Overview of Patient and Family Preparation

Chapter 3

Patients and families must be educated, prepared, and empowered in order to engage effectively in their own health and health care.[1] Patients and families can engage at all levels (i.e. direct care, organizational design and governance, and policy making), but must have the skills, knowledge, and confidence to do so effectively. A change in culture is necessary for patients, families, and providers to build partnerships and share responsibility for health. Increasing health literacy, education, and training on how to fully engage in one's health care, as well as the issue of peer support, are important tools to prepare patients and families.[1] Prepared and empowered patients and families benefit from better experiences of care, while the larger community benefits from improved population health and potentially reduced costs.[2]

The New Patient Role

Historically, the health care system in the United States has been a paternalistic system with the doctor or other health professional providing knowledge and expertise and the patient being fairly passive in the diagnosis and treatment of whatever ails them.[3] At the heart of patient and family engagement is the redefinition of the patient as a key player in their health and health care and a redefinition of the patient-provider relationship.[4] The role of health care provider and patient can vary widely—at one end of the spectrum is the traditional paternalistic model where the health provider makes decisions on behalf of the patient without considering the patient's preferences. At the other end is informed decision making—where the health provider diagnoses the patient and then details all treatment options and their implications so the patient can make the decision based on their own preferences.[5] The goal of patient and family engagement is for patients and their families to be active participants in their health and health care.

At the heart of patient and family engagement is the redefinition of the patient as a key player in their health and health care.

However, it is important to note that willingness to accept this new patient role varies greatly.[3-5] A representative survey of American adults found that while 96% of Americans want to be offered choices by their health provider and asked their opinions, only 48% wanted to make the final decision on their care.[3] Furthermore, age, gender, education level, race/ethnicity, and health status all influence the degree to which individuals want to engage in their own health care decision making.[3,4]

Patients and families will not all choose or be able to have the same level of engagement. Thus, it is essential to help patients and families prepare for the level of engagement they desire and to move them up the ladder to higher levels of engagement and partnership when appropriate. Preparing patients and families is not only the responsibility of those individuals, but also health care providers, health care systems, and the community as a whole.

Health Literacy

Patients and Families

One way to increase patient and family engagement is to improve the health literacy of patients and families. Health literacy is the ability to obtain and understand basic health information as well as services needed in order to make appropriate health decisions. Literacy—or the ability to read—is not the same as health literacy. Many who can read without difficulty may have difficulties understanding complex medical or insurance terminology. Some groups of people, including older adults, people with less education, those who are cognitively impaired, racial and ethnic minorities, and people with low incomes are more likely to have problems with health literacy.[6] Health literacy skills include the ability to interpret documents, read and write prose (print literacy), use quantitative information (numeracy), and speak and listen effectively (oral literacy).[7,8] These skills are important for patients and family to fully engage in their own care. According to the National Institutes for Health (NIH), more than one in three adults in the United States have difficulties understanding and acting upon health information.[8] Recent studies have demonstrated that health care interventions, such as disease management programs paired with educational materials, can have a positive effect on health outcomes for individuals with low health literacy.[9,10]

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Provider Efforts

Health care providers may use a number of approaches to overcome low health literacy among patients and their families. The NIH recommends that written materials used to communicate health information to patients be kept between the 6th and 7th grade reading levels.[11] During patient encounters, providers can relay medical and health related information into language that is easy to understand.[1] Providers can also use the teach-back method to ensure the he or she has explained the information clearly and the patient has understood what the provider has explained.[12]

Health Literacy Efforts

A number of organizations across North Carolina have been devoted to improving health literacy for many years. In 2007, the North Carolina Institute of Medicine Task Force on Health Literacy released its report, "Just *What* Did the Doctor Order? Addressing Low Health Literacy in North Carolina,"[6] which included 14 recommendations for improving health literacy. In 2010, a review of the recommendations found that 79% of the recommendations had been partially or fully implemented.[13] These included educating health providers about how to use effective communication strategies; enhancing the role of pharmacists as medication counselors; increasing the readability of materials provided by health providers, the Department of Health and Human Services, and insurers; and improving health communications practices at all levels of patient interactions.[13]

The University of North Carolina (UNC) at Chapel Hill Program on Health Literacy—a joint initiative between several UNC professional and graduate schools, UNC Greensboro, Duke University, and other universities, community groups, and state agencies—fosters collaboration throughout the academic community to advance health literacy research and improve practice. The Program on Health Literacy provides resources and expertise to help organizations interested in promoting health literacy in practice and research.[14] They have also developed toolkits to help providers assess their practice, raise awareness, and take steps to increase patients' health literacy.[12]

Training and Education

The skills and knowledge patients and families need varies greatly based on their backgrounds, community resources, diagnoses, and the form and level of engagement they desire.[3,4] At the direct care level, patients and families may need skills on how to engage effectively with their health care team as well as more knowledge specific to their health needs. Various strategies can be used to prepare patients and families to engage more fully in their care. There are many educational models and tools that community-based organizations, health care providers, and others can utilize to increase patients' skills, knowledge, and confidence to meaningfully engage. Well known models include the Engagement Behavior Framework, the Chronic Disease Self-Management Program, and the Collaborative Care Model.

Various strategies can be used to prepare patients and families to engage more fully in their care.

Engagement Behavior Framework

The Engagement Behavior Framework focuses on actions that patients and families can take to support their health and benefit from health care.[15] The Framework provides a comprehensive list of 10 steps, each with measurable actions, that individuals and/or their caregivers can perform in order to maximally benefit from the health care available to them. In specifying the 10 steps, the Framework emphasizes the challenges people face in finding and using quality health care.[16] The 10 steps include: find quality health care, communicate with health care providers, organize health care, pay for health care, make good treatment decisions, participate in treatment, promote health, obtain preventive health care services, plan for end-of-life care, and seek knowledge about their health care needs.

The Framework provides examples of the actions needed to accomplish each step; however, many individuals will not have the skills or knowledge needed to complete the steps without additional guidance and training. Patients and families with low levels of health literacy may find the steps particularly challenging without assistance. Thus the Framework can also be used by health systems, community organizations, and other partners to assess the types of information, education, and support that patients and families may need.

Chronic Disease Self-Management Program

Stanford University has developed a series of internationally recognized, evidence-based patient and family education and engagement programs collectively referred to as the Chronic Disease Self-Management Program. In North Carolina, the implementation of the Chronic Disease Self-Management Program occurs under the program name Living Healthy, and is offered statewide through all 16 Area Agencies on Aging and/or their partner organizations.[a,b] Living Healthy consists of a series of weekly workshops, lasting 2.5 hours each, for 6 to7 weeks, in community settings such as senior centers, churches, libraries, and hospitals.[17] Many of these classes are provided at no charge to patients and families. Individuals with various chronic health problems attend together, as the workshops focus on topics that relate to the individual's responsibility for managing their own specific health condition, rather than on the condition itself. Caregivers also benefit from attending the program with the person for whom they care or as an individual participant. Workshops are facilitated by two trained leaders, one or both of whom are non-health professionals with chronic diseases themselves. Classes are highly participatory, where mutual support and success build the participants' confidence in their ability to manage their health and maintain active and fulfilling lives. In addition to the Chronic Disease Self-Management Program for all health conditions, North Carolina agencies offer the Diabetes Self-Management Program, the Positive Self-Management Program for HIV/AIDS, and the Chronic Pain Self-Management Program in English and in Spanish.

Collaborative Care Model

Collaborative care is a multi-component, health care system level intervention using case managers to link primary care providers, patients, and specialists. The Collaborative Care Model is designed to improve clinical and community support for active patient engagement, improve routine screening and diagnosis of health problems, and increase provider use of evidence-based protocols for proactive management of diagnosed disorders. The Collaborative Care Model is recommended by the US Preventive Services Task Force in the clinical setting.[18] In North Carolina, Community Care of North Carolina (CCNC) uses a model similar to the Collaborative Care Model.[19] CCNC uses coordinated care to help meet its goals of patient education, case and disease management, and ongoing relationships building with patients and families.[20,21] For example, in the initial encounter with patients, care managers identify the patient's personal goals which act as a foundation on which to build relationships and collaboration around the patient's health care needs and behaviors. Health care notebooks are provided to patients as practical tools for organizing health care information, learning to proactively manage all facets of their health care, and as a strategy to communicate with providers at any point in the health care system. Patient-centered, self-management care plans are also developed in collaboration with patients and are focused on patient-centered goals, self-management education,

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[a] Miller, Nicolle. Chronic Disease Self-Management Education/Living Healthy Coordinator, Division of Aging and Adult Services, North Carolina Department of Health and Human Services. Personal (email) communication. Thursday January 29, 2015

[b] CCNC networks and local health departments are also major providers of these programs, but it varies among regions.

and contact information for community resources. CNCC has also worked with multiple adult and pediatric practices to teach patient-centered care, which includes the development of low health literacy teaching tools and the use of motivational interviewing techniques.

Increasing Training and Education in North Carolina
As discussed, a variety of community-based organizations across North Carolina, including Area Agencies on Aging, CCNC networks, local health departments, faith-based organizations, and free clinics offer a wide array of services that can support patient and family engagement in direct care. Many offer training and technical assistance to patients and families that could be enhanced to include strategies supporting patient and family engagement. Offering proven models of engagement, such as the Engagement Behavior Framework and Living Healthy, and partnering with patients and families can help prepare them to more fully engage in their health and health care. The Task Force recognized the importance of preparing patients and families to engage, therefore, the Task Force recommends:

Recommendation 3.1: Educate and Train Patients and Families about Partnering and Engaging (PRIORITY RECOMMENDATION)

North Carolina Area Health Education Centers should lead a collaboration of state agencies, community and faith-based organizations, and payers to identify and implement model curricula and tools for educating and training patients and family members about partnering and engaging with their health care providers.

a) **Trainings should be delivered in a variety of settings to various stakeholder groups including, but not limited to, peer support networks, lay health advisors, advocacy groups, caregivers, community and faith-based organizations, school nurses, social workers, agencies serving the older population, and youth councils or youth-focused health groups.**

b) **Trainings should include information on navigating and overcoming challenges in the health care system, working with health care providers, patient and family-centered care, serving on patient and family advisory councils, shared decision-making tools, peer support, improving health literacy, health insurance literacy, and advocating for one's own health.**

c) **Community and faith-based organizations should tailor and adapt trainings and their content to their community's priorities, including those of local patients and families.**

d) **Organizations should consider regular evaluation of trainings to assess knowledge, attitude, and behavior change.**

Peer Support

Health and well-being are fundamentally correlated with social connectedness and support.[22] People are more effective and happier when they have someone who cares about them who they can talk to about personal matters, and who is available to help them when needed.[23] Health care providers typically spend just a few hours with a patient during the year; for the majority of the time, patients and families are managing their health and wellness on their own.[24] Peer support, coupled with education and training, can provide additional resources to strengthen the individual and family and better prepare them to engage more fully in their health care.[24]

Health and well-being are fundamentally correlated with social connectedness and support.

Peer support refers to linking a patient with another individual who has some level of training and knowledge from their own experiences with a condition.[25] Peer support includes four core functions: assistance in daily management; social and emotional support; linkages to clinical care and community resources; and ongoing support that is extended over time. For example, linking a patient newly diagnosed with a chronic condition with another patient with that same condition who can share knowledge and experience, including some that may not be shared by health professionals. Peer support can complement and enhance other health care services by creating emotional, social, and practical assistance for managing the disease and staying healthy.[25]

Peer support can provide additional resources to strengthen the individual and family and better prepare them to engage more fully in their health care.

Research overwhelmingly shows the positive impact of social and peer support on health, well-being, and engagement.[26] Overall, studies have found that social support decreases morbidity and mortality rates and increases life expectancy.[27] Peer support increases knowledge of a disease, improves self-care skills, including medication adherence, and reduces the use of emergency services. Peer support provides emotional and social support, but also helps people cope with the stress that often accompanies illness and disease.[28] Peer support can build individual and community capacity for understanding health problems, promoting ways of addressing those health problems, and advocating for patients, families, and their communities.[29]

Peer support may vary by location and setting. In chronic disease management, there are several models of peer support. They include professionally led group visits with peer exchange, peer-led, face-to-face self-management groups, peer coaches, community health workers, support groups, telephone-based peer support, and web and email-based programs.[28] Alcoholics Anonymous is a long-standing, well-known example of peer support for a chronic disease. In some locations, peer supporters are called lay health workers, community health workers, or promotoras. Group peer support may be based on diagnosis, age, ethnicity, gender, or other demographic characteristics. Peer support can also be used to provide support to patients' family members; for example, it may focus on parenting a child with a chronic disease, caregiving for older adults, or other challenges families may be facing in caregiving. Peer support may also be used to help individuals facing specific life circumstances such as divorce, death of a spouse or child, or recovering from an abusive relationship. It is important to take into account the local, regional, and cultural influences when implementing peer support programs for patients and families.[30]

In addition to benefits for patients and families, peer support offers benefits to health care providers, organizations, and systems that provide health care services, when peer support is linked to clinical services and care management. Peer support can be a strategy for culturally sensitive outreach and follow-up that enhances the link between patients and provider teams.[31] Peer support can also help providers recognize and promote appropriate care for psychosocial issues and provide an outlet for the patient and family, which then allows the provider to focus on clinical care. Integrating peer support into their care models can also help health providers, organizations, and systems meet the National Committee on Quality Assurance's Patient-Centered Medical Home standards.[32]

Peer support increases knowledge of a disease, improves self-care skills, and reduces the use of emergency services.

Peer support is generally not reimbursed by insurers. Insurance companies may understand the importance of peer support but stop short of seeing this as the responsibility of the insurer rather than the family or community. However, with mounting evidence for both the effectiveness and cost-effectiveness of peer support, this may change. Particularly as insurance practices move towards pay-for-value models (such as accountable care organizations) and away from fee-for-service, models that include peer support may be particularly effective at improving population health while reducing cost. One reason reimbursement for peer support is limited or nonexistent is due to licensing issues. It is challenging for a health insurer to reimburse for a health service delivered by an unlicensed health professional. This issue is currently under examination by the North Carolina Division of Public Health.

Peer support can provide benefits for patients, families, and providers; therefore the Task Force recommends:

Recommendation 3.2: Increase Availability of Peer Support

Organizations that provide care management services should encourage health care systems and payers to recognize the critical aspect of peer support, build peer support into their systems, and facilitate linkages to existing peer support groups, online networks and resources, and condition-specific support groups.

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