

Chronic illness is one part of a life story

Although chronic illness remains a major cause of death in Canada, many serious diseases once considered life threatening are now being treated and managed. Nonetheless, chronic disease takes its toll on individuals and their families, and the typical trajectory of decline in health is stressful for all involved. I have been studying the quality of life of people with chronic illness for many years. We know much more about treatment and management than we did when I started this work, but I believe the standards and guidelines developed through evidence-based practice often get in the way of recognizing the uniqueness of individuals and their right to make choices about their care.

In a series of narrative interviews we conducted over 18 months with people who have life-threatening chronic illnesses, my colleagues and I have observed that their illnesses are only a small part of their life stories and their unique circumstances. A former diplomat views his kidney disease as a minor inconvenience when compared with the experience of being shot at in a war-torn country; one woman has needed much more support since the loss of her husband through a tragic accident than during the ups and downs of her treatments for HIV/AIDS; and a man who has cancer wants to talk about the importance of a triad of significant others in his life. These stories illustrate the ebb and flow of lives lived.

In chronic illness care, health professionals typically do not treat people as though they are unique. They tend to fit them into a category and try to manage their care according to prescribed protocols. Through narrative inquiry, our team gains an understanding of someone's story, until it changes —

sometimes for the better and sometimes for the worse. One woman who had lived with cancer for over 20 years was suddenly faced with a recurrence. Her outwardly confident manner and seeming acceptance of the disease were shattered as she began to reconsider her priorities and wonder anew “why me?”

Recently, I was involved in a randomized controlled study of nurse-run, physician-monitored clinics for people with early chronic kidney disease

for change. People want input into the decisions that affect them. In the end, we agreed to document the type of nursing care that was provided rather than trying to standardize it.

The long-term outcomes of that study are not yet clear, but clients were highly satisfied with the care provided, and there was evidence of higher quality of life scores on one measure in the group participating in the intervention clinic. However, it was a comment made by one

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(the Canadian Prevention of Renal and Vascular Endpoints Trial, known as CanPREVENT). The research team explored biomedical outcomes as well as quality of life. During the process of designing the study, there was considerable discussion about developing specific protocols to guide care.

The medical protocols were based on extensive research evidence and established clinical practice guidelines and included such strategies as the use of specific antihypertensive agents and cholesterol-lowering drugs. I was encouraged by my medical colleagues to develop standard protocols for nursing care. I resisted, arguing that nurses typically plan their care in consultation with clients — this type of partnership is highly effective in managing chronic illness. And what works in terms of strategies for weight management and smoking cessation depends on a client's past experiences and motivation

of the physicians after the study ended that intrigued me. He had come to realize that medical care could not really be “protocolized” either — because clients sometimes refuse to take prescribed medications, and it just isn't possible to always adhere to the guidelines (despite the evidence that shows we should).

Narrative inquiry brings out the human story that puts the illness in context. As a researcher, I have been privileged to be part of the process and be given access to so many of these stories. Recognizing and respecting the uniqueness of each human being is at the core of our profession. Why is it, then, that more time is devoted to standardization than to supporting unique approaches to care of the individual? ■

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