

Designer's Corner

Capturing Day-to-Day Aspects of Living with Chronic Illness: The Need for Longitudinal Designs

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You see, my time is occupied trying to live... There are those adjustments that you have to make if you're going to cope with it at all... Somehow things work out. But to say they get easier is far from the truth. They get harder. Because it's harder this year for me to even get around... It's so tremendous a frustration that I don't even think of it as a frustration. I mean, I can't explain it... But I don't sit around saying "I'm frustrated" I don't think. But I know life is one huge mountain of frustration. I think it's so big that you can't, you can't, ah, you just can't talk about it. It's hard to know what is the worst part. Because it's from the time you open your eyes in the morning until you close them at night. Your frustration never stops. And I think that's what gets ya. I can't sit and cry about it. Sometimes I wish I could... You get to the end of your tether some days and I wish sometimes I could just sit down and get a little release from it. But you can't. That's the worst part of it. Its omnipresence, you know. It never ceases.

This quote from an elderly woman who has advanced macular degeneration and is caring for a spouse who has advanced Parkinson's disease (Russell, 1994) reveals how her current life's work focuses on their illnesses. She experiences the unremitting omnipresence of chronic illness as it pervades every aspect of her life, from the moment she wakes up in the morning until the moment she falls asleep at night. However, it is not the dramatic and unexpected situations that she is referring to. Her discourse is about her ordinary, daily routine of living with chronic illness, the taken-for-granted everyday activities of one who is chronically ill.

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The chronic illness literature offers limited understanding of this space of people's lifeworld, where most of their time is spent. In this paper, we invite researchers to consider the importance of longitudinal research that addresses everyday life in chronic illness. After providing a foundation for the need for such research, we offer brief suggestions for conducting it.

Although ordinary human life is often portrayed as a simple phenomenon whose actors employ a standard problem-solving metaphor, in reality it is a problematic and complex process that has spawned an entire field of study (Caughey, 1983). Everyday life in the presence of chronic illness is likely more complex than life without illness. While the complexity is not caused by major interruptions and catastrophic occurrences — although such interruptions and catastrophes do occur along the trajectories of the chronic illness experience — researchers tend to focus on the problematic, dramatic, and unexpected situations that punctuate everyday life in chronic illness. In many respects, funding agencies implicitly dictate this focus through mandates for research that contributes to problem resolution.

There is a distinct discrepancy between the temporal patterning of chronic illness as it is played out slowly and the majority of research that is undertaken and funded in 1-, 2-, or 3-year cycles with an eye to achieving statistical significance. Although knowledge about the extreme or extraordinary situations offers a valuable perspective, persons living with chronic illness do not spend most of their lives in such situations. Their days consist primarily of the ordinary, mundane, and routine. It is within this ordinariness, however, that the self as harbour to chronic illness is continually shaped, refined, and reformed, reflecting one's experiences and emotions as well as one's interactions with institutions and other individuals. People living with chronic illness must continually adjust to their disease as it is played out and as their bodies and their lives yield to accommodate it. At the very moment when people are occupied with trying to live with chronic illness, they are also testing out personal hypotheses about caring for self, making decisions about their health and illness, and experiencing a range of emotions, from the depths of suffering to the humour found in life's most absurd moments. There is an ebb and flow to everyday life in chronic illness, life in all its bitter-sweetness (Gregory & Russell, 1999). More fully understanding the chronic illness experience necessitates longitudinal research into everyday life as it is lived.

Conducting such research is not a simple matter, as attention to the processual nature of the chronic illness experience and its many facets

sets specific conditions. First, attending to process and change/stability over time requires longitudinal methods of data collection and analysis that favour observation of individuals in their lifeworlds as they go about their daily activities. An over-reliance on interviews is problematic, as the routine and mundane (the "normal") is so embedded in the taken-for-granted that people have difficulty discussing it or even thinking it worthy of comment (Douglas, 1976; Olesen, 1992; Robinson, 1988; Thorne, 1993). Such studies require innovative, novel approaches to gathering, tracking, and analyzing large longitudinal data sets. Second, the facets that affect one's life and one's illness experiences are numerous and pervasive, existing as they do on micro and macro levels — physiological-individual, interpersonal-interactional, social-institutional (Kleinman, 1988; Mechanic, 1995; Olesen; Thorne). Any effort to reach a more complete understanding of everyday life in chronic illness must be accompanied by the realization that no one disciplinary perspective will be singularly useful; the topic requires incorporation of phenomenological and existential perspectives as well as interactionist and functional/structural ones (Caughey, 1983; Ellis, 1991; Olesen; Thorne). Such complex and time-consuming investigations call for an interdisciplinary approach, and the valuable time of researchers and participants can best be maximized by ensuring interdisciplinary collaboration throughout, from design through data collection and analysis.

In summary, researching the everyday lives of persons with chronic illness presents numerous challenges. It requires that disciplinary boundaries be transcended, time and resources be invested in developing and implementing innovative research approaches, and funding agencies be pressed to tolerate complex studies and to fund proposals by investigators who are innovative and have the courage to research the chronic illness experience beyond the comfort of narrowly defined studies. Such narrowly defined studies remain important for their potential to contribute statistically significant findings; however, they should be complemented by creatively designed longitudinal research studies that might enhance our understanding of clinically significant and meaningful findings about everyday life in chronic illness. Complex longitudinal designs will lead ultimately to a more complete knowledge base that reflects the complexity of everyday life in chronic illness.

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