

# Self within a climate of contention: Experiences of chronic fatigue syndrome

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## Abstract

Chronic fatigue syndrome (CFS) is a contested condition associated with scepticism and dispute. This qualitative project examines the illness experiences, and specifically the experiences of self, for people affected with CFS living in Australia. Using grounded theory methods, theory related to the process of self-renewal and adaptation associated with CFS is explicated. Narratives were derived from semi-structured interviews with 19 adults, including 3 people recovered from CFS. Analysis generated the narrative of the struggling self seeking renewal that defined the illness experience of CFS. The struggling self articulated the negative effects to self and personhood associated with CFS, defined as the violation of self, and the consequent efforts of participants to manage symptoms and decrease their violation by use of what was termed the Guardian Response and the Reconstructing Response. The Guardian Response provided protection and self-reclamation. The Reconstructing Response fostered self-renewal and meaning. The struggling self occurred within a climate of threats, and it was these threats which provided the catalyst for violation and the responses. Under different conditions the relative strengths of violation, guardianship or reconstruction fluctuated, and it was these fluctuations that presented the participants with the ongoing struggle of CFS.

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## Background

The potential for chronic illness to disrupt the integrity of self-perceptions has been well documented and there is a substantial body of research that describes a general process of damage and repair to self. Chronically ill people have been described, for example, as “transcending the self” (Lindsey, 1996, p. 465) “regaining a valued self” (Swanson & Chenitz, 1993, p. 270), or developing a “redefinition

of self” (Anderson, 1991, p. 712). These transformative findings provide a partial understanding of chronic illness that reflects current trends. Over two decades, there has been a conceptual shift in the constructions of chronic illness from loss and burden to normality and transformation, and caution has been expressed regarding the idealisation of the chronically ill person as powerful and able, while minimising the multifaceted nature of chronic illness that includes disabling aspects (Thorne & Paterson, 1998). The lives of people with chronic illnesses, for example, have also been described as “tumultuous existences” and “fractured” (Vickers, 2000, p. 4). Alongside the

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potential for positive transformation resides on-going loss and suffering.

Chronic illnesses that are outside the confines of medical legitimacy, that is, contested illnesses, offer a different prism for the investigation of self-perceptions. Illness experiences of people with contested conditions include an additional burden related to scepticism and dissension. People with contested conditions typically report disbelief from medical practitioners regarding their symptomatic accounts (Glenton, 2003), psychological explanations for physical symptoms (Garro, 1994) and an absence of medical care (Gibson, Placek, Lane, Brohimer, & Lovelace, 2005). Contention brings with it judgments about those affected. There is evidence that medical practitioners perceive people with contested conditions as possessing negative qualities, such as illness-fixation and pessimism (Åsbring & Närvänen, 2003). This context of delegitimation influences illness experiences, with reports of contention contributing to altered self-perceptions, for example, disrupted identity among people with multiple chemical sensitivity (Gibson et al., 2005), and feelings of worthlessness and 'character blemish' (p. 2249) among people with back pain (Glenton, 2003).

Chronic fatigue syndrome (CFS) is a high profile contested condition. Although the syndrome has been the focus of substantial scientific attention, population heterogeneity and methodological differences have contributed to considerable variation among findings (Cairns & Hotopf, 2005). CFS is characterised by ongoing, extreme fatigue that is unchanged by rest and exacerbated by minimal activity, and by unpredictable flu-like symptoms (Fukuda et al., 1994). Causes remain unknown and there is no standardised treatment. Improvement is generally reported but residual symptoms persist, relapses occur, and recovery is rare (Cairns & Hotopf, 2005). Detrimental effects to the individual are significant, with research indicating marked functional impairment (Buchwald, Pearlman, Umali, Schmalig, & Katon, 1996), low levels of social support (Schoofs, Bambini, Ronning, Bielak, & Woehl, 2004) and a poor quality of life (Rakib et al., 2005). These detrimental personal effects are reported in other contested conditions and represent burdens common to delegitimised illnesses (Gibson et al., 2005). There is robust medical disagreement about the legitimacy of CFS as a distinct condition (Steven et al., 2000) and debate regarding physical/organic versus mind/psychiatric explanations of

causation (Shepherd, 1997; Wessely, 1997). Consistent with other contested conditions, there is a school of thought that postulates that people with CFS are, to some degree, contributors to their disability as a result of personality or behaviours (Fischler et al., 1997; White & Schweitzer, 2000).

While a comprehensive articulation is limited, research has begun to address experiences of CFS. An exploration of the illness experience using Frank's narrative typologies described a CFS trajectory beginning with restitution that progressed to a chaos narrative, back to restitution, and on to a quest narrative (Whitehead, 2006). Another study of the ways people learn to live with CFS identified two experiential phases (Edwards, Thompson, & Blair, 2007). Phase 1, 'overwhelmed by CFS', was characterised by 'a really awful time', 'an invisible illness' and 'fighting it' (p. 206). Phase 2, 'learning to live with CFS' included characteristics of self-help, learning to 'pace', and positive thinking (p. 206). Movement occurred between phases, with mediating factors influential to feelings of control. The characteristic of movement/progression described in the findings of these two studies is a feature widely reported in the chronic illness literature (Paterson, 2001), suggesting it is related to chronicity rather than representing a phenomenon specific to contested conditions or CFS in particular.

There is a paucity of studies that address self-perceptions and CFS, and the extent of identity disruption has not been substantially explored (Gray & Fossey, 2003). In a study that addressed the effects of contention on self among people with CFS, Clarke and James (2003) reported that, over time and in response to separation from their previous everyday lives, people with CFS rejected former selves and established new selves. Clarke and James noted that their findings contrasted with earlier chronic illness research in which a desire for a former, restored self is reported. They explained this difference as arising from the contested nature of CFS and suggested that this contention denied people with the condition a legitimate place in the social order. In the absence of legitimising discourses, people created new identities, that is, a radicalised self. These findings suggest that contention results in experiences of self different to those encountered with legitimated chronic conditions.

Other researchers have reported a disrupted sense of identity and competence (Gray & Fossey, 2003), a loss of self (Edwards et al., 2007), and low levels of self-esteem among people with CFS

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