



A revised Self- and Family Management Framework

Margaret Grey, DrPH, RN, FAAN^{a,*}, Dena Schulman-Green, PhD^a,
Kathleen Knafl, PhD^b, Nancy R. Reynolds, PhD, FAAN^a

^a Yale University School of Nursing, West Haven, CT

^b University of North Carolina at Chapel Hill, Chapel Hill, NC

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ABSTRACT

Background: Research on self- and family management of chronic conditions has advanced over the past 6 years, but the use of simple frameworks has hampered the understanding of the complexities involved.

Purpose: We sought to update our previously published model with new empirical, synthetic, and theoretical work.

Methods: We used synthesis of previous studies to update the framework.

Discussion: We propose a revised framework that clarifies facilitators and barriers, processes, proximal outcomes, and distal outcomes of self- and family management and their relationships.

Conclusions: We offer the revised framework as a model that can be used in studies aimed at advancing self- and family management science. The use of the framework to guide studies would allow for the design of studies that can address more clearly how self-management interventions work and under what conditions.

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The impact of chronic conditions is substantial (Rijken, van Kerkhof, Dekker, & Schellevis, 2005; Ward & Schiller, 2013). In the United States, 70% of deaths annually are attributable to chronic conditions (Devol, 2007). Nearly one half of the U.S. population, over 133 million people, suffer from a chronic condition, and more than one in four Americans have multiple chronic conditions (Murray & Lopez, 2013). The number of chronic conditions an individual has is directly related to risks of adverse outcomes including mortality, poor functional status, unnecessary hospitalizations, adverse drug events, pervasive symptoms, duplicative tests, and conflicting medical advice. Furthermore, some combinations of chronic conditions, or clusters, have synergistic interactions (Parekh, Goodman, Gordon, Koh, & HHS Intra-agency Workgroup on Multiple Chronic

Conditions, 2011). For example, taking multiple medications for different conditions may magnify symptoms such as fatigue. Chronic conditions are responsible for 80% of all medical expenses in the United States, with those with the most complex and extensive conditions accounting for the greater part of these costs (Agency for Healthcare Research and Quality, 2006). Treating people with multiple chronic conditions costs up to seven times as much as treating those who have only one. With the alarming rise in obesity in the world population and the number of those over the age of 60 expected to grow to almost two billion by 2050, the prevalence of chronic conditions will intensify along with the economic cost; it is currently estimated to account for 46% of the global disease burden (Mitchell, Catenacci, Wyatt, & Hill, 2011).

* Corresponding author: Margaret Grey, Yale University School of Nursing, 400 West Campus Drive, Orange, CT 06477.

E-mail address: Margaret.grey@yale.edu (M. Grey).

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It is increasingly recognized that self- and family management of chronic conditions are essential aspects of today's health care (Newman, Steed, & Mulligan, 2009). Self-management has been defined in several ways in the literature, but it is usually defined as a dynamic, interactive, and daily process in which individuals engage to manage a chronic illness (Ruggiero et al., 1997). It also is defined as the ability of the individual, in conjunction with family, community, and health care professionals, to manage symptoms; treatments; lifestyle changes; and psychosocial, cultural, and spiritual consequences of health conditions (Richard & Shea, 2011). Corbin and Strauss (1991) were among the first to describe the work related to living with a chronic illness; they defined the work as illness-related work (e.g., managing symptoms or crisis prevention, often termed illness management), everyday life work (e.g., managing work or household tasks, often described as role management), and biographical work (e.g., managing emotions or identity). In a report from the Institute of Medicine (IOM), self-management was defined as including the tasks related to the management of medical or behavioral treatments, role management, and emotional management (Adams, Greiner, & Corrigan, 2004).

Condition management has been defined as a family process that entails the family's efforts to incorporate the treatment regimen and special needs of the person with the condition into everyday family life (Knafl, Deatrck, & Havill, 2012). In our previous article in which we presented the Self- and Family Management Framework, we linked self-management with family management because they are intimately linked and vary over the life cycle (Grey, Knafl, & McCorkle, 2006). Self-management occurs in the context of family management in nearly all cases, but the relative importance of each varies across developmental stages. For example, children are usually dependent on their families for the management of chronic conditions, and the process of transitioning over time to shared management in adolescence and independent management in adulthood is critical to successful self-management (Schilling, Knafl, & Grey, 2006). Furthermore, as people age, families may take on increasing importance in the management of chronic conditions (Levine, Halper, Peist, & Gould, 2009). Across the family life course, an important aspect of family management is the efforts family members make to incorporate condition management into usual family routines and everyday family life. Thus, we believe that self- and family management must be understood in tandem.

Self-management by those with chronic conditions and their families is paramount to ensuring the best possible outcomes. Thus, interventions that provide patients and their families with information and skills that enhance their ability to participate in their health care (e.g., communicate with health professionals, identify relevant information, manage symptoms, perform health behaviors, and adhere to multiple treatment requirements) are increasingly recognized,

not only as an essential component of the management of chronic conditions but also as part of secondary prevention and as a way of reducing the burden of chronic conditions on individuals, families, and communities. Accordingly, self- and family management of chronic conditions is receiving increased attention in health care reform. Supporting patient self-management is, for example, a key component of Wagner's Chronic Care Model (Wagner et al., 2001) and the patient-centered medical home (Parekh et al., 2011) and is one of the four goals in the U.S. Department of Health and Human Services' framework for addressing complex chronic conditions (Department of Health and Human Services, 2011). An IOM and National Research Council (2011) report also pointed to the importance of identifying family-level risk and protective factors that contribute to the health and well-being of family members.

Nursing plays a central role in addressing the challenges of chronic condition management as reflected in the recent recommendations by the IOM and the National Institute of Nursing Research (NINR; IOM, 2010; NINR, 2011). The enhancement of individuals' and families' capacities to prevent or manage chronic conditions is a core activity of nursing that is supported by a growing body of knowledge. Enhancing self- and family management to improve quality of life and health outcomes continues to be a scientific priority supported by the NINR (2011). As noted in the NINR Strategic Plan, "the science of self-management examines strategies to help individuals with chronic conditions, their families and caregivers better understand and manage their illness and enhance health behavior. This science area relates to assisting individuals and their families to live with their chronic illness by developing effective self-management approaches to improve quality of life and reduce the burden of illness" (NINR, 2011).

The Original Framework

Faculty at the Yale School of Nursing developed the Self- and Family Management Framework (Figure 1) from a synthesis of the foundational work of the faculty and others to organize and guide research to advance self- and family management science (Grey et al., 2006). Factors influencing self- and family management across chronic conditions as well as potential outcomes from enhanced management were articulated. Individual and family self-management were seen as interactive and influencing a variety of outcomes, including those directly related to the condition as well as those related to the individual and the family. Self- and family management may also influence how environmental resources such as the health care system and community support are accessed and used as well as the nature of interactions with health professionals.

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