The Neglect of Chronic Disease Self-Management in Medical Education: Involving Patients as Educators

Angela Towle, PhD, and William Godolphin, PhD

An estimated 133 million Americans and 16 million Canadians (roughly half the population of both countries) live with at least one chronic illness; about one in four suffers limitations to daily activities as a consequence. As the population ages and people live longer, we can expect to see an increase in the prevalence and complexity of chronic illness. Chronic disease management will become a major part of the work of health professionals, both as individuals and as members of interprofessional teams. The need to align medical education with changes in health care delivery will require more emphasis on chronic disease management as well as on the related topics of behavioral and social sciences and interprofessional teamwork. Yet medical education is still focused on, acute care. A PubMed search of all issues of two top medical education journals for the term “chronic disease management” yielded four papers in Academic Medicine and nine in Medical Education.

In chronic disease, the patient/family is the chief provider of care. Patient chronic disease self-management (CDSM) and self-management support by clinicians have been identified as essential components of chronic care programs. The need for health professionals to be trained in the core competencies required in CDSM support has been identified. Yet there appears to be a wide gap between health professionals' understanding of CDSM and the wider concerns and realities of patients. Whereas health professionals identify self-management primarily as structured patient education, patients identify self-management as a process initiated to bring about order in their lives that involves recognizing and monitoring the boundaries, mobilizing resources, managing the shift in self-identity, and balancing, pacing, planning, and prioritizing.

A seminal study identified three lines of work that people managing chronic illnesses at home must undertake: illness work, referred to as trajectory management (symptom management, diagnostic-related work, crisis prevention and management); everyday life work (house work, looking after family, paid work, eating, etc.); and biographical work (reconstruction of the patient’s biography). These tasks may compete or conflict with medical management, especially in patients with multiple chronic conditions. Since this research, more recent studies of patients’ experiences have identified further forms of work including information work, moral work, and time work. Through doing this work, many patients living with chronic illness become “experts by experience.”

There is strong evidence in the literature that many physicians are unaware of the scope of work involved in CDSM, do not recognize the expertise that patients acquire, and do not provide appropriate support. These problems are hardly surprising given the lack of, or narrow (biomedical) focus on, chronic disease management in medical education. Learning about chronic disease has a low profile, and the few educational programs described have been defined by professionals within a biomedical model, the goal being primarily to influence patients’ behavior so they can better control their disease and improve their health status.

It is important that medical students and trainees learn about chronic disease from the patients’ perspective and explore more fully their roles in supporting the many tasks of self-management. We believe that this is best done through the active involvement of patients as teachers. Examples of such initiatives in North America and the United Kingdom include longitudinal programs in which learners are mentored by an individual or family, taught by parents of children with disabilities, or learn from users of mental health services. Our own work, in which interprofessional workshops are designed and delivered by patients (community educators) with chronic conditions, has demonstrated the acceptability and impact of this patient-led and patient-centered model of education.

These and other examples demonstrate the increasing recognition that patients and community members have important experiences that can enrich medical education at all levels, from basic education through residency and continuing professional development. However, currently these are sporadic, often single, educational experiences that rely on a small group of enthusiasts and external funding. We need to move to a systemic approach which includes institutional commitment and an infrastructure that supports and values patients as educators.

If medical education is truly to address the pressing health problem of chronic disease management, it needs to embrace the concept that patients with chronic disease and their families should be partners in education so that students and trainees can learn directly from “experts by experience” about the work involved in living with and managing chronic disease. This will lead to better support for CDSM within the context of a partnership relationship between professionals and patients, and ultimately better health outcomes.

References