

# Review: research on chronic illness has shifted towards viewing the individual as empowered and a partner in the health management process

Thorne S, Paterson B. *Shifting images of chronic illness. Image J Nurs Sch* 1998;30:173-8.

## Question

How have healthcare relationships in chronic illness changed over the past 15 years?

## Data sources

Studies were identified by searching Sociological Abstracts, Psychological Abstracts, Dissertation Abstracts, CINAHL, Medline, and Allied Health databases. Monographs, articles, and chapters were identified by searching refereed nursing, social science, and allied health journals and books.

## Study selection

Published and unpublished studies of qualitative research in the English language were selected if they were produced between January 1980 and July 1996, investigated the individual or collective firsthand perspective of the chronic illness experience, described the data analysis process, and provided participant demographic data.

## Data extraction and analysis

Data were extracted on data collection and analysis methods, research findings, theoretical frameworks, and emergent theories. Meta-ethnography was used as an organising framework for appraising the research methods of selected studies, interpreting and synthesising results, and identifying and explaining emergent theory. The trustworthiness of the data was ensured by analytical consensus between reviewers and assessment of the study quality using established guidelines.

## Main findings

158 of over 400 studies met the selection criteria. Selected studies encompassed the distinct or generic chronic illness experience across a range of chronic disease conditions and incorporated multiple qualitative research strategies, disciplines,

and theoretical frameworks. Between 1980 and 1995, changes in chronic illness research began to occur. Analytical frameworks and research questions began to shift from a researcher perspective of the person with a chronic illness as "sufferer" to a perspective emphasising the healthy, transformative, and positive aspects of the chronic illness experience. For example, between 1980 and 1985, 20 studies on chronic illness identified major themes of *suffering, loss, biographic disruption, and sick role*. Between 1990 and 1995, 90 studies identified major themes of *being courageous, maintaining hope, restructuring, reframing, reshaping or reconstituting self, regaining control, redefining health, finding meaning, managing, self transcendence, empowering potential, transformation, normality, and discovery* that focused on the person living with chronic illness. Furthermore, as research began to focus on a more optimistic viewpoint, findings showed the competence of patients in relation to self care and decision making. The healthcare process shifted from viewing the client as a patient to a partner, with researchers suggesting the management process should promote empowerment and be based on patient needs rather than professional expectation.

## Conclusions

Over 15 years, qualitative health research has exposed a shift in healthcare relationships from the negative image of the chronic illness "suffering" experience to a conceptualisation of the person with a chronic illness as someone with power and competence within their lives. People living with chronic illness are seen as capable of participating in healthcare decisions and in a partnership model of care relationships.

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## Commentary

Thorne and Paterson present a unique interpretation of qualitative studies in chronic illness. In this meta-study of 158 qualitative inquiries spanning almost 2 decades, they report a shift in healthcare relationships from a care recipient model to a participatory model.

This overview provides us with an idea of the possible changes in healthcare relationships that have occurred over time. However, the influence of variables such as whether people experiencing chronic illness were living in institutionalised or community settings was not considered. Furthermore, although researchers analysed the data separately for specific chronic illnesses, there is no discussion of whether any differences were found. It is unclear therefore whether these results can

be generalised to patients experiencing specific chronic illnesses. In addition, the potential always exists in any attempt to synthesise qualitative studies that the richness and depth of data associated with individual studies is lost or compromised.

Future research should focus on patient centred preferences in decision making relationships with professionals including the conditions under which such partnerships are desirable. For example, Degner *et al* show how some patients prefer an active partnership whereas others may prefer a more passive role in their care.<sup>1</sup> Also, researchers should recognise that patient expectations regarding healthcare relationships may change during their illness and be influenced by their environmental setting.

The investigators caution against idealising the chronically ill person as "strong, powerful, and competent." Nurses must be aware of the changing expectations of patients experiencing a chronic illness and of their healthcare relationships. Patient preferences about the level of involvement in care issues must be continually assessed and adjusted to provide optimal care.

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1 Degner LF, Kristjanson LJ, Bowman D, *et al*. Information needs and decisional preferences in women with breast cancer. *JAMA* 1997;277:1485-92.