

Discourse

"Are We in Kansas Yet, Toto?" The Construction of Chronic Illness in Research

Barbara L. Paterson

This article is a discursive analysis of researchers' constructions of chronic illness and the implications of these for how we currently understand the experience of living with a chronic disease. For 2 decades, chronic illness research has been dominated by 3 main constructions of chronic illness: as generic, as static, and as decontextualized. These constructions have persisted despite recent empirical evidence that runs contrary to their underlying assumptions. Research that has upheld these constructions has provided a narrow, limited profile of the chronic illness experience, failing to account for the complexity, diversity, fluidity, and depth of the experience. The article concludes with a call for alternative constructions of chronic illness and directions for future research.

There has been a whirlwind of activity in the realm of chronic illness research in the past 2 decades. The evolution of innovative research methods and a new awareness of the ontological and epistemological underpinnings of research, combined with an expansive body of individual inquiries, have underscored the need for a critical review of this body of research (Thorne & Paterson, 2000). It is time to evaluate the accomplishments of the past 2 decades and to determine the direction of future research. In the comments that follow, I will use insights derived from a review of the research carried out over the past 2 decades to argue that the contributions of chronic illness research, though significant, are limited by the researchers' construction of chronic illness as static, generic, and/or decontextualized. From this, I will argue that the experience of living with a chronic illness is far more complex than is typically portrayed by the products of research.

Barbara L. Paterson, RN, PhD, is Associate Professor, University of British Columbia School of Nursing, Vancouver, Canada.

Chronic Illness as Generic

One of the predominant assumptions underlying research in the area of chronic illness is that elements of living with a chronic disease are common to each person and each disease. Researchers who consider the experience of chronic illness to be common across diseases have investigated constructs such as courage, support, hope, and loss among people with a variety of chronic diseases, to form a generic conceptualization of chronic illness. This body of research has been helpful in delineating shared denominators in the chronic illness experience — for example, support has been determined to be significant, no matter what the disease. However, it has resulted in a list of ingredients for the chronic illness experience with little direction as to how these interact to form the whole. This phenomenon is evident in the investigation of constructs such as courage and hope. An assumption underlying such studies is that these constructs are necessary to the acceptance of and adaptation to chronic illness (Paterson, Thorne, Crawford, & Tarko, 1999). Because researchers have investigated constructs as individual entities, we know little about how they shape and interact with other elements in the chronic illness experience, such as loss or meaning, and about the experience of people who have more than one chronic disease. Nor do we understand how and why people who do not express these constructs might still achieve satisfactory quality of life.

Identifying the commonalities in chronic illness has been useful in establishing models and standards of care. It has also helped health professionals and people with chronic illness to conceptualize chronic illness as different from acute illness in its trajectory, experience, and social and personal construction. However, it does not make sense, intuitively or experientially, to equate the experience of chronic illness in a disease such as asthma, which generally consists of periodic acute exacerbations that are resolved with medication, to that of amyotrophic lateral sclerosis, with its trajectory of increasing debilitation and ultimate death. Very few studies that include a variety of chronic diseases make distinctions among diseases in their findings. For example, several researchers have interviewed people with hypertension, generally an asymptomatic condition, together with people diagnosed as having severely debilitating diseases, when investigating concepts such as self-care, compliance, spirituality, and perceptions of health (e.g., Belgrave, Wyckle, & Cogan, 1997; Loomis & Conco, 1991; Roberson, 1992; Young, 1993). In their data analyses, these researchers did not conduct cross-group comparisons, such as for differences among people with specific diseases.

Researchers who construct chronic illness as a common experience do not consider the many variations in the chronic illness experience or why these occur. Some researchers include both newly diagnosed persons and those with longstanding disease among their sample population, despite the fact that these two groups report their experience of living with a chronic illness differently (Paterson & Thorne, in press). As well, most researchers do not differentiate between the experience of people with symptoms or disabilities and the experience of people who are asymptomatic or have no functional impairments. In diseases such as HIV and multiple sclerosis (MS), non-progressors and people in remission have been found to have different experiences of living with the disease from those who experience progression or exacerbations of the disease (Evers & Karnilowicz, 1996; Grimshaw, 1995).

Another manifestation of the generic construction of chronic illness is trajectory-based models of chronic illness, in which individuals are assumed to go through predictable stages from diagnosis to acceptance and adaptation. In these models, people with chronic illness are viewed as on a continuum from withdrawal to normalization, with normalization as the ideal (Russell, 1989). However, recent research (e.g., Dewar & Morse, 1995; Paterson et al., 1999) has challenged the assumption that there is a common and linear trajectory in chronic illness with normalization as a desirable end-point.

Context in Chronic Illness

A significant oversight in many studies of chronic illness is that the researcher fails to consider the influence of personal and social context. Although this decontextualization has been most prominent in quantitative research, it is also evident in qualitative research in this field. It often emanates from the researcher's positivistic view of chronic illness as a discrete entity that can be studied apart from its contextual influences. Researchers who construct chronic illness in this manner have tended to view the experience of living with chronic illness as determined solely by the individual's response to the disease.

Despite efforts by some researchers to study chronic illness among specific ethnic groups, the majority of qualitative studies in chronic illness include mainly white, educated, employed women (Paterson, Thorne, & Dewis, 1998). A consequence of the decontextualized construction of chronic illness is that constructs such as powerlessness have been researched as narrowly defined outcomes of the disease rather than as part of the broader social and personal matrix in which the individual lives. For example, some researchers report that participants

with MS were depressed. They conclude that having the disease made them that way (e.g., Hainsworth, 1994; Pollock & Sands, 1997). It may be that people have other reasons for their affective response that are not directly related to the disease. In our study among people with MS (Paterson, Russell, & Thorne, 2000), we found that some participants were depressed because the services they required were inaccessible. One woman spent over a week trying to arrange a vacation, only to discover that the arrangements were not honoured by the airline. Although it is entirely possible that there are elements of the disease experience that generate depression, researchers must be prepared to entertain the notion that contextual factors also shape individuals' response to their disease. For example, they may have been depressed before the illness or may be depressed for reasons unrelated to the illness.

Some researchers have attempted to validate disease-specific experiences of chronic illness by comparing the responses of people with one chronic disease to those of people with another. Because researchers have not commonly included details about the health status of the sample population or the sociocultural context of the study, the findings of much research appear to be indirectly related or completely unrelated to the disease. For example, Charles and Walters (1998) discovered that it was age and generational experience that determined how the women in their study spoke about their illness, not the disease.

Some of the research over the past decade has investigated specific chronic illnesses as a socially constructed experience. For example, research in chronic fatigue syndrome has considered how the disease has been constructed by health-care professionals because it is difficult to diagnose, invisible in its symptomatology, and found mostly in women (e.g., Goodwin, 2000). Research in HIV/AIDS has considered the effects of social stigma on the experience of living with the disease (e.g., Alonzo & Reynolds, 1995; Gatter, 1995). Rittman, Northsea, Hausauser, Green, and Swanson (1993) question the influence of the social norm of strength in the face of adversity on the experience of British people with renal failure. However, the social construction of many diseases, such as arthritis and diabetes, has been largely ignored.

Chronic Illness as Static

Researchers who construct chronic illness as a static experience have relied mainly on one-time interviews. The limitations of this method are identified by Daltroy, Larson, Eaton, Phillips, and Liang (1999), who discovered that elderly people with arthritis reported greater degrees

of disability and ill health when events caused them to focus on their illness, such as when they experienced an exacerbation of joint pain and stiffness, became depressed, or had a new medication prescribed. It is apparent in this study and others (e.g., Belgrave et al., 1997) that the ill person's perspective on the experience of chronic illness is ever-changing and that research strategies should account for this fluidity. The prevalence of one-time interviews and surveys may explain why intervention studies and recommendations for interventions arising from research findings are so exceptional in this body of research. In recent years there have been some studies of the efficacy of interventions such as the narrative approach (Kelley & Clifford, 1997) in chronic illness, but these are rare (Morse, Penrod, & Hupcey, 2000).

Directions for the Future

This has been a brief analysis of the contributions of research to the understanding of chronic illness. Three predominant constructions have been identified as lenses through which researchers have studied and interpreted the experience of living with a chronic condition. The question remains: have researchers been able to describe and deconstruct the complex reality of chronic illness? Although significant progress has been made, there is still a need for research that captures the richness and complexity of the experience of living with chronic illness. For example, the current media focus on the actor Michael J. Fox, who has Parkinson's disease, presents an opportunity to study the experience of living with this disease. Such research could consider the effect of the publicity on how Parkinson's disease is viewed socially and by people with the disease. Now that HIV/AIDS has been classified as a chronic rather than terminal disease, we need to question how the past and present conceptualizations of this disease have affected those who have it, their caregivers, and society at large (Clarke, 1994). As well, we need historical and other research into the effects of different professional approaches in health care, such as patriarchy and empowerment, on how the public, health-care professionals, and people with chronic illness perceive and respond to chronic illness.

Conclusion

Have we arrived in Kansas yet? If the destination of chronic illness research has been an explication of the complexity and richness of chronic illness as experienced over time within social and personal contexts, the answer is no. The constructions of chronic illness to date have provided only a snapshot of the chronic illness experience, because they

have limited the breadth and depth of investigations in this field of study. The hope of nurse researchers is that the findings will make a difference to the care and health of those with chronic illness. In order to reach this destination, nurse researchers in the next decade must be prepared to take into account the fluid, contextually based, individual experiences in living with chronic illness. They must be prepared to refrain from assuming that the traditional constructions of chronic illness are representative of the totality of the chronic illness experience. This will require creativity in our methodological strategies, courage in our interpretive claims, and a commitment to more in-depth and multilayered representations of what the complexity of chronic illness entails.

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