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Good Days, Bad Days: The Self in Chronic Illness and Time

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Kathy Charmaz provides the reader with a well-written, thorough, and complete rendition of the effects on the self of living with a chronic illness. We are led through the lives of 55 people who have chronic illnesses such as arthritis, diabetes, emphysema, Hodgkin's lymphoma, lupus erythematosus, multiple sclerosis, mixed connective tissue disease, renal failure, and many others. These diseases are characterized by periods of remission, when illness symptoms are quiescent and may not interfere with life and are not apparent to others, and exacerbation, when symptoms again demand attention and may leave the person incapacitated.

The author states several goals. She wants the reader to experience through her interpretive sociology the "private face of a public problem" (p. 4), what illness and disability mean to people who have a chronic disease. Further, she is interested in the concepts of time and self, how people define and experience time and self and how self changes because of illness. "Living with serious illness and disability can catapult people into a separate reality—with its own rules, rhythm, and tempo" (p. 4). The literature in the sociology of health and illness is rich with ethnographies, studies of emotions, and investigations into how medical students are socialized, and is characterized by an interactionist perspective in the tradition of Mead precisely because definitions of diseases and the meanings attached to illness are changeable. Charmaz states that she has gone beyond these prior works by focusing on the depth of the experiences portrayed, and on how the struggle for control over time and illness is a "struggle to control the defining images of self" (p. viii).

Charmaz presents a well-documented and insightful telling of her interviewees' stories following the Glaser and Strauss grounded theory method, which emphasizes refining and developing one's theoretical constructs from emergent categories. She not only conducted lengthy qualitative interviews once but reinterviewed half her subjects and then followed 16 of them for 5 to 11 years, acting in effect as a participant observer. She refers to her methodology as social constructionist and phenomenological. Given the elusive nature of self and time, and the inevitable change in her subjects over time because of the nature of their diseases, she is able by reinterviewing to demonstrate how people construct and reconstruct their identities.
The book is broken into three major sections plus an introduction, epilogue, methodological appendix, notes, and glossary of medical conditions. Part I focuses on “Experiencing Chronic Illness,” including illness as interruption, intrusive illness, and immersion in illness. Each chapter is presented as a series of categories which can have subcategories. For example, in Chapter 2, “Chronic Illness as Interruption,” she lists and illustrates from her interviews four ways in which a person might define illness as interruption. She then introduces the experience of time as elusive time, waiting time, or crisis time. For example, someone who believes illness will be temporary will experience waiting for recovery. In Chapter 4, “Immersion in Illness,” time is categorized as unchanging time, dragging and drifting time, and immersion time in retrospect.

Part II deals with the practical problems of living with chronic illness. The chapter “Disclosing Illness” illustrates the many dilemmas disclosure can present with regard to employment, spouses, and other family members. Two categories, for example, which she examines in the chapter “Living with Chronic Illness” are simplifying life and reordering time and scheduling.

Part III contains four chapters: “Time Perspectives and Time Structures,” “Timemakers and Turning Points,” “The Self in Time,” and “Lessons from the Experience of Illness.” The first two of these chapters focus on such issues as living one day at a time, mapping a future, creating a chronology of one’s illness, finding positive events, and looking at past selves and past emotions. Finally the book culminates with looking at the self in the past, present, and future. The last chapter is a brief excursion into social policy.

Although very well written, this book felt a bit tedious. Each category and subcategory is well-illustrated, but at times I felt as if I were reading only strings of excerpts from people’s lives.

Stylistic points aside, Charmaz does not define social policy implications. Only four pages are devoted to this very large topic, which is far more complicated than she indicates. She essentially calls for the health care system to provide more services. She does “grant” that some hospitals might offer a rehabilitation program, but she glosses over that. At a time when the health care system is itself in a deep crisis, suggesting that more services be offered is not practical and, worse, trivializes the rest of her message. A challenge for Charmaz or other researchers in health care would be to document the many programs which do exist to support patients and to show their strengths and deficiencies for supporting a positive view of self. Also, how might Medicare and Medicaid be restructured to emphasize prevention, wellness, and positive views of self for the chronically ill which might have the spin-off of reducing health care costs?