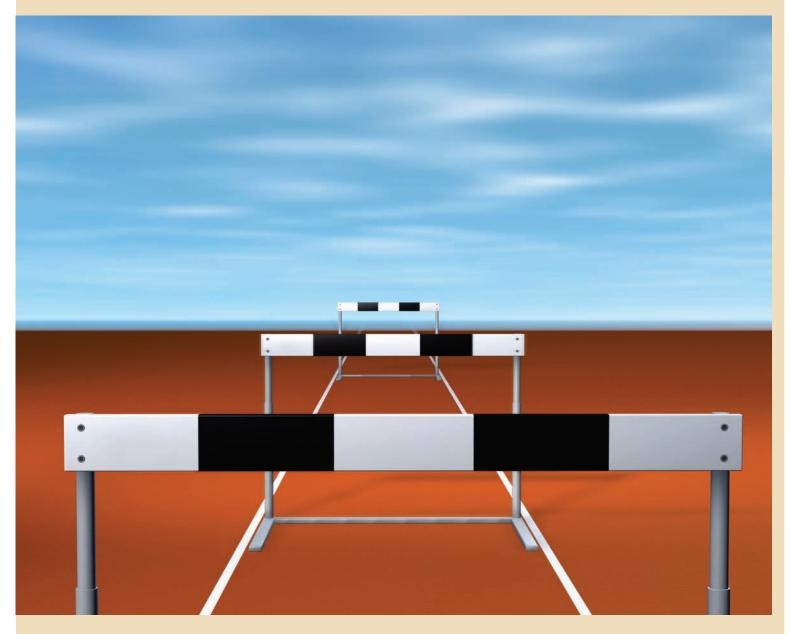
Helping patients with chronic conditions OVERCOME barriers to self-care



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Abstract: This article provides an overview of barriers to self-care, patients' perceptions and understanding of their chronic illness, interviewing techniques, and approaches nurse practitioners can use to reduce or eliminate barriers to self-care in adults with chronic conditions.

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he World Health Organization defines chronic conditions as those that require ongoing management over a period of years. Heart disease, diabetes, and asthma are considered chronic conditions. Conditions that result in disability, such as injuries and socioenvironmental conditions (limited food and healthcare resources, poverty) also fall into this category. Treating chronic conditions requires coordinated involvement among a wide range of providers and access to essential medications and monitoring systems.2

On a population health level, the goal of enhancing self-care abilities for chronic conditions is to reduce the global burden of disease. On an individual level, optimal self-care can enhance quality of life and functioning.1 It is imperative that nurse practitioners (NPs) are aware of the barriers patients with chronic illnesses face when learning to manage their own diseases and treatment. By helping to overcome barriers to self-care, practitioners can improve patient outcomes and empower patients to take ownership of their treatment.

■ Features of chronic conditions

Although unique self-care behaviors are required to selfmanage some chronic conditions, most share certain features. Long-term conditions require daily attention because a "cure" is not the goal. Instead, management aims to reduce the disease burden of the condition. There is also a high comorbidity among chronic conditions. About two-thirds of individuals with diabetes also have hypertension.3 The leading chronic conditions worldwide, including heart disease, stroke, cancer, chronic lung disease, and diabetes, share common risk factors of smoking, inactivity, poor diet, and environmental exposures.

Alongside the growing disease burden of chronic conditions, there is an increased interest in the role of self-care to control disease progression; however, this approach presents a number of challenges.4 Patient education about specific disease conditions is not sufficient to inspire sustained behavioral changes necessary for ongoing self-management. For example, patients with diabetes make decisions that affect glycemic control every day, while contact with healthcare providers is usually brief and periodic.5 With high comorbidity among major chronic conditions, lifestyle skills that support healthy behaviors have benefits beyond a single diagnosis. Further, many low-resource settings not only have a severe shortage of healthcare workers, but also are part of healthcare systems that do not provide continuity of care or basic equipment needed to monitor care and disease outcomes, such as BP cuffs or weight scales.6

■ The chronic care model

The chronic care model (CCM) is a framework to improve care for chronic conditions and an excellent tool for improving care at both the individual and population level. This model encourages more productive interactions between patients and healthcare providers. The CCM identifies the essential elements of a healthcare system that encourage high-quality chronic care (see The chronic care model). These elements include the community, the health system, selfmanagement support, delivery system design, decision support, and clinical information systems.⁷

The CCM is an example of a social ecologic perspective that emphasizes the interaction of all factors related to health on multiple levels including individuals, families, communities, and macrolevel social and economic policies.8 An ecologic approach to self-management integrates the skills and choices of patients with the services and support they receive from family, friends, worksites, organizations, and cultures, as well as the physical and policy environments of neighborhoods, communities, healthcare systems, and governments.9

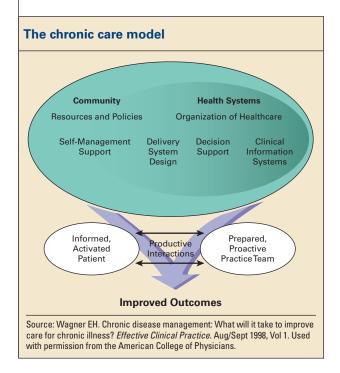
Key words: barriers to self-care, chronic care model, chronic conditions

Definitions of care

Self-care is "the ability of individuals, families and communities to promote health, prevent disease, and maintain health and to cope with illness and disability with or without the support of a healthcare provider." Dorthea Orem, a nurse theorist, defined self-care as learned behavior that was purposeful, with patterned and sequenced actions, and suggested that individuals acquire the capacity for self-care during childhood, principally in the family, where cultural standards are learned and transmitted intergenerationally. Self-care encompasses health promotion and prevention, self-diagnosis, self-monitoring, self-medication, and self-management. Self-care in the context of a chronic health condition may or may not involve a partnership between health service users and health professionals.

Self-management is an individual's ability to manage the everyday effects of a chronic condition. It involves a complex and diverse set of skills and activities that are influenced by knowledge and attitudes, such as confidence or self-efficacy. Individuals are tasked with applying these skills on a daily basis to solve disease-related problems and to set goals.¹³

Self-management support is the assistance given to someone with a chronic condition to encourage daily decisions that improve health-related behaviors and clinical outcomes. Self-management support includes techniques and tools that help an individual choose healthy behaviors. It involves a paradigm shift in the patient-caregiver relationship into a collaborative partnership, and includes wider support networks that participate in the delivery of care. ¹⁴



Barriers to self-care

Identifying barriers is the first step in collaborating with a patient with a chronic condition to improve self-management strategies. 15 Barriers to self-care are a patient's own perception of how challenging are the social, personal, environmental, and economic obstacles to achieving or maintaining a specific behavior or a set goal for that behavior.¹⁶ These barriers have many dimensions, including those related to healthcare providers, healthcare systems, and sociocultural issues. Providers may lack time or appropriate skills, or may incorrectly label a patient's behavior as "non-adherent" or "non-compliant". Providers should also consider how social and health system factors contribute to these barriers.¹⁷ Access to healthcare services and resources, especially primary care, can also be a significant barrier to optimal self-care. Another issue is that not all providers work in settings that include an integrated approach to chronic care and support or advocacy for self-management.

Barriers to self-management of chronic conditions can be placed into five categories: physical, psychological, cognitive, economic, and social and cultural.

Physical barriers: Chronic conditions often result in physical disability due to reduced strength, sensation, or vision. ¹⁸⁻²⁰

Psychological barriers: Major depression and emotional distress are the most studied psychological challenges that affect self-care practice in people with diabetes, chronic obstructive pulmonary disease, and heart disease. 19,21,22 Depression is two times more prevalent in patient's with type 2 diabetes than in the general population. 23 While high levels of distress and frustration may initially serve as the impetus for someone to seek help, it may become the barrier to achieving behavioral goals. Low self-efficacy is also a major psychological barrier to optimal self-management. 24,25

Cognitive barriers: A patient's knowledge about a specific chronic condition has a powerful influence on his or her ability to perform optimal self-care. For example, if someone with heart failure does not understand the purpose of the medications, he or she may be unable to distinguish the symptoms of heart failure from the adverse effects of the drugs.²² The most frequently reported barrier to self-care for people with diabetes was lack of knowledge and understanding of a specific diet plan.¹⁸

Health literacy includes the ability to make decisions that allow a patient to apply new information to navigate the healthcare system successfully. Low health literacy is a potential barrier to active participation in care. It has been reported that people with low literacy levels have more difficulty learning self-care skills. ²⁶ Language issues, dementia, and poor memory also prevent patients from learning and utilizing new skills. ²⁰ Patients with low literacy levels need

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an active healthcare provider who will make a conscious effort to simplify care, tailor education to individual abilities, and reduce the complexity of the healthcare system to remove or reduce barriers to optimal self-care.²⁷

Economic barriers: Socioeconomic position is a significant factor in determining health status. Resources needed to support optimal self-care, as well as access to continuing care can be very expensive (medications, self-monitoring supplies, and durable equipment). The adequacy of health insurance for ongoing monitoring and treatment represents a major challenge for those who require life-long monitoring and treatment.

Social and cultural barriers: The involvement of a patient's family can either support or hinder patient self-care behaviors. Women are usually more integrated into extended family networks and are more likely to be living with members of other generations, while men often rely on spouses for support. 28 Older Asian Americans tend to receive a lot of health-related assistance from friends, which may translate into a greater use of traditional medicine strategies. 29,30 For Blacks, support from local church communities may be integral to family networks. It is helpful to take into account the role of spirituality, participation in community religion, and cultural practices such as traditional healing to understand how family and social context will affect self-care directives. 31

■ Strategies to overcome barriers to self-care

There are a number of strategies healthcare providers can use to help patients achieve the ability to self-care. These include motivational interviewing, assessing cultural beliefs, enhancing self-efficacy, and peer support.

Motivational interviewing

The overall goal of motivational interviewing is to increase a patient's motivation so that they feel empowered to change their own behaviors to benefit their health status. The interviewer uses directive questions and reflective listening to encourage participation in the discussion. This interview style may reveal important self-management issues. Practitioners use three core skills (asking, listening, and informing).³²

Asking: the use of open-ended questions allows the person to convey more information, encourages engagement, and opens the door for exploration. Ask open-ended questions that can be answered with change talk. There are seven types of change talk that can be helpful using the DARN CAT mnemonic:

D–Desire. Why do you want to make this change?

A–Ability. If you decide to make this change, how would you do it?

R–Reasons. What are the three most important benefits that you see in making this change?

N–Need. How important is it to you to make this change?

C–Commitment. What do you think you will do?

A–Activating. What are you ready to do?

T–Taking steps. What are you already doing to be healthy?

Listening: Reflective listening is a skill that demands alertness and patience. Reflective listening is the ability to capture and reflect back the experience of the patient in a few words, which encourages him or her to recognize and resolve ambivalence about behavior change.

Informing: Use an "explore-offer-explore" approach, and ask what the patient knows, has heard, or would like to know. There are two general ways to explore. First, "What would you most like to know (talk) about?" This question invites a patient to share what seems most important to know from his or her perspective; however, when coupled with the question, "What do you already know about...?" it also prevents both the patient and provider from wasting time. Explaining an issue or providing unwanted information is most likely to elicit resistance when the patient isn't ready. Therefore, the practitioner provides information only if given permission by the patient to do so. For example, when a patient is asked, "May I share some information with you?" the practitioner, now having received permission, may offer information in a neutral, nonjudgmental manner. This information includes experiences of other, similar patients along with evidence-based information about the target behavior. An example of offering information is "Some patients in your situation ..." Explore the patient's thoughts and feelings about the information provided by asking, "What do you think about this information?" Before ending the conversation, summarize how the patient will approach changing behavior and acknowledge what the patient is experiencing (see Case study).

Assessing cultural beliefs

Assessing cultural beliefs can be approached using two models and can lead to a more comprehensive understanding of a patient's beliefs and behaviors about a health condition. The two models are the explanatory model and the common-sense model of illness.

The explanatory model opens clinicians to human communication and sets their expert knowledge alongside the patient's own explanation, understanding, and viewpoint.³³ It is especially effective in working with people from a variety of cultures to understand their experience and beliefs about a health problem (see *Questions to ask when using the explanatory model*).

A second approach used to elicit an individual's beliefs about a particular health condition is the common-sense model.³⁴ An assumption of this model is that people are natural self-regulators of their behavior and are motivated

to avoid adverse effects of illness, based on their beliefs about a particular condition. The dimensions of illness beliefs include the presence of specific symptoms and a diagnostic label; the timeline or duration; the consequences, inconsequential to fatal; the beliefs about cause; and the control or curability. These beliefs will determine what actions an individual takes and how they evaluate the effectiveness of these actions. Research using the common-sense model has shown that people with chronic conditions often have an "acute" timeline, believing that once they feel better their diabetes or hypertension is cured and they can discontinue treatment. 35,36

Enhancing self-efficacy

Self-efficacy is one's confidence in his or her ability to take action and to persist in that action despite obstacles or challenges.³⁷ A person's perception of self-efficacy evolves as they become more experienced and hence more knowledgeable. This shift in perception influences the likelihood of a given behavior being adopted. Four main sources of self-efficacy

are mastery experiences, vicarious experience through watching others' behaviors (modeling), verbal persuasion from a significant other, and physiologic feedback produced by an individual's own physiologic state. Success in the initiation and practice of self-management tasks using one or all of these self-efficacy sources helps patients gain a greater sense of control over chronic diseases.³⁸

Collaborative goal setting is an exercise that results in the development of concrete, realistic goals for the patient. It requires a specific plan of action. Just the process of having a patient set goals increases self-efficacy because the patient is now an active participant in the treatment plan. However, for goal-setting to be effective the patient must feel confident about performing self-management tasks and that the goal is related to a positive health outcome. ³⁹ Practicing self-management activities indicates an expectation that intermediate goals will be achieved (that is, optimal blood glucose levels, blood lipid control, and a healthy weight), leading to better long-term health outcomes (see *Five steps to setting goals*). ⁴⁰

Case study

The following case study demonstrates how to use motivational interviewing techniques when talking to a patient with a chronic illness.

NP: Hello, Mr. Smith, my name is Ann and I am a nurse practitioner here at the clinic. I would like to talk with you for 10 minutes about your experiences with diabetes [opening the conversation [name, job, time]. I would like you to think about how you take care of yourself. Before we start, what would you most like to talk about today? [explore: open-ended question]

Mr. Smith: My work and family demand so much time that I often forget to take my pills every day.

NP: Your concern is that you are very busy and have difficulty remembering to take medication daily. [reflective listening]

Mr. Smith: Yes, taking pills at the right time daily is a big problem for me. But I know I need to take the medication as prescribed for the best results.

NP: Why do you want to make this change? [explore: change talk, desire]

Mr. Smith: My last A1C was 9% and I think it must be related to not taking my medication.

NP: If you decide to make this change, how would you do it? [explore: change talk, ability]

Mr. Smith: I think I should find some ways to remind me to take my pills.

NP: What have you done to try to remember to take your pills? [explore: change talk, taking steps]

Mr. Smith: I put reminder notes on the refrigerator, bathroom mirror, and my desk at work.

NP: It seems as if you are trying to take your medication daily, but your approach doesn't work well for you. [reflective listening]

Mr. Smith: That's right.

NP: Can I share some information with you? [ask permission]

Mr. Smith: Of course, please do.

NP: Some people in your situation have found it helpful to get a special device to remind them to take pills such as vibrating watches, beepers, or alarms. Others have asked a family member or friend to help. Sometimes, just a few weeks of friendly reminders can help you get into the habit of taking your medication at the right time each day. [offer information]

Do you think any of these might work for you? [explore: patient's response]

Mr. Smith: I think it is a good suggestion to try another reminder method.

NP: What is the most important benefit that you see in making this change? [explore: change talk, reasons]

Mr. Smith: It will really help me better control my blood sugar.

NP: How important is it to you, on a 1 to 10 scale, and why? [explore: change talk, need]

Mr. Smith: I rate it as 8 out of 10 because my note system doesn't work, and I know taking my pills as prescribed is the best way to control my blood sugar.

NP: What do you think you will do? [explore: change talk, commitment]

Mr. Smith: I have a wristwatch that has an alarm. I think I will set it for the times I need to take my medication.

NP: When do you think you will start? [explore: change talk, activation]

Mr. Smith: I will start tomorrow.

NP: You are really serious about this change. I hope the alarm will work to remind you to take your pills.

Questions to ask when using the explanatory model³³

- What do you call this problem?
- What do you believe is the cause of this problem?
- What course do you expect it to take?
- · How serious is it?
- What do you think this problem does inside your body?
- How does it affect your body and your mind?
- What do you most fear about this condition?
- What do you most fear about the treatment?

Source: Kleinman A, Benson P. Anthropology in the clinic: the problem of cultural competency and how to fix it. *PLoS Med*. 2006;3(10):1673-1676.

Peer support

People who have the same chronic condition or disability can share knowledge and experiences with others in a way that many healthcare workers cannot. 41,42 Peer support can take many forms, including phone calls, text messaging, group meetings, home visits, and face-to-face visits. Peer support complements and enhances other healthcare services by creating emotional, social, and practical assistance necessary for managing a condition over time and staying healthy. Some peer supporters, such as paid health promoters, volunteers from the community, or other individuals with the same chronic conditions, receive training to provide education, emotional support, appraisal support, and problem-solving for a specific population or community. 43

Peer support has four main functions for the individual with a chronic condition. The first is to provide assistance with daily self-management. Peer supporters use their own knowledge and experience to help others manage a chronic condition within the context of their individual circumstances. Key resources are also identified, such as where to buy healthy foods or appropriate locations for exercise. The second function is social and emotional support. Peer supporters, through empathetic listening, provide support and encouragement to help patients cope with social or emotional barriers and remain motivated to achieve their goals. The third is to provide a *link to clinical care*. Peer supporters can help bridge the gap between patients and healthcare providers by encouraging patients to seek clinical care when needed. The fourth and most important function is to provide ongoing support. Peer supporters can successfully keep someone with a chronic condition engaged by providing proactive, flexible, and continual long-term support. This may be especially true when peers are drawn from naturally occurring groups in the community.44

■ Implications for practice

A person with a chronic condition who fails to engage in optimal self-care or self-management behaviors does

Five steps to setting goals⁴⁰

- 1. Explore the problem. What is your concern?
- 2. Clarify feelings and meaning. Are you feeling (sad, frustrated) because of ... ?
- 3. Develop a plan. Where would you like to be (3 months, 6 months) from now? What are your options? What are barriers? Who could help?
- 4. Commit to action. What are you going to do? When? How confident are you?
- 5. Experiment with and evaluate the plan. How will you know you have succeeded?

not exclusively have an adherence problem or a patient—provider issue. As the CCM depicts, appropriate and optimal self-care must include the support and involvement of family, community, providers, and the healthcare system. Healthcare providers can help patients engage in optimal self-care by identifying the source of barriers. Practitioner understanding and support of individuals' needs is crucial to the well-being of patients with chronic illnesses.

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