

## Chapter 27

# Social Construction of Chronic Disease: Narratives on the Experience of Chronic Illness

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### **ABSTRACT**

*In this study of narratives in relation to chronic illness, a number of themes relevant to patients were identified from the literature for discussion and analysis. Themes included responsibility and control of chronic illness, stigma and non-legitimation. Discussions and blogs on the Internet were identified and examined representing patient experiences of chronic illness. For some patients taking responsibility for their chronic illness conflicted with some of their important life roles. There were also questions about the degree to which people who already manage busy lives should also be managing their disease. It was found that some patients experience control over their illness and behaviour as a difficulty they faced with a chronic condition. This included being placed on a regimen and reviewed for compliance. Some referred to the experience as policing. Patients who reported some greater difficulties were those with illnesses which struggled to achieve legitimacy through medical means. Their illness experience and outcomes were largely dependent on seeking out sympathetic medical practitioners. Overall the authors conclude that notwithstanding the benefits of selfmanagement programs for patients, the uncertainty surrounding chronic illness creates problems for patients and reinforces the importance of having effective and trusting relationships with their health care providers. A typical biomedical perspective on illness tends to focus on disease and its causes without considering the social world within which health and illness occur, and the way in which social forces shape these concepts and experiences. Sociologists and some progressive medical practitioner researchers are concerned with social process and with the effect of factors such as gender relations, social class and the broader political economy on understanding the experience and prevalence of disease. The aim of this chapter is to present some narratives by patients, consumers, medical and health practitioners, and other stakeholders in blogs, discussions and forums*

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*on the Internet. This chapter looks at a number of aspects of chronic illness that have been identified in a range of studies, from aspects of responsibility of patients and control processes on chronic illness patients through to non-legitimate and resistance themes.*

## **NARRATIVE ANALYSIS**

Williams (2006) argues the way that people's beliefs about the causes of illness or disease can best be understood is by a process of narrative reconstruction. A number of authors have reviewed studies of illness and narrative (for example Hyden, 1997, Kleinman, 1988, Foster, 2008). According to Whitehead 'narrativising the chronic illness within the framework of one's own life history makes it possible to give meaning to events that have disrupted and have changed the course of one's life' (2006: 2236). Key factors to affect narrative reconstruction include the nature of diagnosis, any relapse and conflicts with providers of care (note Whitehead, 2006).

Whitehead argues that 'narrative theory is increasingly employed to understand the subjective experience of illness with growing recognition that narratives are the means by which we render our existence as meaningful' (2006:2237).

Previously the narrative approach was seen as an alternative to positivist approaches to understanding. Frank (1998) explored how stories were an opportunity for self expression and led to more power in wider relations. One example of using Frank's work in linking themes and types of narratives is Ezzy's (2000) study of people living with HIV. Most recently Kahan (2009) has used Frank's framework to investigate narratives of public dentistry patients in Australia.

Other studies to use narrative analysis include Fox and Ward's (2006) exploration of health identities originating in the sociopsychological contexts of modernity. They looked at health experts who took on biomedical explanations of health and illness and 'resistant consumers' who explored experiential models of health and the body.

Writers within the tradition of conflict theory such as Coburn (2004) and Navarro (2007) have ar-

gued that neoliberal interpretations of relationships in modern developed societies, underpin competing narrative about health and illness. Societies pursuing neoliberal policies they argue are creating larger divisions between the wealthy and the poor. Those disadvantaged by lack of income and power are more likely to develop counter explanations of phenomena including for their health and illness. We can see that some of these counter narratives are based on differences in power, influence and opportunity that are reflected in people's stories about their illnesses, as Blaxter (2004) found in her classic study of health. Consequently, based on Coburn (2004) and Navarro's (2007) analysis class difference and disadvantage for some is at the root of differing narratives.

At the core of most medical sociological explanation of chronic illness is a social constructivist epistemological base. Social constructivism became particularly prominent during the 1990s. Brown (1995) argues that while social construction is a commonly used term it has not been defined systematically and therefore has many meanings. In medical sociology he argues there are three versions of social constructivism. The first is concerned with social definitions of illness, and focuses on individual and group activities related to illness conditions. An important consideration often not considered strongly enough is that social structures play an important role in health and illness. The second was based on the work of Foucault and postmodernism and sets about to deconstruct language together with symbols to show knowledge creation, and explore the situation's "realities." (Brown, 1995). This includes some of the important work of Bryan Turner on the Sociology of the Body (2008), and its concerns with symbols. The third version focuses on the proposition that facts are based on mutual actions by scientists at work together with their efforts

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