From Violation to Reconstruction:
The Process of Self-Renewal Associated with Chronic Fatigue Syndrome

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Declaration of Authorship

I hereby certify that this thesis is original work, and that, to the best of my knowledge and belief, it contains no material previously published and/or written by another person, nor material which to a substantial extent has been submitted for a degree or diploma to any other university or institution, except where due acknowledgement has been made in the text.

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Abstract

Chronic Fatigue Syndrome (CFS) is a contested condition that generates scepticism and occupies a marginalised position within medical and social contexts. The thesis examines the illness experiences, and specifically the experiences of self, for people affected with CFS. Using qualitative inquiry, a substantive theory related to the process of self-renewal and adaptation associated with CFS is explicated. The theory encompasses the trajectory of CFS from onset to chronicity, and in exceptional instances, recovery. Illness narratives were derived from in-depth, semi-structured interviews of 19 adults, including 16 people affected with, and 3 people recovered from, CFS. Data was coded and analysed using a grounded theory approach.

Analysis generated two parallel narratives that defined the illness experience of CFS: the narrative of the illness biographies and the narrative of self, specifically the struggling and diminished self seeking renewal. The illness biographies encompassed the stories of symptoms and their explanations, the encounters that ensued and their contentious milieu. The narrative of self was the primary narrative. It articulated the negative consequences to self and personhood associated with CFS, named the Violation of Self, and the consequent efforts of participants to decrease the struggle and violation by use of the Guardian Response and the Reconstructing Response. The Guardian Response provided protection and self-reclamation. The Reconstructing Response fostered self-renewal and meaning. The two narratives were bridged by the threats of CFS. That is, the illness biographies were accompanied by threats of disruption related to chronic illness, and by threats of invalidation that arose from CFS as a contested condition. In turn, these threats provided the catalyst to the violation and responses as described in the narrative of self. 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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Preface

The study is concerned with the illness experiences of chronic fatigue syndrome (CFS), with special reference to a narrative of self. While ‘self’ (and its dimensions) is a commonly used construct, it is not necessarily an agreed upon construct, and theoretical and conceptual differences are found within the literature. In this study the narrative emerged through the use of grounded theory methods, therefore it is the participants’ perceptions and definitions of self that have been used in the analysis.

Participants defined themselves in terms of past, present and future. The known-self was the before CFS, symptom free, and almost always preferred (past) self. The future-self was conceptualised in terms of possibilities and reflected the construct of possible selves as defined by Markus and Nurius (1986), that is, representations of what individuals could become, would like to become, or were afraid of becoming. Additionally, within the text, self-with-CFS is the term used to identify experiences of self while affected with CFS. The participants’ specific meanings of self are described in detail in Chapter 7.

The study included people who had a current diagnosis of CFS and were continuing to experience its symptoms and effects. These participants are referred to as “affected participants”. People with a past diagnosis of CFS who considered themselves to be recovered or significantly improved were also included, and are referred to as “recovered participants”. When the recollections of the recovered participants were found to be consistent with the experiences of the affected participants, findings were incorporated and presented as *participant findings*. Consequently, statements such as “pain was a common and ongoing symptom among participants” refer to the affected participants **and** the recovered participants recalling their CFS experiences.

Key to Transcripts

Participant 1 – Participant 19	Identifying code for participants, indicating the order of the interview sessions
Italics	Extracts from the participants' interviews
Participant 5R Participant 17R Participant 19R	R denotes recovered participants
X, Y	Pseudonym for name, place or other potential identifying label
[square brackets]	Researcher's comments added to provide clarity or explanation
. . .	Material edited out

Chapter 1

Introduction

Overview of Chronic Fatigue Syndrome

This thesis is about the experience of Chronic Fatigue Syndrome. Chronic Fatigue Syndrome (CFS) is a debilitating, multi-systemic and distressing condition for which there is currently no known aetiology, an uncertain prognosis, no agreed-upon treatments or management strategies, and confusing recommendations for people affected with the syndrome. The condition presents a complex and puzzling picture for researchers and has been a focus of investigation from a number of disciplines. For people who have CFS, the illness remains a challenging and frequently overwhelming experience.

Debate and conflict surrounds the diagnosis, classification, treatment and prognosis of CFS. Medical disagreements are common and span the entirety of CFS from its legitimacy and credibility as an illness through to its outcomes. Specifically, there are marked differences in medical opinions regarding its existence, nature, possible causes, its natural progression as a syndrome, and ways to treat or manage it. There are also significant discrepancies in the symptoms, course, functional impairments and outcomes of the condition among the CFS population. This is reflected in a dissimilar, heterogeneous population that has proven problematic to diagnosis and research. Some researchers argue that the heterogeneity arises from an erroneous categorisation of unrelated and non-specific symptomatology that does not signify a single syndrome. Others argue that CFS is a distinct entity with a unique pathophysiology and that heterogeneity may reflect the presence of CFS subtypes (Fukuda et al., 1994; Jason & Taylor, 2002; Loblay, 1995).

Although the symptom cluster was first named Chronic Fatigue Syndrome by the Centers for Disease Control and Prevention (CDC, Atlanta, USA) in 1988 (Holmes et al., 1988), its existence as a new diagnostic entity has been contested (Kim, 1994). Internationally, a number of diagnostic criteria are in use including those from the

CDC, United States of America (Fukuda et al., 1994), Australia (Lloyd, Wakefield, Boughton, & Dwyer, 1988) and the United Kingdom (Sharpe et al., 1991). There is no specific diagnostic test and routine medical investigations usually do not find significant abnormalities. Therefore, CFS is defined clinically and diagnosed when other conditions associated with chronic fatigue have been excluded (Fukuda et al., 1994).

CFS is relatively common and affects people of all ages, with rates tending to peak during middle age. More women than men are affected and it is found across ethnic and socioeconomic groups (Jason et al., 1999). Typically, CFS presents as an acute viral or flu-like illness although onset can also be gradual (DeLuca, Johnson, Ellis, & Natelson, 1997). The symptom complex is diverse and unpredictable. It is characterised by extreme and disabling fatigue that is not modified by rest and that is exacerbated by minimal physical and mental activity. Contrary to the nomenclature, fatigue is not the only, or necessarily the most distressing, symptom. Chronic symptoms of post-exertional malaise, myalgia, arthralgia, muscle weakness, headache, sore throat, painful and swollen lymph nodes, non-restorative sleep, and neuropsychological symptoms such as difficulties in concentration and loss of short-term memory are commonly reported. Other symptoms include disturbances of balance, light sensitivity, speech disturbances, gastrointestinal disturbances, light headedness and perceptions of fever (de Becker, McGregor, & de Meirleir, 2001; Fukuda et al., 1994).

The symptomatic experience is complicated by unrelated and frequent variations in severity, intensity and type of symptom. Consequently, the person’s well-being can fluctuate markedly from day to day or within the same day (Dougall, Baum, & Jenkins, 1998). Typically improvement is slow, occurring over a number of years. The prognosis for CFS is not well understood with different definitions of recovery and the heterogeneous population proving problematic. Recovery is most likely in the early years but it is not always permanent and relapses of the condition appear to be common. It is clear, however, that many people remain, to varying degrees, chronically ill (Pheley, Melby, Schenck, Mandel, & Peterson, 1999; Reyes et al., 1999).

The causes of CFS have not been determined. Aetiological hypotheses, possible contributors and related findings have included central nervous system dysfunction (Evengard, Schacterle, & Komaroff, 1999), immunological abnormalities (Patarca, 2001), post-infection syndromes (White et al., 1998), psychiatric conditions (Wessely, 1997) and sleep disturbances (Fischler, Le Bon et al., 1997). Current thinking on causation suggests that no single or simple aetiology is likely to be found (Loblay et al., 2002). There are no treatments for CFS and management is aimed toward the relief of symptoms and gradual rehabilitation.

Research has indicated that CFS is frequently associated with a significant reduction in personal, social and occupational activities. Functional impairment, restrictions to social involvement, difficulties with relationships, decreased ability to fulfil social/familial roles, and disruptions in work practices have been commonly reported (Komaroff, Fagiolo, Doolittle et al., 1996; Tuck & Wallace, 2000). Additionally, people with CFS report a poor quality of life (Hardt et al., 2001).

CFS is a chronic illness and as such requires ongoing adaptation and management. CFS is also a contested illness that has been typified by opposing stances, medical and social debate, and frequently, conflicting multiple agendas among groups with vested interests in how the condition is understood and defined. Much of the controversy involves the perceived credibility of the syndrome. There is a strong school of thought that CFS is not a "real" or unique medical condition. There is also debate regarding the physical/organic versus mind/psychological explanations of causation. These differing viewpoints communicate, or are associated with, dichotomous attitudes or responses such as belief or scepticism, support or stigma. Further, given the absence of any defining physical pathology, there has been a tendency to hold individuals with CFS responsible for their condition with attributes of malingering or personal failings being ascribed to them. For example, the label of "yuppie flu" (Richman, Jason, Taylor, & Jahn, 2000, p. 178) that was popular in the 1980s and 1990s signified the disdain with which the condition and those affected have historically been viewed. It is this specific medical and social climate, in

addition to the general challenges of managing a chronic illness, which affects the lives of people with CFS.

Foci of the CFS Research

Although there has been a marked increase in the medical, psychological and sociological research related to CFS in the last 20 years, the literature has tended to focus on a number of defined areas. Medicine has focused on aetiologies, classification and diagnosis, prognosis, prevalence and outcomes, and neuropsychiatric status. To a lesser extent functional impairments and medical management have been investigated. Comparative studies have featured amongst the medical research, and include comparisons of CFS with Epstein-Barr virus, fibromyalgia, rheumatoid arthritis, multiple sclerosis, irritable bowel syndrome, repetitive strain injury, Gulf War syndrome, depression, and somatisation disorders. The psychological literature has concentrated on functional impairments (particularly neuropsychological and cognitive), psychosocial antecedents and predispositions, illness attributions and behaviour, and psychobehavioural characteristics and personality. There has been some work related to quality of life, coping, and management with cognitive behaviour therapy (CBT) accounting for most of the management focus. (The medical research on management has similarly focused on CBT.) Sociological research has addressed social course and process, social construction, legitimation, and the professional and popular views related to CFS. With a few exceptions, there has been limited research reported in nursing journals. The nursing literature has focused on updates, overviews and summaries, and personal accounts. Consequently, there is little that informs nursing's view of CFS, nor how patients with the condition are nursed.

The different discipline perspectives have addressed the same research questions so that common issues and debates are evident. Research questions have mostly centred around the "what" (classification), "how" (causation), and "when and where" (epidemiology) of CFS, in addition to assessment of dysfunction. Measurement and quantification are most appropriate to answering these questions, and most CFS research has utilised a quantitative methodology. The dominance of quantitative

research, however, results in a CFS knowledge base that is derived from a singular and narrow perspective[1].

The emphasis on aetiology, classification and dysfunction contrasts with the lack of research regarding the experiences of living with CFS. The daily lives of people with CFS, the everyday consequences, the personal and social worlds of CFS, and the meanings attached to the experiences of CFS have not been adequately articulated. In sum, qualitative aspects of living with CFS have attracted little attention. By neglecting the lived experiences and dimensions of everyday activities, the potential benefits of such a research focus remain unexplored. This research gap is of clinical and societal concern because of the chronicity, severity and intrusiveness of the symptoms, and the predominantly pessimistic outcomes, marked functional impairments, poor quality of life and consequent distress that is reported among people with CFS.

The present study helps to address this imbalance within the CFS research. The study examines the experiences of people with CFS, their everyday worlds, and the effects of the syndrome on their lives. The use of qualitative method aims to generate a fresh perspective and a different understanding of CFS to that which dominates the current knowledge base.

Aims of the Study

The general aim of the study was to explore the illness experiences of people affected by CFS, with a particular emphasis on exploring their sense of self. Specifically, the study aimed to examine the nature of the self-with-CFS, and the relationships between self and the illness experiences of CFS.

[1] In the main, the literature review of the thesis does not identify individual studies as quantitative, although most qualitative studies are identified as such. Generally, it is clear which studies are quantitative because reference is made to measures, standardised tests and so forth.

Need for the Study

Living with any chronic illness presents special challenges in societies that value independence, productivity, self-reliance and action. In addition, CFS presents a clinically complex picture that is complicated by the questions and doubts associated with the condition. It requires responses and a tolerance of uncertainty not easily accommodated within existing societal and medical frameworks. Consequently, experiences and perceptions of self are likely to be affected by the symptoms, course and outcomes, by the medical and social climates, and by the debates among researchers and clinicians regarding the essential nature of the syndrome, including its existence as a discrete condition. Additionally, the functional impairments that contribute to an often poor quality of life and the need for ongoing management in the absence of agreed upon protocols are also likely to affect experiences of self. To date there has been little research that examines experiences of illness and self for people with CFS.

Origins of the Study: My Experiences

My interest in CFS as a research topic was initially sparked from my personal experience of the syndrome. Additionally, it was consistent with my occupation as a university lecturer in nursing. CFS has affected me for 14 years, and I was at my worse for nine of those years. My medical specialist told me that I was moderately affected and had presented as a classic case of CFS. I am now markedly improved and the last 6 years have been typified by a slow recovery with occasional relapses. I still have periods of illness and experience some symptoms most days, but I am mostly able to live my life without the constant constraint of CFS.

Midway into the illness I enrolled as a part-time PhD candidate to investigate the psychosocial aspects of CFS. The motivation to do so and the choice of topic came from a number of sources. The process of immersing myself in such an intellectual endeavour had been a long-standing goal. I was also motivated to turn the presence of CFS into a positive force within my life. Studying for a PhD became a way to compensate for the losses associated with CFS while working towards an ambition that predated my illness. The belief that I was in a unique position to conduct research into CFS was an additional motivator. I had read much of the CFS research,

had a good grasp of its clinical status, was able to identify substantial gaps in the research, and was familiar with the controversies and discourses surrounding the syndrome. I believed that my qualifications and clinical and teaching experience would provide me with some of the skills and knowledge necessary to research the area. Additionally, my own experiences of CFS provided insights and glimpses of possibilities that perhaps only emerge from an insider's perspective.

In retrospect, given how ill I was at that time and the marked limitations on my life, I am surprised at how little I thought about my physical, mental or emotional resources and whether these resources were adequate for a project the magnitude of a PhD. I purposefully adopted an expectation that my health would improve and the time frame afforded to part-time candidates seemed to be reasonable. Therefore I (naively) envisaged improvement in my health and progression with the study as achievable outcomes. At a deeper level, a self-evaluation of my capabilities was too great a threat, and to a large extent I refused to think about the possibility of failure or the potentially adverse effects on my already marginal health. I began with a mind-set of optimism, denial and a belief in my ability to persevere.

Given that the study originated from my experiences of being ill with CFS, it is important that aspects of my story are articulated. The insider's perspective is of influence during the entire research process and throughout the thesis I have endeavoured to make explicit my place within the study. Therefore, my story is included as a context to assist the reader in understanding and evaluating the direction, method and analysis of the study.

I was 34 years of age when I became sick with a flu-like illness that was diagnosed as a viral infection. The treating medical practitioner recommended that I rest, treat the symptoms, drink plenty of fluids and come back if I did not improve. The symptoms of muscle aches and pains, headaches, tender lymph glands, sore throat and fatigue did not particularly worry me. Since the time I had worked in a respiratory Intensive Care Unit 10 years previously I had become ill with these symptoms, usually each winter. I had always recovered and it did not occur to me that this time would be any different. I was on annual leave when I became ill and

after a couple of weeks of resting I returned to work when expected. It was some months before I acknowledged to myself that I had not improved, that I wasn't simply tired because I'd gone back to work, that my muscles ached regardless of whether I rested, and that the symptoms had remained a constant presence since their initial onset. Some symptoms such as the muscle pain were becoming worse. I went back to the medical practitioner.

I was now diagnosed with post-viral syndrome. It seemed that the defining quality of post-viral syndrome was a longer-than-normal recovery period and I didn't know how to manage this, or indeed, what I was meant to manage or expect. The medical practitioner told me to rest and not over-extend myself but was unclear as to what and how much constituted rest or over-exertion. Specific questions such as "should I take sick leave" elicited vague responses. That was up to me, I wasn't contagious, I should do what I could manage. But what was "managing"? When I wasn't working I was in bed. The symptoms were unrelenting, my usual activities became impossible and I felt constantly ill. Was that managing? Meanwhile, diagnostic tests were carried out and although there were anomalies, they were mostly non-significant. During this time I felt my relationship with the medical practitioner changing. Previously I had consulted the medical practitioner infrequently, and considered the relationship to be one of collaboration and equality. I was familiar with the language and culture of medicine and possessed skills (and status) beneficial to the negotiation of medical encounters. To my confusion, numerous diagnostic tests continued to report mostly normal findings, yet my symptoms persisted, and I started to feel like a "bad" patient. I could see the doctor's frustration and began to question whether she believed me. I dreaded consultations.

A sense of failing to meet my obligations began to pervade my relationships. Initially the ongoing nature of the symptoms had been associated with sympathy from others that I was still unwell, but as the symptoms continued and the tests remained mostly normal, I was aware of changing attitudes. I began to detect impatience, and inquiries regarding the results of diagnostic tests now included suggestions of stress or burn-out as possible causes. I was not threatened by these interpretations because I too had questioned such possibilities. Rather, feelings of

puzzlement and failure arose from my apparent inability to rectify the stress or burn-out.

After 11 months from the initial onset, the medical practitioner told me that she thought I might have CFS. There was some initial relief at having a diagnosis other than the vague post-viral syndrome, but I soon felt that one generic label had been swapped for another generic label that was also typified by an absence of information. The outcomes of CFS were unclear and the absence of treatment meant that my hit-and-miss attempts at management would have to continue. What little information was available was of small comfort (and as I found out, wildly inaccurate). I opened the first book I could find on CFS to the heading, "How to obtain a wheelchair".

At the time I was diagnosed few people had heard of CFS. With an increase in media coverage, the syndrome and its controversies entered the public domain. CFS was rapidly becoming politicised, debated and associated with strong and opposing views. Usual social boundaries regarding the privacy of illness did not appear to apply to CFS and even strangers who (somehow) knew of my diagnosis automatically shared their beliefs with me about the causes of the illness. I was asked if I thought CFS was "just depression", or a physical manifestation of not coping, or an unconscious strategy for "time out". My behaviour, personality, values and existence were now subject to interpretation, discussion and judgement in ways that had not happened before my diagnosis. This left me feeling exposed and vulnerable within my relationships and interactions. I felt that for others I had become my illness.

The effects of CFS on my life were profound. Activities and interests that I had previously enjoyed were no longer possible. Relationships and friendships gradually faded and disappeared as my ability to participate in social activities diminished. Financial needs dictated that I maintain my employment for as long as possible, however, continuing to work was important for other reasons. My work was professionally and personally fulfilling and was a remaining link with my "healthy" life. To keep working I implemented many changes to my work practices, including

periods of part-time employment. Sometimes I felt myself to be a pale reflection of who and what I once was, while at other times I perceived myself as antithetical to the person I had been. It was a number of years before I realised that CFS might be contributing something positive to my personal development. CFS required me to examine and reflect upon my life and it was through this extended process that I learned different ways of being that enriched my everyday experiences.

In summary, my decision to study CFS formally was based on two factors. First, there was a desire and opportunity to create meaning and positive outcomes from my experiences of CFS. Secondly, I occupied a privileged position that was conducive to investigating CFS because research was crucial to the occupational culture I inhabited, it was a valued pursuit, and resources and support were available. Specifically, my personal experiences and knowledge of CFS, chronic illnesses and the social sciences influenced the choice of research questions for a major study into the experiences of people diagnosed with CFS.

The Research Questions

The aims of the present study fall within the realm of illness experience, and seek to provide insight into this largely unexplored field of how people experience CFS. Research that reflects what it means to live with CFS, how people construct meaning while living with CFS, and the consequent experiences of self-with-CFS have not been a foci of investigation. This subjective perspective is crucial to understanding CFS, particularly given that the condition remains an enigmatic illness located on the fringes of medical and scientific acceptance. As such, people with CFS are relegated to the status of fringe-dwellers, with a unique view of the experience of illness. Exploring their illness vantage-point, their subjective and everyday worlds, social location and ways of living with a contested reality, and the associated experiences and perceptions of self, is worthy of intellectual articulation.

In order to address the aims of the study as outlined in the introduction, three research questions were proposed.

1. What are the illness experiences of people affected with the condition of CFS?
2. What are the experiences of self for people affected with CFS?
3. What are the relationships, factors, contexts and processes important to experiences of self for the person affected with CFS?

The first research question provided a broad and general perspective of the subjective world of CFS. Questions two and three focused on self as a way to further delineate and explore the illness experience of CFS and provided specificity in articulating that experience. In addressing these research questions the present study generated an understanding of CFS that is largely absent from the research to date.

Organisation of the Thesis

The thesis is arranged in 10 chapters commencing with a review and analysis of the ways in which CFS has been conceptualised, theorised and investigated (Chapters 2 and 3). Chapter 4 examines the methodology and design of the thesis. The data analysis of the study is presented and discussed in Chapters 5 through 9. Chapter 5 describes the narrative of the illness biographies, a contextual snapshot that provides insights into the symptomatic experiences of the participants. Chapter 6 articulates the threats of disruption and invalidation that are found within the CFS experience. The narrative of self is addressed in Chapters 7 (violation), 8 (guardianship) and 9 (reconstruction). Chapter 10 discusses the data analysis with reference to other relevant theories and research and identifies future research directions.