continued, with periodic peer review from noncoding authors, until the final categories of self-management processes were produced. The data display matrix containing all reviewed articles is available at http://nursing.yale.edu/qualitative.studies.self.management.

Findings

Sample Description

A total of 253 articles were identified during the literature review. Of these, 152 did not meet study inclusion criteria, most often due to including youth or caregivers, conditions that were not a chronic illness (e.g., disabilities), or because they were review articles. Therefore, the sample for this metasynthesis was 101 articles.

Several qualitative methods were represented in the sample, including qualitative description (n = 20), phenomenology (n = 12), grounded theory (n = 11), content analyses (n = 10), interpretive description (n = 5), narrative analysis (n = 5), thematic analysis (n = 3), participatory action research (n = 3), focus group (n = 5), ethnography (n = 2), and other (n = 25). The papers included studies on 49 different chronic illnesses with the three most common being types 1 and 2 diabetes (n = 34), cancer (all types, n = 16), and cardiovascular disease (n = 13). Samples, which ranged in size from 4 to 282 (median = 20), represented 19 different countries and included men and women of diverse races and ethnicities who were 18 to 93 years of age.

Final Conceptualization of Self-Management Processes

Three categories of self-management processes were identified: focusing on illness needs, activating resources, and living with a chronic illness (Table 1). Within each of these processes, tasks and skills were delineated. These terms are used interchangeably in the literature. Samson and Siam (2008) defined tasks as the essential work of self-management, while skills describe the ways an individual accomplishes tasks. This work adopted that conceptualization: both tasks and skills were viewed as behaviors, but skills were conceived as specific ways or abilities needed to complete tasks. Processes underlie tasks and skills. Each category is discussed in more detail below.

Focusing on Illness Needs

Focusing on illness needs represents the self-management tasks and skills necessary for individuals to take care of their bodies and illness-specific concerns of a chronic illness (e.g., using a bronchodilator for chronic obstructive pulmonary disease). As part of this process, individuals learn about the chronic illness, take ownership of their health needs, and perform health promotion activities. Tasks and skills of learning about self-management include acquiring information about the illness and learning requisite regimens, skills, and strategies, in order to manage daily illness needs. Taking ownership of health needs involves the tasks and skills of learning about and managing body responses, completing health tasks (e.g., keeping appointments), and becoming an expert. Performing health promotion activities includes changing or maintaining health behaviors to minimize the impact of the illness and sustaining health promotion activities. The process of Focusing on Illness Needs can be performed solely by the individual or by the individual in conjunction with family members and healthcare providers depending on the individual's needs, values, resources, and other situational variables. The time and attention an individual pays to illness needs can also vary depending on the illness trajectory as well as the individual's life context.

Activating Resources

Resources that are integral to optimum self-management include individuals (e.g., family members, friends, healthcare providers) and community resources and services (e.g., spiritual resources, social and transportation services). Such community resources assist individuals to manage various aspects of their illness, including medical, psychosocial, spiritual, and financial facets. Self-management tasks and skills related to activating resources include communicating with healthcare providers, coordinating services, identifying and benefiting from psychological resources, being part of a spiritual community, obtaining and managing social support, and addressing social or environmental challenges.

Activation of resources may vary in intensity and complexity depending on the illness and the role that the individual can assume in managing the illness. Although self-management is an interactive process, individuals vary in their ability and willingness to take a role, or to let others take a role, in management of their illness. For example, older adults with chronic illness often do not want their children to be burdened with the responsibilities of caring for them (Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004). The specific resources that individuals choose to activate is a personal process that can vary over time as they create a structure of resources, as they optimize their self-management skills, and as their illness and subsequent needs change.

Living With a Chronic Illness

Living with a chronic illness is a self-management process that includes tasks and skills related to coping with the illness and growing as a person, as well as to transitioning from a

focus on the illness needs to integrating the illness into the context of the individual's life. Four tasks were identified: processing emotions, adjusting, integrating illness into daily life, and meaning-making.

To improve psychological outcomes, addressing emotions is an important aspect of self-management. Emotional processing includes exploring and expressing various emotions, as well as grieving in response to a loss of health or functioning. Adjusting to a chronic illness refers to regulatory tasks and skills related to coming to terms with a changed life and a changed self as a result of the illness. Integrating the illness into daily life includes the tasks and skills of modifying one's lifestyle and seeking normalcy in life through balancing the pursuit of meaningful activities with appropriate attention to illness needs. Meaning-making refers to the individual's efforts to determine the meaning of the illness in one's life, and describes the tasks and skills of reevaluating life, personal growth, and striving for personal satisfaction. It is possible that there is a temporal aspect to these processes where emotional processing must to some extent precede adjusting, which must in turn precede meaning-making; however, these processes likely overlap and interact with each other.

Factors Affecting Self-Management

Common factors that can affect self-management were identified. These included demographic factors such as socioeconomic status and culture, clinical factors such as comorbidities and complexity of the treatment regimen, and system factors such as quality of relationships and communication with providers. For example, in a number of studies, African Americans reported high use of spiritual resources (Harvey, 2006; Popoola, 2005), and individuals with comorbid illnesses reported difficulty prioritizing illness needs (Elliot, Ross-Degnan, Adams, Safran, & Soumerai, 2007). These factors influenced individuals' ability and motivation to self-manage, as well as the quality of their self-management experiences, that is, how challenging or smoothly self-management proceeded. Further examination of factors affecting self-management is indicated.

Discussion

The results of this metasynthesis provide a more complete spectrum of self-management processes from the perspective of adults living with a chronic illness than has been previously described in the literature. The processes of focusing on illness needs, activating resources, and living with a chronic illness, similar to Corbin and Strauss' (1988) “illness work,” “everyday work,” and “autobiographical work,” encompass physical, psychological, social, spiritual, existential, and system-related processes, reflecting a more holistic picture of self-management and addressing conceptual gaps in current self-management models.

While the processes of self-management are described as discrete tasks and skills in this analysis, the actual experience of self-management is ongoing and dynamic, with overlapping processes, tasks, and skills (Barlow et al., 2002; McCorkle et al., 2011). For example, an individual living with rheumatoid arthritis who is attempting to reorganize everyday life to accommodate pain and affected functioning (identified as part of living with a chronic illness) may simultaneously have to prioritize work and family activities to ensure adequate daily rest (identified as part of focusing on illness needs). The intent of the conceptualization of self-management processes resulting from this review is to begin to articulate the complexity and variability that encompass the self-management experience. Quantitative research is needed to identify associative and temporal relationships between processes, tasks, and skills, as well as outcomes.

In addition, the processes of self-management do not appear to be linear. An individual does not necessarily progress from a focus on illness needs, to activating resources, to

successfully living with a chronic illness. For example, a new diagnosis of a chronic illness may require an initial focus on illness needs for one individual, while another may need to explore and express emotions before focusing on illness needs. Thus, there is considerable individual variation in how or when processes of self-management are prioritized and undertaken (Livneh & Antonak, 1997). Further, the skills identified in this conceptualization describe proficient self-management; however, individuals do not necessarily self-manage optimally and vary in their ability to develop effective coping strategies.

The overall experience of living with a chronic illness changes over time, which can impact an individual's self-management. The trajectory of the illness as well as the development of complications or comorbidities can significantly alter well-established self-management routines and overall adjustment. For example, an individual with type 2 diabetes who requires insulin injections to optimize metabolic control after years of taking oral medications may not only have to refocus on illness needs to learn appropriate skills, but may also need to consider emotional responses to a difficult skill and progressed illness.

An individual's life context is likewise dynamic and can influence established self-management routines. Living with a chronic illness has been described as a continually shifting process in which individuals experience a complex interaction between their illness and their life context (Paterson, 2001). Change in individual or family health, as well as change in psychological, social, spiritual, and financial status, can significantly impact self-management needs, expectations, and routines. Ongoing access to self-management support and the development of self-management expertise also influence the ability to carry out self-management processes.

Limitations

This qualitative metasynthesis captured self-management processes across a wide range of individual characteristics and chronic conditions. In seeking the range of self-management experiences, this metasynthesis captured the breadth of self-management processes more so than the depth. For example, differences in self-management processes by diagnosis or by sociode mographic characteristics were not identified. While a limitation, the breadth of this metasynthesis is also a potential strength. These findings enable researchers and healthcare providers to look at self-management processes in a way that transcends particular chronic illnesses and allows for consideration of comorbidities across various patient populations.

Since some self-management processes are more common or are of greater import with certain health conditions (e.g., monitoring diet is more standard in self-management of inflammatory bowel disease than it is in asthma), researchers and healthcare providers should be attuned to the self-management processes most salient to their patient populations. Future research is needed to examine how and when individuals engage in self-management processes, and to identify similarities and differences in self-management processes across chronic illnesses and illness trajectories, and among individuals with multiple chronic illnesses. Analyses of quantitative studies would add to the descriptive data on self-management processes and to the information about outcomes of self-management.

Clinical Relevance

This metasynthesis of self-management processes has implications for how healthcare providers may work with patients, their family members, and other providers during assessment, intervention, and follow-up of chronic illness. Of import is recognition of the array of clinical resources available to support patients' self-management. In addition to nurses and physicians supporting patients' self-management of their illness needs, other providers, such as social workers, psychologists, psychiatrists, chaplains, nutritionists,

naturopaths, and physical therapists, should be involved in self-management related to activating resources and living with a chronic illness. Tailoring various clinical resources to individuals' needs can facilitate whole person care.

As noted, self-management processes will vary in importance to patients according to the trajectory of their chronic illness and related concerns. Because self-management processes overlap and affect each other, each self-management process must be regarded in the context of the whole. Thus, although different types of health-care providers may focus on different tasks and skills of self-management, providers need to be aware of the other self-management tasks and skills in which the patient is engaged, as well as how self-management activities may affect each other. For example, a patient who has recently completed chemotherapy may discuss scheduling daily rest time with the oncologist while making plans to return to full-time employment with the social worker. These are not mutually exclusive self-management activities but must be planned in relation to each other. Therefore, throughout assessment, intervention, and follow-up, it is important for healthcare providers to have ongoing communication with patients and other providers to explore patients' self-management preferences and how they may change over time.

Nurses and other healthcare providers that provide self-management support for adults may consider developing an assessment form based on the proposed tasks and skills. This form could be used in the clinical setting to identify strengths and limitations of current self-management efforts to prioritize care. The proposed tasks and skills might also form the basis of a patient-oriented guide to educate patients about various aspects of self-management and to help them monitor their self-management activities. Integration of tasks and skills into nursing curricula in chronic illness management would help nurses to recognize the range of self-management activities and to support patients' self-management.

Conclusions

As chronic illness management will continue to be an important component of health care, identification of self-management processes can help to guide future research and clinical practice that support self-management efforts.

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Clinical Resources

- Primary Care Resources and Supports for Chronic Disease Self-Management,http:// improveselfmanagement.org/pcrs̀background. aspx
- Stanford School of Medicine Chronic Disease Self- Management Program, http://patienteducation.stanford.edu/programs/cdsmp.html

Table 1

Self-Management Processes

Processes	Tasks	Skills
Focusing on illness needs		
Learning	Learning about condition and health needs	• Acquiring information • Learning regimen, skills, and strategies
Taking ownership of health needs	Recognizing and managing body responses	• Monitoring and managing symptoms, side effects, and body responses • Recognizing limits • Adjusting treatment regimen to manage symptoms and side effects
	Completing health tasks	• Keeping appointments • Managing/taking medications • Performing treatments and keeping up with changes in one's regimen
	Becoming an expert	• Goal setting • Decision making • Problem solving • Planning, prioritizing and pacing • Knowing if/when to take a break from one's regimen • Developing confidence and self-efficacy • Evaluating effectiveness of self-management
Performing health promotion activities	Changing behaviors to minimize disease impact	• Modifying diet, nutrition, smoking, and physical activity • Reducing stress • Taking action to prevent complications
	Sustaining health promotion activities	• Keeping up with screenings, immunizations, and lifestyle modifications • Using complementary therapy
Activating resources		
Healthcare resources	Creating and maintaining relationships with healthcare providers	• Finding the right provider(s) • Communicating effectively • Making decisions collaboratively
	Navigating the healthcare system	• Coordinating services/appointments, insurance • Using resources effectively • Creating and revisiting advance care plans
Psychological resources	Identifying and benefiting from psychological resources	• Drawing on intrinsic resources, e.g., creativity • Drawing strength and wisdom from past experiences • Cultivating courage, discipline, and motivation • Maintaining positive outlook and hope • Maintaining self-worth

Processes	Tasks	Skills
		• Advocating for self
Spiritual resources	Sustaining spiritual self	• Acknowledging a higher power
		• Nurturing the spirit
		• Praying
		• Being part of a spiritual community
Social resources	Obtaining and managing social support	• Seeking support of family and friends
		• Being proactive to limit isolation
		• Creating a community of peers with similar experiences
		• Working through issues of dependence/independence
		• Assisting others to become partners in disease management (e.g., distributing tasks)
Community resources	Addressing social and environmental challenges	• Seeking resources, such as financial assistance (e.g., prescription subsidies), environmental support (e.g., assistive devices), and community resources (e.g., transportation)
Living with a chronic illness		
Processing emotions	Processing and sharing emotions	• Exploring and expressing emotional responses
		• Dealing with shock of diagnosis, self-blame, and guilt
		• Grieving
Adjusting	Adjusting to illness	• Making sense of illness
		• Identifying and confronting change and loss (e.g., changes in physical function, role, identity, body image, control, and mortality)
		• Managing uncertainty
		• Developing coping strategies (e.g., self-talk)
		• Dealing with discouraging setbacks
		• Focusing on possibilities (e.g., envisioning the future, reframing adversity into opportunity)
		• Accepting the “new normal”
	Adjusting to “new” self	• Clarifying and re-establishing roles
		• Examining health beliefs
		• Making social comparisons
		• Choosing when and to whom to disclose illness
		• Dealing with stigma
Integrating illness into daily life	Modifying lifestyle to adapt to disease	• Reorganizing everyday life
		• Obtaining assistance with activities of daily living
		• Creating a consistent health routine
		• Controlling environment
		• Being flexible
	Seeking normalcy in life	• Carrying out normal tasks and responsibilities as much as possible

Processes	Tasks	Skills
		• Managing disruptions in school, work, family, and social activities
		• Balancing living life with health needs
		• Finding new enjoyable activities
Meaning making	Reevaluating life	• Reflecting on/rearranging priorities and values
		• Reframing expectations of life and self
		• Coming to terms with terminal condition and end of life
	Personal growth	• Learning personal strengths and limitations
		• Becoming empowered
		• Being altruistic
	Striving for personal satisfaction	• Finding meaning in work, relationships, activities, and spirituality
		• Creating a sense of purpose
		• Appreciating life