A framework for the study of self- and family management of chronic conditions

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With an increasing emphasis on consumer responsibility for health, more research is needed to understand, develop, and test new interventions to enhance self- and family management toward better outcomes in people with chronic conditions. In the Center for Self-Management Interventions at the Yale School of Nursing, we have developed a framework to guide our research efforts. Based on the literature, the framework is intended to specify key aspects of self- and family management, therein providing direction for future research and further development and testing of a theory of self- and family management of illness. Both individuals and families participate in the management of chronic conditions. Risk and protective factors influence individuals' and families' abilities to manage chronic illness and, as such, may be the target of interventions in support of self- and family management. Certain outcomes may be associated with effective self- and family management. Interventions to enhance self-management can address risk and protective factors or focus on altering self- and family management behaviors with the goal of improving outcomes.

Each year, well over 1 million Americans die from chronic illnesses such as cancer, cardiovascular disease, and diabetes. Countless individuals and families must cope with serious chronic illnesses such as these. Those who are at risk for conditions such as obesity or teenage pregnancy, which have life-long consequences, are also a major public health concern. All of these conditions are responsible for tremendous health care expenditures as well as mortality and morbidity.

In recent years, changes in medical reimbursement and insurance coverage, including the widespread use of managed care, have moved more care to community and home settings. In addition, shifting demographics toward an aging American population, a nationwide increase in prevalence of chronic diseases, and increased concerns over sedentary and unhealthy lifestyles, have demanded that the approach to supportive interventions be re-examined. Primary, secondary, and tertiary prevention all require new modes of management by individuals and families to prevent, and in some cases adapt to, disease and disability. More focused examination must be undertaken to determine what interventions are effective for which populations and what outcomes are facilitated. Conceptual frameworks are needed to guide research aimed at developing theories of self- and family management and testing interventions to promote optimal health outcomes.

Several years ago, the National Institute of Nursing Research released an initiative to test interventions that “involve social support, provider-client interactional style, improved self-efficacy, problem-solving or coping skills, and certain follow-up activities” across chronic diseases. Building on that initiative and the base of ongoing research at the school that focuses on individual and family response to illness, the Yale School of Nursing established an NINR-funded Exploratory Center for Self Management Interventions for Populations At Risk, and subsequently, a Core Center with the same focus. The Center’s focus on research aimed at developing and testing interventions that support and enhance self- and family management of illness and risk for illness. In the absence of an established framework of self- and family management to guide the work of the Centers, the investigators turned to the literature to develop such a framework. In this article, we report the results of our efforts to synthesize the literature on the factors influencing self- and family management as well as potential outcomes from enhanced management. The article describes the framework and its use for providing direction for our
research centers and further theory development in self- 
and family illness management. 

We developed the initial framework in conjunction 
with writing our proposals for center funding by re-
viewing the literature on self- and family management, 
chronic conditions, and interventions. In a systematic 
manner using the search terms self-care, self-
management, family management, and chronic condi-
tions, we sought literature via databases (CINAHL, 
Medline) and hand search. We reviewed the literature 
and sought to organize all of the work under broad 
conceptual themes that could provide direction to our 
work in the future. In doing so, we attempted to bridge 
the gap across chronic conditions and self/family con-
ceptualizations. Our goal was to identify themes that cut 
across conditions and were germane to both individual 
and family response to chronic conditions. The addition 
of family management as a major concept enhances 
what is already known about self-management.5,6 Co-
sistent with Fawcett,7 we took the view that “a concep-
tual framework provides a certain frame of reference 
for members of the discipline, telling them what to look 
at and speculate about. Most importantly, a conceptual 
framework determines how the world is viewed and 
what aspects of the world are taken into account.” We 
anticipate that the framework will continue to be refined 
and elaborated based on the work of Center investiga-
tors as well as others. 

We were guided by several assumptions: (1) indi-
viduals perform self-management in the context of their 
families, communities and environment; (2) self- and 
family management of chronic conditions is a dynamic 
process; that is, it is modified by individual outcomes 
and the influence of risk and protective factors; (3) 
interventions are multi-faceted and can be directed to 
selected risk or protective factors or to the management 
behaviors themselves; (4) since self-management often 
takes place in a family context, it is important to 
develop knowledge that addresses how self-
management is manifested as both an individual and 
family construct; (5) it is important to situate self-
management in the context of other, related concepts 
and to advance theory development related to self-
management. 

**SELF- AND FAMILY MANAGEMENT 
OF CHRONIC CONDITIONS** 

Although self-management has been associated with 
certain chronic diseases (eg, diabetes) for some time, 
the concept of self-management and its practice is 
changing.8 Self-management has been defined as the 
“cluster of daily behaviors that individuals (and their 
families) perform to manage (a condition).”9 It is a 
dynamic means of maximizing health rather than the 
submission to prescribed orders implied by the term 
compliance.10 Schilling, Knafl and Grey11 noted that 
the concept of self-management, in contrast to the ideas 
of compliance and adherence, captures the complexity 
of living with a condition and suggests the need to 
manage the condition in the context of one’s everyday 
life. 

The literature contains a wide variety of studies that 
are germane to self- and family management of chronic 
conditions. Investigators have described actual manage-
ment behaviors as well as variables associated with 
different behaviors and outcomes. Considerable work 
has been done on the interplay of individual and family 
factors related to illness management and outcomes. 
The framework incorporates this diverse body of 
knowledge and reflects the influence of a number of 
condition, individual, family, and environmental factors 
on individual and family self-management. Table 1 lists 
these factors. 

Individual and family self-management are interact-
ive and influence a variety of health outcomes, includ-
ing those directly related to the condition as well as 
those related to the individual and the family (Table 2). 
Self- and family management may also influence how 
environmental resources—such as the health care sys-
tem and community supports—are accessed and uti-
лизed, as well as the nature of interactions with health 
care professionals. Interventions may target certain risk 
or protective factors, such as psychosocial factors or 
family functioning. Interventions can also be targeted to 
working with individuals or families to develop or 
 enhance their self-management capabilities. Depending 
on the situation, the intervention may be directed to the 
individual, to the family, or both. The complexity of 
self- and family management research is illustrated in 
Figure 1 in that several reasonable targets provide 
potential for altering outcomes. As such, our synthesis 
can contribute to the systematic development of knowl-
edge in this important area of science. 

**RISK AND PROTECTIVE FACTORS** 

**Condition factors** 

The need for self- and family management interven-
tions is affected by several risk and protective factors, 
as shown in Table 1. The severity of the condition, the 
treatment regimen, and its trajectory will all affect the 
need for self- and family management. Severity can be 
understood from the provider’s point of view, which is 
usually reflected by prognosis, or from a patient’s or 
family’s point of view, which may be considered as 
perceived burden.12 In addition to condition severity, 
there is growing evidence that the genetic basis of the 
condition also influences self- and family management. 
In the wake of the Human Genome Project, individuals 
and families are increasingly aware of the genetic basis 
of many conditions and the unique challenges they face 
when they or a member of their family has a genetic 
condition.13 

The treatment regimen may be relatively simple, as 
in hypothyroidism, where a single daily dose of thyroid
hormone is necessary, or it may be quite complex and involve lifestyle, pharmacologic, and other approaches. The treatment regimen for diabetes provides a good example of a complex regimen, involving multiple medications, self-monitoring, and significant lifestyle change. Families, as well as individuals, vary in their ability to incorporate the condition into their usual routine, therein decreasing the perceived burden of management. However, there is evidence that, over time, most families come to view themselves as skilled at managing the treatment regimen and are able to develop a management regimen that minimizes the disruptiveness of the illness to family life. Despite a considerable body of research on how families respond to chronic conditions, few studies have addressed the contribution of health care providers to family illness management.

Trajectory refers to the various stages experienced by people over the course of a condition. For individuals and families, this course represents the cumulative effects of the condition, including physical symptoms, and the impact of the illness on the social world. The first stage occurs before the onset of symptoms. As noted by Street and Soldan, even this stage can be stressful in families in which there is a known genetic condition for which other family members are at risk. When signs and symptoms appear, these can lead to a crisis in the individual and family. The onset of symptoms may lead to an acute phase, where active intervention is necessary to support management. When this intervention is effective, a stable phase may follow, during which varying degrees of intervention may be necessary to maintain health. Exacerbation of the condition may lead to an unstable phase, where interventions to promote coping and stability may be necessary. Ultimately, a downward phase may occur, to the point where the individual may be terminally ill (dying phase). The focus of intervention must be specific to the individual’s current trajectory stage, while simultaneously incorporating experiences the individual has had in other stages and has yet to experience in subsequent trajectory stages. For example, diabetes is

<table>
<thead>
<tr>
<th>Condition Factors</th>
<th>Relationship</th>
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<tbody>
<tr>
<td>Severity</td>
<td>Higher severity, higher self-management needs</td>
</tr>
<tr>
<td>Regimen</td>
<td>Higher complexity, higher self-management needs</td>
</tr>
<tr>
<td>Trajectory</td>
<td>Variable, depending on condition and stage</td>
</tr>
<tr>
<td>Genetics</td>
<td>Variable, depending on condition</td>
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</table>

<table>
<thead>
<tr>
<th>Individual Factors</th>
<th>Relationship</th>
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</thead>
<tbody>
<tr>
<td>Age</td>
<td>Variable, younger and older age, higher family</td>
</tr>
<tr>
<td></td>
<td>management needs</td>
</tr>
<tr>
<td>Gender</td>
<td>Variable, women may neglect self-management</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Psychosocial Characteristics</th>
<th>Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>Decreases self-management capability</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>Enhances self-management ability</td>
</tr>
<tr>
<td>Integration</td>
<td>Enhances self-management ability</td>
</tr>
<tr>
<td>Diversity</td>
<td>Variable, but largely unknown</td>
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</table>

<table>
<thead>
<tr>
<th>Family Factors</th>
<th>Relationship</th>
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</thead>
<tbody>
<tr>
<td>Socioeconomic status</td>
<td>Lower status associated with poorer self-management</td>
</tr>
<tr>
<td>Structure</td>
<td>Largely unknown</td>
</tr>
<tr>
<td>Function</td>
<td>Higher functioning, better self-management</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Environment</th>
<th>Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social networks</td>
<td>More supportive networks, better self-management.</td>
</tr>
<tr>
<td>Community</td>
<td>Variable</td>
</tr>
<tr>
<td>Health care system</td>
<td>Higher access, better self-management</td>
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Data from references 5, 12, 13, 21, 24, 29, 34, 38, 41, 46, 50, 51
a serious disease that requires a complex regimen of lifestyle alteration and pharmacologic treatment that will vary over the course of the disease. This complexity and interaction among severity, trajectory, and regimen is true in other conditions as well. Moreover, there is considerable variability across conditions with regard to the predictability of the illness course, and those conditions characterized by an uncertain trajectory impose greater psychosocial demands on the family.

Individual factors

Individual factors play a role in determining how individuals and families self-manage a chronic condition. Young children are completely dependent on their families for care of chronic illness, and this dependency changes over time. As children mature, they take on increasing responsibility for self-management, but they still require parental oversight and guidance into young adulthood. Through young and middle adulthood, self-management is more prominent, but still occurs in the context of the family. Elders may again require more assistance than they had previously to perform self-management. Gender and other demographic characteristics may affect the nature of self-management. For example, Fisher and colleagues have demonstrated that women with diabetes are likely to care for their own diabetes differently than they assist their spouse to manage his care, and that such gender differences may vary by ethnic group.

Psychosocial characteristics such as depression, avoidance coping, and low self-efficacy have been demonstrated to influence the ability to self-manage chronic conditions. The degree to which people believe that they can accomplish what they wish to accomplish will also influence self- and family management. Bandura has suggested that individuals can actively influence many areas of their lives, and that when a person can practice and rehearse a new behavior, such as learning how to cope successfully with a problem situation, self-efficacy can be enhanced. Whitemore has recently argued that such integration is necessary for self-management.

Factors related to diversity (ethnic and racial background, culture, educational level, language, sexual orientation) may affect the specific approach to self- and family management. Members of minority groups are more likely to have higher mortality and morbidity for many diseases than do whites, regardless of socioeconomic status. These statistics point to the importance of understanding how self- and family management is defined and carried out in varied social contexts, as well as the contribution of over-arching social norms and structures to optimal self- and family management.

The experience of illness and perceptions of health are culturally related and, thus, may affect the ability of individuals and families to participate in self-care. Further, culture may affect how individuals communi-
cuncate with health care providers and may lead to dissatisfaction with care.

**Family factors**

It is important to understand self-management in the context of the family and community in which it takes place. Considerable research has been directed to describing the impact of illness on family life and identifying factors associated with the quality of family functioning. Regardless of whether the ill member was a child or an adult, better family functioning has been related to social support, adequacy of resources, hardness, the ability to find positive meaning in the experience, and fewer stressors. In studies of childhood chronic conditions, family functioning has been linked to the quality of the child’s adjustment to the illness as well. A comprehensive review of the literature on the contribution of family variables to the management of a family member’s chronic condition found that the families variables of closeness, caregiver coping skills, mutually supportive family relationships, clear family organization, and direct communication about the illness and its management were consistently linked with better family and individual outcomes. The family caregiving literature demonstrates that not only are caregivers influenced by the management experience, but that caregiving influences outcomes for both the person with the chronic condition as well as for the caregiver.

In addition to understanding how a condition impacts family life, investigators also have addressed management from a family perspective. There has been a growing emphasis on identifying patterns or typologies of family response in recent years. Family typologies incorporate data from multiple aspects of family life and have the advantage of conveying how the family, as a system, responds to and manages illness. Knafl, Deatrick, and colleagues have identified a framework for studying family management style that describes how management style influences child and family functioning in families in which a child has a chronic condition.

**Environment**

The interplay between condition, individual, family, and environmental variables in shaping self-management behaviors has been well-documented and has lead to the development of various frameworks that situate individual response to the condition in a broader sociocultural context. This body of work supports the importance of developing interventions that take into account the varied individual, family, and environmental contexts in which self-management occurs. The family or social network, as well as the individual, may be the appropriate target of intervention. Families face environmental health concerns such as pollution, as well as relationships with the community (eg,

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**Figure 1. Self and Family Management Framework**

<table>
<thead>
<tr>
<th>Risk and Protective Factors</th>
<th>Self and Family Management Behaviors</th>
<th>Outcomes</th>
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<tbody>
<tr>
<td>Health Status</td>
<td></td>
<td>Health Status</td>
</tr>
<tr>
<td>- Severity of Condition</td>
<td></td>
<td>• Control</td>
</tr>
<tr>
<td>- Regimen</td>
<td></td>
<td>• Morbidity</td>
</tr>
<tr>
<td>- Trajectory</td>
<td></td>
<td>• Mortality</td>
</tr>
<tr>
<td>- Genetics</td>
<td></td>
<td>Individual Outcomes</td>
</tr>
<tr>
<td>Individual Factors</td>
<td></td>
<td>• Quality of Life</td>
</tr>
<tr>
<td>- Age</td>
<td></td>
<td>• Adherence</td>
</tr>
<tr>
<td>- Gender</td>
<td></td>
<td>Family Outcomes</td>
</tr>
<tr>
<td>- Psychosocial Characteristics</td>
<td></td>
<td>• Function</td>
</tr>
<tr>
<td>- Diversity/Culture</td>
<td></td>
<td>• Lifestyle</td>
</tr>
<tr>
<td>Family Factors</td>
<td></td>
<td>Environmental Context</td>
</tr>
<tr>
<td>- SES</td>
<td></td>
<td>• Access</td>
</tr>
<tr>
<td>- Structure</td>
<td></td>
<td>• Utilization</td>
</tr>
<tr>
<td>- Function</td>
<td></td>
<td>• Provider Relationships</td>
</tr>
<tr>
<td>Environmental Context</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Social Networks</td>
<td></td>
<td></td>
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<tr>
<td>- Community</td>
<td></td>
<td></td>
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<tr>
<td>- Health Care System</td>
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have tested family-focused interventions. On the one hand, the Calgary family assessment and intervention model has identified important functional, structural, and developmental aspects of family life that may influence the management of a chronic condition. Researchers have also begun to systematically test some of the intervention strategies described in the Calgary model. Nonetheless, little is known about the replicability of outcomes across diseases, potential health problems, and at-risk groups.

OUTCOMES

Effective self- and family management of chronic conditions has been associated with a variety of outcomes. Enhancing self- and family management has been associated with improved condition outcomes and individual outcomes, such as higher self-efficacy or empowerment, better adherence to treatment regimens, and improved quality of life. In comparison to research on individuals, relatively few studies have tested family-focused interventions. On the other hand, the Calgary family assessment and intervention model has identified important functional, structural, and developmental aspects of family life that may influence the management of a chronic condition.

Condition outcomes

The main goal of enhancing self-management is to improve health outcomes. To improve the illness or problem, to prevent complications, or to prevent complications from worsening is a key goal of nursing and health care. Key outcomes related to self- and family management interventions include variables representing the illness or problem of concern. For example, if we are concerned with reducing the risk of complications of Type 1 diabetes, metabolic control (glycosylated hemoglobin) would be a primary outcome. By achieving adequate metabolic control as measured by glycosylated hemoglobin—through enhanced self-management—morbidity and mortality from diabetes can be reduced. Lorig et al have demonstrated that community-based self-management programs for adults with arthritis can improve functional status and decrease health care utilization.

Individual outcomes

As important as these condition-specific outcomes are, it is equally important to assess outcomes related to quality of life for both individuals and families. Another goal of self-management intervention is to achieve the highest possible quality of life for populations and their families. Research has shown that quality of life is an important factor in morbidity and mortality outcomes, in particular patient perception of quality of life as it manifests itself in social, physical, spiritual, and psychological well-being. The goal of treatment of a chronic condition is to help patients function and feel better. Traditional medical care, which focuses primarily on physical symptoms and signs, may neglect other key components through which patients assess their own well-being, and families incorporate illness into ongoing family life. Other relevant outcomes include behavior change or enhanced self-efficacy.

Family outcomes

Enhancing self- and family management may also improve outcomes for the family members as well as the family as a whole. Although family intervention research is in its infancy, there are several studies that suggest that enhancing management of conditions can improve family functioning. Gilliss and colleagues demonstrated that a nursing intervention for post-cardiac surgery patients could not only affect patient outcomes, but family functioning as well. Comana, Brown and Thomas found a significant improvement in family coping following an intervention that used reminiscence to enhance coping. Caregivers of cancer patients who received a home care intervention focusing on symptom management had improved psychosocial status and family outcomes. Similarly, a reduction in depressive symptoms in caregivers of cancer patients was found after a 16-week supportive nursing intervention. In a recent pilot study examining the impact of a comprehensive intervention to prevent Type 2 diabetes in youth, Grey and colleagues found that the intervention, while focused mainly on youth, led to significant improvements on parental lifestyle behaviors as well.

Environmental Outcomes

Improvement in health status, quality of life, and family outcomes may also affect the organization and cost of health care. The work of Naylor and colleagues is illustrative. By providing a post-discharge intervention for hospitalized elders with cardiovascular disease, need for re-hospitalization and costs were significantly decreased. In a recently completed study, Funk et al used wearable cardiac event recorders to examine the occurrence of atrial fibrillation in patients who had been discharged after undergoing cardiac surgery. Often, patients are kept in the hospital to monitor and treat atrial fibrillation. Use of cardiac event recorders may enable patients to be discharged safely. Such devices may also assist patients in self-management by enabling this arrhythmia to be detected earlier, thus preventing further morbidity.

IMPLICATIONS FOR RESEARCH

In recent years, there has been a growing emphasis on individuals and families taking a more active role in preventing and managing their health. In the wake of these trends, our review suggests that there is a growing body of literature that supports the positive outcomes associated with individuals and families being more actively involved in the management of their health. This literature supports the salience of developing and testing interventions aimed at enhanc-
The framework helps to point out where there are gaps in the literature and what research is needed to enhance our ability to improve self- and family management behaviors in the care of chronic illness. While there are myriad studies examining the relationships of individual risk and protective factors on self- and family management, few studies take into account multiple factors. To truly understand the relationships among mutable and non-mutable factors, such studies must be accomplished. Further, research is needed that carefully defines effective self- and family management behaviors and develops instruments that can be used to assess these behaviors. While our presentation is linear, it is clear that many of these factors may be interactive, and such interactions can affect the efficacy of interventions.

Interventions to enhance self- and family management can address any of several factors in this framework. Within the risk and protective factors, some characteristics such as age and gender are not appropriate targets of intervention, but must be controlled in research. Others, such as psychosocial characteristics (eg, self-efficacy) may serve as a focal point of intervention to enhance the ability to self-manage a chronic condition toward ultimately improved outcomes. Similarly, interventions may be directed to aspects of family functioning such as communication or problem-solving. The family, the health care system, or a combination of these, may be the focus, but all interventions are directed at enhancing the ability of the individual and/or family to achieve better self-management behaviors toward improved outcomes. Interventions may be directed at management of symptoms, management of behaviors, management of a regimen, management of technology, management of the trajectory, or family management. To be successful, such interventions must be provided in concert with the cultural and environmental context of the individual and the family.

SUMMARY
Our framework provides a beginning approach for the understanding, development, and testing of self- and family management interventions for people with chronic conditions, or at risk for their development. By identifying key variables that influence self- and family management of chronic conditions and key outcomes of interventions aimed at improving such management, the framework can become the platform for the development of a conceptual model related to self- and family management. Although the field of self-management research is just emerging, more researchers and more studies are needed to describe self-management as it is carried out by individuals and families, to identify correlates and outcomes of self-management, and to develop and test interventions that promote effective self-management. Researchers can use the framework we describe to begin to more carefully delineate the factors associated with the need for self-management, the role of the individual and family members in self-management, the target of the intervention, and the outcomes to be expected. Building on prior conceptual and empirical work on self- and family response to illness, the Framework for the Study of Self- and Family Management was formulated to guide future research directed to the development and testing of interventions to promote optimal health outcomes for families and individuals. The current version of the framework is viewed as a starting point, and we anticipate further refining and elaborating its various components through further research by researchers interested in this important area of inquiry.

Work on this framework is supported by grants number P20NR07806 and P30NR008999 from the NIH/NINR.

REFERENCES


