The Shifting Perspectives Model of Chronic Illness

Barbara L. Paterson

Purpose: To present the Shifting Perspectives Model of Chronic Illness, which was derived from a metasynthesis of 292 qualitative research studies.

Design: The model was derived from a metasynthesis of qualitative research about the reported experiences of adults with a chronic illness. The 292 primary research studies included a variety of interpretive research methods and were conducted by researchers from numerous countries and disciplines.

Methods: Metastudy, a metasynthesis method developed by the author in collaboration with six other researchers consisted of three analytic components (meta-data-analysis, metamethod, and metatheory), followed by a synthesis component in which new knowledge about the phenomenon was generated from the findings.

Findings: Many of the assumptions that underlie previous models, such as a single, linear trajectory of living with a chronic disease, were challenged. The Shifting Perspectives Model indicated that living with chronic illness was an ongoing and continually shifting process in which an illness-in-the-foreground or wellness-in-the-foreground perspective has specific functions in the person's world.

Conclusions: The Shifting Perspectives Model helps users provide an explanation of chronically ill persons' variations in their attention to symptoms over time, sometimes in ways that seem ill-advised or even harmful to their health. The model also indicates direction to health professionals about supporting people with chronic illness.

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he Shifting Perspectives Model is a model of chronic illness that arose from the synthesis of qualitative research findings. This model allows users to extend the contributions of previous attempts to describe the experience of chronic illness, clarify certain perplexities that have confronted students of chronic illness in the past, and offer new understanding about why people with chronic illness may manifest behaviors that at first glance seem illadvised and even harmful. Many paradoxes that occur in living with a chronic illness, as well as some unintended outcomes when people with chronic illness attempt to use the health care system, are revealed.

Research Design

The data for this paper were derived from a metasynthesis, or a metastudy, of 292 qualitative research reports pertaining to chronic physical illness. The metastudy research team consisted of seven investigators; the author was the principal investigator. Metastudy is a systematic analytic and synthesis research method (Thorne & Paterson, 1998). It is an interpretive qualitative research approach in the constructivist paradigm in which the researcher's role is to understand how people construct knowledge about the

phenomenon under study (Guba & Lincoln, 1994). Metastudy researchers analyze and synthesize what has been reported by researchers as findings, research design, and theoretical perspectives in qualitative research reports (primary research) in a substantive area to identify similarities and differences among them and to generate new or expanded theory about the phenomenon under study. The two phases or components of metastudy are analysis and synthesis. Traditionally, qualitative researchers who have attempted metasynthesis have focused entirely on the analysis of primary research findings, but in metastudy, analysis and synthesis are separate. To analyze in a metastudy is to identify commonalities, differences, patterns, and themes in a body of qualitative research. Synthesis extends beyond analysis as the analytical findings are used to identify the "truths" that primary researchers have held in their interpretation

Barbara L. Paterson, RN, PhD, Associate Professor, University of British Columbia School of Nursing, Vancouver, BC, Canada. The author gratefully acknowledges funding for the project from the Canadian Nurses Foundation, and the contribution and support of the co-investigators, Dr. Sally Thorne, Dr. Sonia Acorn, Connie Canam, Dr. Carol Jillings, Gloria Joachim, and Marilyn Dewis. Correspondence to Dr. Paterson, University of British Columbia School of Nursing, T201-2211 Wesbrook Mall, Vancouver, BC, Canada V6T 2B5. E-Mail: paterson@nursing.ubc.ca

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of research data and their choice of research design and theoretical frameworks. In synthesizing qualitative research new understandings of the phenomenon under study are generated.

The three aspects of the analytic component of metastudy are meta-data-analysis, metamethod, and metatheory. Metadata-analysis is the interpretive analysis of findings of primary research studies to identify similarities and discrepancies among them. Although the meta-data-analysis can incorporate any one of several data analytic approaches, we chose to analyze data of primary research in accordance with metaethnography (Noblit & Hare, 1988). Metamethod is the study of the appropriateness and influence of particular research methods and procedures in research (Szmatka, Lovaglia, & Mazur, 1996). Metatheory includes the major schools of thought inherent in theoretical frameworks and emerging theory of primary research studies, relating that theory to larger social contexts and underlying assumptions (Ritzer, 1990). Procedures for the analytic component are detailed the **Table**.

In developing metastudy as a research method, our research team has resisted codifying the procedural steps of the synthesis component of metastudy. This decision was made because, in contrast to the concrete analytic phase, synthesis is a creative, dynamic, and interactive process that defies procedural codification. For example, the analytic component enabled us to identify differences in people's experiences of chronic illness as they lived with the disease over time and as they encountered new or crisis situations. Reflecting on why these differences occurred led us to conclude that the traditional view of living with chronic illness as a predictable trajectory was misguided and incomplete. That conclusion led us further to the development of the Shifting Perspectives Model of Chronic Illness.

In the analytic phase, each primary research report was reviewed by at least three members of the research team, using a standardized appraisal form. If consensus was not achieved in the review, we met with other members of the research team to arrive at a defensible decision. We recorded our decision processes in field notes. In addition, we also maintained theoretical notes regarding our thoughts about the data derived from the metastudy. For example, we made notations about how the authors' disciplinary perspectives were revealed in their interpretation of the chronic illness experience.

Sandelowski (1997) noted that the challenge for metasynthesists is to maintain the integrity of primary research studies while at the same time avoiding producing so much detail that "no usable synthesis is produced" (p. 130). A high quality metasynthesis provides sufficient information for readers to track sources and decisions, but is focused on the synthesis of the primary research. This method adds to understanding of the body of research in the field of study by enlightening users on the influence of context, on researchers' perspectives, and on alternative and overarching interpretations (Zhao, 1991).

Table 1. Analytical Components of Metastudy

Meta-data-analysis:

- (a) Translating the findings of each primary research study into metaphors that explain them
- (b) Comparing and contrasting the metaphors in research reports with other studies, as a whole or in subgroups (e.g., all those that pertain to a particular ethnic or age group), noting the similarities and differences between key metaphors
- (c) Determining how the key metaphors of each study relate to those of other accounts and hypothesizing about the nature of the relationships between metaphors in various studies

Metamethod:

- (a) Appraising, according to agreed-upon criteria, the research design, the role of the researcher(s), sampling procedures, and data collection procedures of each research report
- (b) Depicting historical, cultural, and disciplinary trends regarding the research questions, methodological orientations, researcher roles, sampling procedures, and data collection procedures that characterize the body of qualitative research in the field of study

Metatheory:

- (a) Reviewing each report to identify the theoretical perspective used and the emergent theory
- (b) Identifying the major cognitive paradigms or schools of thought that underlie each theory
- (c) Identifying the assumptions underlying each theory
- Examining the historical development of each theory, including significant markers
- (e) Determining how the context may have influenced the choice of theoretical frameworks
- Evaluating the quality of the selected theory according to agreed-upon criteria

Selection Criteria

The metastudy project included research reports in nursing, medicine, social science, and allied health that were identifiable as a qualitative, interpretive research investigation and were reported from January 1980 to January 1996 in refereed journals, research-based books, or theses in which (a) the researcher(s) investigated the experience of living with a chronic illness from the perspective of the person with the disease, (b) participants had a chronic physical illness, (c) reports provided evidence of the data trail, and (d) demographic profiles of participants were provided. Computer searches, citation indexes, reference lists, reviews of research, and professional and journal networks were used to obtain relevant reports of primary research.

The Shifting Perspectives Model

Previous researchers have described living with chronic illness as a phased process in which the person follows a predictable trajectory. Although many writers have acknowledged the possibility of regressive steps in this journey, the implication is that an end goal exists and it can be reached only if the person has lived with the disease long enough to progress through previous stages. In contrast, the

Shifting Perspectives Model shows living with chronic illness as an on-going, continually shifting process in which people experience a complex dialectic between themselves and their "world." The experience of chronic illness is depicted as everchanging perspectives about the disease that enable people to make sense of their experience.

People with chronic illness live in "the dual kingdoms of the well and the sick" (Donelly, 1993, p. 6). The measure of wellness is determined by comparing the experience to what is known and understood about illness and vice versa. Consequently, the perspective of chronic illness contains elements of both illness and wellness. Perspectives of chronic illness are illustrated in the schematic representation of the Shifting Perspectives Model as illness in the foreground or wellness in the foreground (see Figure 1). A perspective is representative of beliefs, perceptions, expectations, attitudes, and experience about what it means to be a person with a chronic illness within a specific context. Perspectives of chronic illness determine how people respond to the disease, themselves, caregivers, and situations that are affected by the illness, such as employment. Each perspective is depicted by overlapping circles in which either illness or wellness takes precedence. As the reality of the illness experience and its personal and social context changes, the people's perspectives shift in the degree to which illness is in the foreground or background of their "world." Whether the illness is as significant and present as the individual perceives is irrelevant. The perception of reality, not the reality itself, is the essence of how people with chronic illness interpret and respond to their illness.

Illness in the Foreground

The illness-in-the-foreground perspective is characterized by a focus on the sickness, suffering, loss, and burden associated with living with a chronic illness; the chronic illness is viewed as destructive to self and others. People who assume this perspective tend to be absorbed in their illness experience and often have difficulty attending to the needs of their

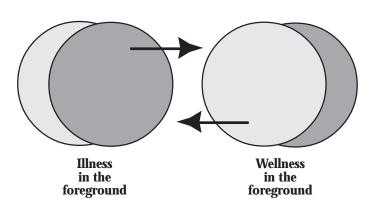


Figure 1: The Shifting Perspectives Model of Chronic Illness.

significant others. The most common depiction of this perspective occurs in newly-diagnosed people who often express being overwhelmed by the disease.

The illness in the foreground perspective has a protective, maintenance, or utilitarian function. An example of the protective function was described by Whipple and colleagues (1996) who reported that after a spinal cord injury, women feared that sexual pleasure was an unattainable goal. They focused on functions such as elimination so that they could avoid confronting their need for sexual intimacy. This perspective can also provide a means for people to maintain the identity that they desire. Some assume this perspective because they wish to maintain an identity as a sick person or because it is congruent with their social identity. People with chronic illness may assume this perspective as a means of conserving energy and other resources. For example, participants with rheumatoid arthritis in one study wanted nurses to function in a mother-surrogate role, particularly when they were in acute crisis (Kirk, 1990).

The diagnosis of a chronic disease or the onset of new disease-related symptoms forces a person to attend to the illness. Focus on illness helps a person to learn about and to reflect on the disease to come to terms with it. For example, people with spinal cord injury must see themselves as having a disability before they can come to terms with having a disability (Carpenter, 1994). In cases with few objective indicators of pathology, such as chronic pain, focusing on symptoms assists the person to provide evidence to others that the illness is real. The illness in the foreground perspective can also provide a means of commentary on one's social world. For example, one woman assumed this perspective because she needed to elicit attention from her family (Stein, 1992).

Wellness in the Foreground

The wellness in the foreground perspective includes an appraisal of the chronic illness as an opportunity for meaningful change in relationships with the environment and others. The person attempts to create consonance between self-identity and the identity that is shaped by the disease, the construction of the illness by others, and by life events (Fife, 1994). For example, Stuifbergen and colleagues (1990) reported that participants in their research described their health as good or excellent, despite significantly impaired physical functioning. That view was not a distortion of reality but a revisioning of what was possible and normal.

In the wellness in the foreground perspective, the self, not the diseased body, becomes the source of identity. The body becomes something to which things are done, not what controls the person. The body is objectified and placed at a distance, altering the relationship between mind and body so that the body is separate and "out there." People gain this perspective in many ways, particularly by learning as much as they can about the disease, creating supportive environments, developing personal skills such as negotiating,

identifying the body's unique patterns of response, and sharing their knowledge of the disease with others.

The wellness-in-the-foreground perspective allows people with chronic illness a means of mediating the effects of the disease. They shift from "a victim of circumstances to creator of circumstances" (Barroso, 1995, p. 44). Distancing from the sickness allows for a focus on the emotional, spiritual, and social aspects of life, rather than primarily on the diseased body. Outcomes of this change have been reported as a renewed sense of appreciation of life and loved ones, greater attention to others, including acting as a resource or advocate for people with the disease, and a renewed or new spirituality (Paterson, Thorne, Crawford, & Tarko, 1999). Finfgeld (1995), for example, said threats that require courage also cause people with chronic illness to learn courage.

Shifting From Wellness to Illness in the Foreground

The major factor that has been identified as fostering a shift in perspective from wellness to illness in the foreground is the perception of a threat to control. Threats to control are personally defined and may be seen by observers as unworthy of attention. Signs of disease progression, lack of skill to manage the disease, disease-related stigma, and interactions with others that emphasize dependence and hopelessness are common threats to control. Any threat to control that exceeds the person's threshold of tolerance will cause a shift in perspective from wellness to illness in the foreground. Raleigh (1992), determined that some people with cancer experienced such periods of transition when symptoms grew worse or when they received discouraging news about their disease. Life incidents and situations also can result in people with chronic illness shifting perspective from wellness to illness in the foreground. For example, mothers in one study (Primomo, 1989) indicated that their children's emotional or physical crises were often sufficient to make their own chronic illness seem overwhelming and their future bleak. Often the cumulative effect of diseaserelated losses results in a shift to illness in the foreground. Kleinman (1988) illustrated this shift in the case of Alice who developed a series of diabetes-related complications that resulted in significant changes in her lifestyle, body image, and social roles. Alice was quoted as saying, "I had to become self-centered in order to control my condition" (p. 37).

Some of the strategies people use to sustain a wellness-in-the-foreground perspective can actually result in shift to the illness-in-the-foreground perspective. Self-help groups can accentuate the sickness focus because they may require that the person focus on the sickness to participate in group discussion. Messages from others that are incongruent with the person's wellness perspective may cause a shift to an illness perspective. One woman with rheumatoid arthritis was forced to hide her illness because of her employer's discomfort with her disability; this situation caused her to abandon appropriate mobility aids and her resultant fatigue increased

her focus on the illness (Pinder, 1995). People with chronic illness learn to select people with whom they can share their experiences in ways that will not be detrimental to their preferred perspective. For example, people with an illness in-the-foreground perspective may choose practitioners who emphasize symptoms of the disease, while others who hold a wellness-in-the-foreground perspective may search for practitioners who assume a holistic stance.

Shifting From Illness to Wellness in the Foreground

The return to a wellness in the foreground perspective from the focus on sickness has been referred to by researchers as "bouncing back" with renewed hope and optimism (Dewar & Morse, 1995). Returning to a wellness in the foreground perspective requires that the person recognize that a shift to an illness-in-the-foreground perspective has occurred, identify a need to return to the wellness perspective, and implement changes or interventions to resolve or accommodate to the situation that has resulted in an illness focus. This challenge may require people to reframe the situation so that it appears less daunting or to locate resources for dealing with the situation. Or they may have to consciously disengage from attention to their illness.

The initial change in perspective from illness in the foreground to wellness in the foreground is either gradual or the result of a sudden awareness. Researchers generally assume that the change is related to the duration of the illness. Loomis and Conco (1991) determined that because participants had chronic illness for many years, their tendency was to place "health in the foreground and illness in the background" (p. 170). However, research reports are not clear about how the duration of the disease, and the experience of living with it, contributes to shifts to a wellnessin-the-foreground perspective. Limited evidence exists in this research that health care professionals and others can assist people with chronic illness to shift to a wellness perspective. Paterson and Sloan (1994) described how people with diabetes actively sought practitioners who would support the wellness-in-the-foreground perspective. Others have noted that a significant other or a person with the same disease was often a major influence on people with chronic illness to make a shift toward a wellness perspective (Raleigh, 1992; Remien, Carballo-Dieguez, & Wagner, 1995).

The Paradoxes That Arise

The Shifting Perspectives Model shows several paradoxes in the chronic illness experience. The major paradox of living in the wellness in the foreground perspective of chronic illness is that, although the sickness is distant, the management of the disease must be foremost; that is, the illness requires attention in order not to have to pay attention to it. The person must recognize the disease as a fact of life while at

the same time rejecting the limitations and significance of it. For people without a chronic illness, living life as normally as possible means the flexibility to be spontaneous in one's activities and behavior. People with chronic illness, however, have to plan and anticipate even minor activities of daily life; spontaneity must be curtailed so they can participate in the experiences they value.

Ignoring disease-related changes in order to sustain the wellness in the foreground perspective may actually contribute to disease progression. Some people with this perspective may not heed the need for supportive devices or restorative therapies until a function is lost (Shaul, 1995). Similarly, being positive is essential to the wellness in the foreground perspective, but people with chronic illness must often face devastating changes and losses. If expressions of grief or loss are seen as antithetical to the wellness in the foreground perspective, they may be reluctant to address their loss or suffering.

Another paradox is that people who find meaning, hope, and quality of life by maintaining a wellness in the foreground perspective are often required to assume an illness in the foreground perspective if they are to receive health care services. For example, one must justify the need for home care by focusing on one's limitations, symptoms, and disability, not one's wellness (Larson, 1998). Social and health care structures and policies also reinforce an illness in the foreground perspective, such as requiring that people who still wish to work instead take disability and unemployment benefits (Crossley, 1998).

The illness in the foreground perspective is a self-absorbing process that may further alienate a person from others. This distancing may result in the person experiencing even more losses and an intensified focus on the sickness. People who attend to their illness in an absorbed way may be regarded as hypochondriacs. In an effort to mediate the supposed hypochondriasis, others may avoid discussing the illness. Consequently, people may perceive that they lost the support of others and, as a result, the powerlessness and suffering of the illness experience are reinforced. A further paradox is that in order to manage the disease so that it may be kept in the background, people with chronic illness consult practitioners and others who may convey that the person is helpless, thereby emphasizing their dependency and sickness.

Discussion

According to the Shifting Perspectives Model, perspectives of chronic illness are not right or wrong but instead reflect people's needs and situations. The role of health care professionals becomes, therefore, to assist people with chronic illness to identify and understand their perspectives about the illness. In turn, practitioners must be committed to hearing what people see as important in health care (Lindsey, 1993). Although people with chronic illness may assume one predominant perspective, it is not a static entity. Health care professionals cannot assume that an approach that was

welcomed last month will be effective or even appropriate today.

The terms "acceptance" and "denial" of illness as they are traditionally used by health care professionals have little or no meaning for those with chronic illness. The Shifting Perspectives Model of chronic illness indicates the need for understanding statements of optimism and pessimism, not as failing to understand the reality of the disease, but as indicators of the person's perspective. Some people with chronic illness hold the burden of the illness in the background, behavior that might otherwise be termed "denial," so that they can sustain the sense of well-being that permits them to live as they desire.

Researchers have tended to view an irregular trajectory of chronic illness as solely based on periods of exacerbation and remission of distressing symptoms. The body of related research does not support such a conclusion. Pakenham, Dadds, and Terry (1996), for example, reported little difference between asymptomatic, newly-diagnosed and long-standing, symptomatic participants with HIV/AIDS regarding their emotional and existential issues of living with the disease. The Shifting Perspectives Model indicates additional factors such as social context and life events that may influence perspectives of chronic illness.

Many health care professionals are caught in a tradition of "rehabilitating" people with chronic illness by assisting them to accept the limitations imposed by their disease. Such an approach might be counterproductive. For example, losses and limitations may not be viewed negatively by a person with chronic illness but rather as opportunities for transformation.

Conclusions

The Shifting Perspectives Model of Chronic Illness indicates a dialectical, constantly shifting perspective in which either illness or wellness is in the foreground. This model indicates that researchers and clinicians extend the focus on chronic illness from how it affects the person's well-being to a conceptualization of the person's perspective of the illness in a larger sociocultural and psychological context. The model has reframed many aspects of living with a chronic illness. For example, what may have been interpreted as an excessive fixation on the body can now be seen as a functional response to a need or desire in living with chronic illness. The model also indicates the individuation of the chronic illness experience. It indicates reasons people vary in their attention to symptoms and it directs practitioners to support persons with either perspective. [JNS]

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