3 themes described how self care management was learned and experienced by patients with chronic illness

Thorne S, Paterson B, Russell C. The structure of everyday self-care decision making in chronic illness. *Qual Health Res* 2003;13:1337–52.

Q In patients with expertise in self care management of chronic illnesses (ie, type 1 diabetes, type 2 diabetes, HIV/AIDS, or multiple sclerosis), how was the everyday self care decision making process learned and experienced?

DESIGN

Qualitative secondary analysis of data from 2 primary studies.

SETTING

The 2 primary studies included patients from British Columbia, Canada.

PATIENTS

43 patients (22 with type 1 diabetes, and 7 each with type 2 diabetes, HIV/AIDS, and MS) who had been chronically ill and had several years of experience in self care decision making for their disease.

METHODS

In both primary studies, data were collected through individual interviews at baseline, and after 2–3 audiotaped think aloud sessions (each lasting 1 week) over the course of 12 months; and focus group interviews done near the end of the study year. Themes and patterns evolved from a qualitative descriptive analysis method.

MAIN FINDINGS

Learning: the decision to assume control. All participants shared a commitment to controlling the disease rather than being controlled by it. Being “in control” meant being able to mediate the effects of the disease so that they could live “as normally as possible.”

Fine-tuning: the disease specific context of self care. Decisions related to self care resulted from primary effects and the trajectory of the disease, social context and lifestyle choices of the patient, disease treatment, support of the healthcare context, and the negative influence of the disease on the patient’s future. In the initial stages, patients often found the intensity of decision making about self care to be overwhelming. All patients identified the value of self help and support groups, especially at the time of diagnosis. They also focused on lifestyle management (eg, healthy eating, healthy sexual practices, and stress management) to control the disease. Patients often made treatment decisions related to the dosage and timing of medication and beginning or ending a medication regimen. Patients had to skilfully manage their healthcare relationships to retain the good will of professionals regardless of whether they adhered to the advice given.

Evaluating: quality measures for self care decision making. Participants used several criteria to evaluate the effectiveness of their self care decisions. These criteria included professional experts, biomarkers

(eg, glucometers to verify bodily cues), and individualised standards that they created (eg, spiritual well being).

CONCLUSION

Patients with diabetes, HIV/AIDS, or multiple sclerosis, perceived self care decision making as a complex process that occurred within the context of a disease trajectory, a healthcare culture, and a uniquely meaningful life that involved assuming control, fine tuning the basis on which decisions were made, and constantly evaluating their self care decisions.

Commentary

The qualitative study by Thorne *et al* adds substantial insight into the perceptions of patients with chronic illness about self care management aimed at improving both quality and length of life. Through a secondary data analysis technique, the authors astutely identified and contrasted common and diverse themes that defined the self care management experiences of patients with 3 diseases (diabetes, HIV/AIDS, and multiple sclerosis). The analysis produced new understandings not initially identified through primary analysis of the 2 studies, each of which focused on patients with a single disease. Overall, the secondary data analysis expands knowledge about the nature and structure of chronic disease management. This understanding that many factors, including sociocultural and political factors, influence the self care efficacy of many patients with chronic illness provides clinicians and patients with important information for developing more effective strategies to improve patients’ health.

Although healthcare providers often use clinical practice guidelines to construct interventions for disease management, the “lived experience” and informed decisions of patients with chronic illness provide clinicians with relevant information that could enhance the appropriateness and efficiency of practice guidelines for chronic diseases. Although clinicians identified patients who met the criterion of being an “expert” (a person with sufficient knowledge of factors influencing their disease and responsive behaviour to promote or restore their health), many patients did not perceive their knowledge and informed self care behaviours as inherent parts of their treatment plans.

The findings of Thorne *et al* highlight the need for further research on patients as experts in managing their chronic illnesses. Additional investigation on the influence of gender, length of diagnosis, work, and social support could offer further direction in defining effective and appropriate self care treatment strategies used by patients with chronic illness and supported by their clinicians.

Carolyn Spence Cagle, RNC, PhD
Harris School of Nursing, College of Health and Human Sciences
Texas Christian University
Fort Worth, Texas, USA

For correspondence: Professor S Thorne, University of British Columbia, Vancouver, British Columbia, Canada. thorne@nursing.ubc.ca

Source of funding: no external funding.