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FROM THE HORSE'S MOUTH: DEMYSTIFYING THE EXPERIENCES OF LIVING WITH CHRONIC FATIGUE SYNDROME

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A research report submitted in fulfilment of the requirements for the degree of Master of Arts in Clinical Psychology in the Faculty of Humanities, University of the Witwatersrand, Johannesburg, 10th of December 2009

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Abstract

There has been an increasing awareness and investigation of Chronic Fatigue Syndrome. While there has been extensive debate as to what it is called, what the symptoms include, and how to treat them, the experiences of people living with the syndrome have largely been lost and unheard. Such research could be beneficial in facilitating the identification of supportive interventions designed to improve the mental health quality of life of this population. The present study sought to explore the experiences of people living with CFS internationally, as well as locally. Using a qualitative research paradigm, the posts of participants on a Facebook group for people with CFS were analysed using thematic content analysis to pick up prominent themes. At the same time a focus group was conducted locally in South Africa. The findings highlight the challenges of living with Chronic Fatigue Syndrome and implications for future research are discussed.

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Chapter 1: Introduction

1.1 Rationale

Chronic Fatigue Syndrome (CFS) is an illness affecting a large number of people internationally. It is very debilitating, often severely hampering the ways in which people with CFS are able to live their lives (McNally, 2008). There has been a significant volume of research addressing the aetiology and treatment options for CFS, these themes still currently remaining the focus of contentious debate (Clark, Buchwald, MacIntyre, Sharpe, & Wessely, 2002; Hempel, Chambers, Bagnall, & Forbes, 2008). There has been extremely limited research, however, focusing on documenting the experiences of living with the illness from the client's perspective, as opposed to that of the medical or health professional (Tuck & Human, 1998).

In the South African context, there have been remarkably few studies conducted on the topic of CFS in general. Those studies that have been accessed have discussed procedures for diagnosing chronic fatigue in athletes (Derman et al., 1997) and the biological causes and maintaining factors of CFS (Jadin, 2000). Once again, therefore, there is considered ample scope for research which focuses on what it is like to live with CFS within the context of South African society. Such research can open the door to exploring what the experiences are for people living with CFS in a country with apparent minimal awareness of the illness and the implications that this can have for interactions with health care workers, insurance companies, colleagues and bosses, friends, and family members.

The particular experiences that are the focus of this research report are those of a psychosocial nature. Many of the studies regarding aetiology and treatment of CFS give ample attention to the variety of symptoms of a physical nature that have been experienced (Hempel et al., 2008). Although there are a few studies that have briefly addressed psychosocial components, there is a scarcity of literature that seeks to broadly cover all psychosocial processes that pertain to living with CFS (Colllins et al., 2006), this being the operational aim of this research. A study by Tuck and Human (1998) which briefly addressed some of the psychosocial experiences of living with CFS, highlighted the need for additional, in-depth research that delves into more holistic experiences and explores coping responses and spiritual components of living with the illness. Whilst there has been extensive research on psychosocial experiences of living with a range of other chronic illnesses, Heijmans and

de Ridder (1998) emphasise the disease-specific nature of chronic illness and the requirement that each be examined separately to determine the particular perspectives of those affected.

A more thorough understanding of the psychosocial experiences involved can have positive consequences for those living with CFS. These include determining possible management approaches, as well as developing required social support through facilitation of empathy and compassion which could be beneficial to improving the lives of those with the illness (Shlaes, Jason, & Ferrari, 1999). As this research is exploratory in nature, the aim is to address the question of 'what are the psychosocial experiences of living with CFS?' in as broad and comprehensive a manner as is possible within the scope of this document. There may hopefully be a time in the future when more is known and understood about the aetiology and treatment of CFS. At this point in time, however, the vast uncertainty and confusion shrouding the illness leads to a very particular kind of lived experience that ought to be explored.

1.2 Outline of the Research

The structure of this research report comprises six chapters. In the first of these chapters, the reader is provided with a brief overview of the motivation for, methodology governing, and configuration of the research report. The second chapter introduces the reader to relevant literature on the topic at hand. This includes briefly outlining some factual information regarding CFS and the research trends thus far, before more closely examining aspects of the academic literature that discuss psychosocial experiences of living with CFS in particular. Chapter three provides clarity as to the methodology applied, giving cognizance to the design and procedural aspects, as well as to participant information and data-analytic methods of the research. Chapter four presents the findings as to the psychosocial experiences of living with CFS in two sections. The first section is derived from the data of the Facebook discussion topics and the second section outlines the experiences of the South Africans with CFS who participated in the study. A discussion of these findings proceeds in chapter five. This discussion highlights both the relation between the findings of this study and previous research (as explored in the literature review), as well as variances and similarities between the South African and more internationally-based findings. This chapter also explores the implications and limitations embedded in the study. Finally, chapter six concludes this report, providing a summary of the salient points, as well as offering certain recommendations that stem from this research.

Chapter 2: Literature Review

2.1 What is CFS?

The following chapter provides a brief overview of CFS in order to familiarise the reader with some central aspects of the illness. This consists of a review of the diagnostic criteria and its associated challenges, the symptoms experienced by those affected, prevalence statistics, epidemiology and some of the controversy surrounding the title of the illness and its existence in general.

2.1.1 Definition and Symptoms

There has been extensive debate as to the name, aetiology, diagnosis, perpetuating factors and treatment of Chronic Fatigue Syndrome (CFS) over the past two decades (Hempel et al., 2008) since being assigned a working case definition in the 1980s (Addington, Gallo, Ford, & Eaton, 2001). CFS is diagnosed when a person experiences severe, debilitating fatigue for a period of six months or longer, with the exclusion of the existence of other known medical conditions (Fukuda, et al., 1994; Ottenweller, Sisto, McCarthy, & Natelson, 2001). In addition, the person must also experience four or more of the following symptoms as defined by the Centre for Disease Control and Prevention (CDC) (2009, Para. 2): "severe impairment in short-term memory or concentration; a sore throat; tender lymph nodes; muscle pain; multi-joint pain without swelling or redness; headaches of a new type, pattern or severity; unrefreshing sleep; and post-exertional malaise lasting more than 24 hours". The CDC has also elaborated that the symptoms must have existed or recurred for a period of at least six months and also not have been present before the onset of the debilitating fatigue for a diagnosis of CFS to be made.

Besides the primary symptoms listed within the diagnostic criteria, there are also a wide variety of potential additional symptoms that have been documented. These include, as suggested (in order of prevalence) by Verillo and Gellman (1998): a low-grade fever, or low body temperature, multiple problems related to the nervous system's functioning such as numb or tingling sensations, dizziness, depression, anxiety or panic attacks, mood swings, severe muscle weakness, photophobia, various cognitive functioning abnormalities such as attention deficit disorder, spatial disorientation, not being able to find the right word or saying the wrong word, severe premenstrual syndrome, weight changes, abdominal pain, thyroid dysfunction, new and severe allergic reactions to various substances, night sweats, heart

palpitations, frequent urination, cold hands and feet, and temperature or weather sensitivity. These symptoms tend to wax and wane, producing a fluctuating experience that adds to the unpredictability of the experience (Evengard, Schacterke, & Komaroff, 1999; Thomas & Bosch, 2005). Although the focus of this research pertains to the psychosomatic aspects of living with CFS, this list of physical symptoms is considered potentially helpful in allowing the reader some familiarity with the diverse physical experiences found to be prevalent in CFS.

2.1.2 Diagnostic Challenges, Prevalence and Epidemiology

The classification of CFS as a syndrome requires the elimination of all other possible known aetiological explanations before a person's symptoms can be diagnosed as CFS (Fossey et al., 2004; Smith, Noonan, & Buchwald, 2004). This is no small task, as Caplan (1998) pointed out that for 95% of patients presenting with fatigue, there is a medical or psychological (and treatable) explanation as to the cause. The remaining 5% may receive a diagnosis of CFS, but then still remain in a state of uncertainty as to the genesis of and solution to their distress. Huibers and Wessely (2006) have debated the drawbacks and benefits of offering the diagnosis of CFS when it is often, in fact, unclear what the label implies and how it will be interpreted by both patients and medical professionals. Although there do not seem to be any recent prevalence rates for CFS available, it is considered to be a relatively common condition (Clark et al., 2002), with past figures being estimated to be approximately 0.42% in the USA (Jason et al., 1999) and 0.5% in the UK (Lawrie & Pelosi, 1995). Information regarding prevalence rates for CFS in South Africa could not be found, which could be a reflection of the scarcity of research into CFS in this country. Although some epidemiological studies have suggested that CFS is found to affect more women than men (Torres-Harding, Jason, & Taylor, 2001), others have not found gender to be a predictor (Hempel et al., 2008). In addition, people from a range of socio-economic and ethnic backgrounds (Jason et al., 1999) and a wide age range (Clark et al., 2002) including children (Hempel et al., 2008) and adolescents (Farmer, Fowler, Scourfield, & Thapar, 2004) have been found to be affected. CFS is thus an illness that is challenging to diagnose and yet has been found to affect a broad spectrum of people.

2.1.3 Controversy over the Existence and Name

Strauss (1991), in an analysis of the representations of the disorder over the past few centuries, pointed out the extent to which this disorder has been attributed to a vast array of

causes and been given hosts of differing titles based on the historical context and medical knowledge at the time. Besides speculation over being possibly linked to other diseases such as Neurasthenia, prevalent in the late nineteenth century in the US (Addington et al., 2001; Evengard et al., 1999), Dhat Syndrome in India (Ware, 1999) and the Gulf War Syndrome (Ismail, Kent, Sherwood, & Hull, 2008), CFS has also been given a host of different titles throughout the years and across countries. These titles include Myalgic Encephalomyelitis (ME) (Cooper, 1999; Hempel et al., 2008; Tucker, 2004), Chronic Fatigue and Immune Dysfunction/Deficiency Syndrome (CFIDS) (McNally, 2008), Icelandic Disease (Caplan, 1998), Multiple Chemical Sensitivity (Caplan, 2001), Post-Viral Fatigue Syndrome (Evengard et al., 1999), Yuppie Flu (Caplan, 1998) and Chronic Fatigue Syndrome and Fibromyalgia (CFS/FM) (Van Houdenhove & Luyten, 2008), to name but a few.

The debate over the labelling of Chronic Fatigue Syndrome relative to the associated aetiological theory is a current one, seen to be fraught with implications in terms of the degree of legitimacy of the illness experience of people living with CFS (Jason, Holbert, Torres-Harding, & Taylor, 2004). Ironside, Scheckel, Wessels, and Bailey (2003) have pointed out that the labelling of the illness based on the single symptom of fatigue, which is associated with many other illnesses, does not do justice to the debilitating effect that Chronic Fatigue Syndrome has on the lives of those who live with it. Much of the lobbying for name changes is on the part of people with CFS themselves, in an attempt to gain recognition of an illness that many people dismiss as either non-existent (in terms of it being applicable to anyone who is tired), or as a product of psychological problems (McNally, 2008). For the purposes of this research, the term Chronic Fatigue Syndrome (CFS) will be used on account of its wide-spread recognition (Evengard et al., 1999; Tucker, 2004), with the acknowledgment that there are other names in use which may be considered by some to be more appropriate in terms of suitability of explaining the illness.

2.2 Past and Current Foci of Research

This section provides a brief examination of the core aspects relating to CFS that have been researched to date in order to illustrate the central debates that have emerged around CFS, thus providing a background for the experiences of living with the illness. Besides setting a contextual framework, this overview of the research demonstrates the extent to which the subjective experience of having CFS has largely been put aside amidst the whirlwind of contention around the validity, cause and optimum treatment strategies for dealing with CFS. There is a small portion of literature on CFS that sought to provide an

overview of current knowledge on the illness. These reviews have typically explored either the history of CFS, or sets of symptoms, thus focussing more on the physical aspects of experience (Afari & Buchwald, 2003; Fukuda et al., 1994; Strauss, 1991). Most of the research conducted thus far on CFS, however, adopts a specific focus on aetiology or treatment, with a particularly marginal focus on psychosocial illness experiences. It must be emphasised that, for the purposes of this study, it is not relevant which aetiological theories are more valid than others, or which treatments might work or not. What is of consequence is recognition of the influence that circulation of these theories may have on the lives of people living with the illness.

2.2.1 Aetiology

A significant portion of research on CFS thus far has focussed on aetiological explanations (Tuck & Human, 1998). These varying explanations include a multitude of frequently contradictory pieces of information (Harrigan, 1998; Moss-Morris & Petrie, 2001) and, as yet, no particular aetiological theory has been recognised as definitive (Evengard et al., 1999; Neisenbaum, Jones, Unger, Reyes, & Reeves, 2003; Ware, 1999). Hempel et al. (2008) conducted an in-depth study of previous research to evaluate the possible risk factors associated with CFS and could find no consistent factors that emerged. The host of suggested precipitating factors include genetic causes (Afari & Buchwald, 2003), previous traumatic experiences including PTSD (Roy-Byrne, Smith, Goldberg, Afari, & Buchwald, 2004) and experiences of victimization (Van Houdenhove, Neerinckx, Lysens, & Vertommen, 2001), infectious causes (related to auto-immune functioning) (Baschetti, Padhan, Barton, & Comuz, 2006; Burke & Cunha, 2008; Jadin, 2000), dysfunction of the hypothalamic-pituitary-adrenal axis (Van Den Eede & Moorkens, 2008), faulty cognitions and their associated perceptions, beliefs, and behaviours (Moss-Morris, 2005), environmental effects as outlined by clinical ecologists (Cooper, 1999), psychosocial factors such as depression or stress (Harvey, Wadsworth, Wessley, & Hotopf, 2008), and personality factors such as being compulsive, overly-driven, having perfectionist character traits, or being highly achievement-oriented (Jason et al., 2004; Moss-Morris, 2005; Shlaes et al., 1999; Van Houdenhove et al., 2002). Whilst some aetiological theories focus particularly on the mind, body or environment, others adopt an integrative approach to the genesis of CFS (Cooper, 1999; Evengard et al., 1999; Van Houdenhove & Luyten, 2008). For the purposes of this report, it is reiterated, with its focus on outlining aspects of the psychosocial experiences of living with CFS, there is no

assertion as to which, if any, of these theories is correct. The focus of this section is to highlight the controversy that surrounds attempts to grapple with the cause of CFS.

2.2.2 Treatment

An area of equal attention in research on CFS is that of the effectiveness of various treatment approaches. As has been mentioned, there is to date no globally recognised aetiological theory for the development of CFS (Fukuda et al., 1994). This is interlinked with the finding that no particular treatment approach has been found to be effective for all persons living with the illness (Asbring & Narvanen, 2002; Clark et al., 2002; Ware, 1999). Current treatment options, therefore, are extremely diverse and, for the most part, palliative in that they aim to control symptoms and improve functioning rather than offer a cure for CFS (Harrigan, 1998; Tuck & Human, 1998). The range of treatment options most commonly employed include pharmacological products, nutritional supplements, immunological treatments, physical and behavioural therapies, and multidimensional treatments (Afari & Buchwald, 2003; Rimes & Chalder, 2005). The only two therapies to date that are generally acclaimed to have positive findings in the effectiveness of symptom alleviation and the increase of functioning in some people with CFS are Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) (Afari & Buchwald, 2003; Knoop, Bleijenberg, Gielissen, van den Meer, & White, 2007; Kroenke & Swindle, 2000). These techniques, however, are typically found to be beneficial, but not curative, and are also found not to be effective for all persons living with CFS (Evengard et al., 1999).

Some researchers have advocated that the multidimensional nature of the symptoms experienced in CFS requires a multidimensional management approach (Gibson & Gibson, 1999). For the most part, treatment seems to be highly case-specific, necessitating the embarkation on a journey of trial and error in the process of trying to establishing which particular recipe might be effective in lending to either the alleviation of symptoms or recovery (Afari & Buchwald, 2003). The reality, as recognised by many of the authors investigating treatment approaches, is that many people with CFS have been living with the illness for many years and despite undertaking many treatment approaches, have not recovered (Shlaes et al., 1999). It seems clear, through this very brief exploration of possible treatment options suggested for CFS, that once again a picture emerges of the diversity, controversy and uncertainty surrounding the illness.

2.2.3 Aspects of Psychosocial Experience

Up to this point, there has been an understandable focus on the above two areas of research given the controversy around the medical aspects of the illness. There seems to have been a corresponding dearth of attention given to a psychosocial exploration of what it is like to live on a day-to-day basis with this illness. The people impacted themselves seem to be silenced to some extent by the magnitude of the uncertainty and confusion.

Much of what has been documented regarding experiences of living with CFS has been via research articles that have touched on psychosocial experiences, even though this was not their primary focus. These include articles relating to the above two sections of aetiology and treatment (Moss-Morris & Petrie, 2001; Soderberg & Evengard, 2001; Van Houdenhove et al., 2001), as well as articles with a more specific focus, such as that of Huibers and Wessely (2006), which examined the illness-perpetuating aspects of diagnosis. Other articles in this category include those which centred more specifically on illness beliefs and perceptions of people with CFS and subsequent links to the possible effectiveness of Cognitive Behavioural Therapy (Moss-Morris, 2005).

The articles which did, in fact, focus more specifically on illness experience tend to be geared towards exploring one particular aspect of experience. Some of these aspects include an analysis of the daily hassles experienced by people with CFS (Van Houdenhove et al., 2002), the social process of marginalisation in relation to CFS (Ware, 1999), experiences of stigmatization (Asbring & Narvanen, 2002), the ways in which people with CFS use their narrative to position themselves as legitimately ill in the hope of avoiding this stigma (Tucker, 2004), and the development of a test to measure the attitudes of other people toward those with CFS (Shlaes et al., 1999). One of the very few studies located that aimed purely to explore the experiences of people living with CFS was authored by Tuck and Human (1998). This was a fairly brief qualitative study, using open-ended interviews with 22 participants with CFS. There were three areas of experience explored in this study, including being consumed by the experience of the illness, what it is like living with the symptoms and the contrast in life before and after having CFS. The impacts on functioning and coping mechanisms employed, however, were not investigated in any detail. A second study by Thomas and Bosch (2005) unpacked some of the experiences of 17 people with CFS, with the goal of assessing the impact that CFS can have on coping mechanisms and the possible benefit of counselling services. The range of experiences explored in this study included the impact of diagnosis with CFS, identity shifts, dealing with scepticism and appraisals of social

support. The contents of the above-mentioned, and any other relevant articles, will be reviewed in the section to follow, to the extent that they pertain to the scope of this research.

2.3 Psychosocial Experiences of Living with CFS

The focus of this section is to provide an in-depth exploration of the literature that is directly pertinent to the focus of this research through a synthesis of the segments of available literature on psychosocial experiences of living with CFS. There are various facets to this experience on account of the profound and often prolonged physical, mental, social and professional disabilities that CFS entails, which can generate a high level of suffering for individuals with CFS and for their families (Clark et al., 2002; Hempel et al., 2008; Van Houdenhove & Luyten, 2008). Although an attempt has been made to lend structure to this review by providing sectional headings, it is concurrently recognised that these aspects in fact interweave with one another as part of a holistic life experience tapestry that is intricately connected and fluid.

2.3.1 Diagnostic Experiences

Huibers and Wessely (2006) discussed the empowering value that finding a label for CFS can have in lending to emotional relief, contributing to feeling recognised, allowing opportunity for group support and providing meaning to an unfathomable experience. Thomas and Bosch (2005) similarly concluded that the fear and despair regarding facing a mysterious, unknown and possibly fatal illness prior to diagnosis was replaced by relief at being given a vocabulary to communicate the experience and lessen the self-doubt or blame that permeates the unknown. These positive elements, however, were found by Asbring and Narvanen (2002) to be mediated by contemporary attitudes towards the illness and frequent feelings of being belittled and marginalised by others, which resulted in an ambivalent response to the diagnosis. The reality is that many people with CFS have been found to have to endure many years of diagnosable symptoms before receiving an official diagnosis of CFS (Thomas & Bosch, 2005). Many felt that they were misdiagnosed at first by only being given psychiatric referrals, which resulted in what they considered unnecessary harm and distress (Harrigan, 1998).

Many people with CFS themselves have a particularly negative view of the illness (Moss-Morris & Petrie, 2001) and it has been reported that 92% of people with CFS would like the name to be changed on account of the stigmatising experiences that have been associated with CFS (Burns, 1998 as cited in Jason et al., 2004). Asbring and Narvanen

(2002) concluded that before a diagnosis of CFS, individuals afflicted experienced stigmatisation directed at themselves personally for not being able to function due to what were commonly considered to be symptoms equating to apparently mild, everyday complaints. After diagnosis, however, the stigmatisation was seen to shift to focus on the meaning and validity of the diagnosis itself rather than the person (Asbring & Narvanen, 2002). The authors thus concluded that early diagnosis is important in lessening this personal affront.

2.3.2 Experiences of Health Care Professionals

The general consensus seems to be that the knowledge that most medical professionals have of CFS is remarkably limited (Tuck & Human, 1998). Smith (2002, as cited in Tucker, 2004) concluded that a large percentage of medical doctors believe that CFS should be regarded as a societal problem (such as depression or obesity) rather than being treated as a medical illness. Thomas and Bosch (2005) reported that females with CFS had found that doctors tended to dismiss their incredible fatigue as either a normal part of life for modern day women, or related it to hysteria or menstruation. Harrigan (1998) regarded such experiences as an indication of the need for increased competence on the part of medical professionals in the diagnosis and treatment of CFS. Inclusion in the medical training curriculum was a suggested means of achieving this (Harrigan, 1998). There is considered to be a general scepticism of the validity of the illness on the part of medical professionals (Evengard et al., 1999; Shlaes et al., 1999; Thomas & Bosch, 2005). This lack of validation has been attributed to CFS being assigned low status on account of not being linked to a particular organic cause which would allow for objective diagnosis and a more straightforward treatment regime (Album, 1991 as cited in Asbring & Narvanen, 2002).

People with CFS have reported their experiences with health care professionals to have been predominantly negative (Thomas & Bosch, 2005), with a statistic of 57% feeling that they were inappropriately treated (Jason et al., 2004). Their sense is often one of having been treated with hostility and resentment for not being able to conform to expectations of full recovery (Shlaes et al., 1999). They also report noticing a dramatic shift in the previously positive disposition of doctors to a marked suspicion once test results return with negative findings (Asbring & Narvanen, 2002). Some patients reported that doctors then tested the credibility of their symptoms with placebo treatments (Asbring & Narvanen, 2002) or portrayed a particularly blasé response (Thomas & Bosch, 2005). The consequences of these types of encounters have been described by Asbring and Narvanen (2002) to include

withdrawal from seeking out medical care, waiting as long as possible before attending repeat consultations, or constantly looking for new doctors to consult in order to avoid being seen as a problem patient. Another consequence, as outlined by Thomas and Bosch (2005), was that persons with CFS frequently turn to alternative forms of treatment rather than allopathic care.

2.3.3 Experiences of Stigmatisation and Invalidation

As has been briefly highlighted already, there are a number of ways in which living with CFS tends to evoke feelings of stigmatisation. For people with CFS these feelings sometimes come about through a sense of their veracity and morality being questioned by others who doubt the existence or seriousness of CFS (Asbring & Narvanen, 2002). This doubt often emerges because of the largely invisible nature of the symptoms which are diffuse and hard to verify (Thomas & Bosch, 2005). The lack of validation of CFS and its symptoms is one of the major thematic foci in literature regarding the experiences of those diagnosed with the illness. The feeling that one's illness experience was not validated was found by Thomas and Bosch (2005) to be "one of the most powerful and painful parts of the CFS experience" (p. 30).

The Collins English Dictionary and Thesaurus defines fatigue as "extreme physical or mental tiredness" (Collins et al., 2006, p. 283). All people experience being fatigued at various points in their lives and some may even evidence small quantities of the additional symptoms. However, experiences of normal fatigue have been differentiated from CFS by the sheer degree and debilitating nature of the latter (Evengard et al., 1999), which typically results in significant impacts on functional capacity (Ironside et al., 2003). People with CFS have been said to frequently experience disbelief and disrespect from others regarding their illness (Clark et al., 2002) on account of a general lack of social recognition of the illness (Van Houdenhove et al., 2002). Their subjective experiences have been reported to often be negated or trivialised not only by health care professionals, insurance agency staff and the general public, but by those closest to home, including family members, friends and colleagues (Thomas & Bosch, 2005; Ware, 1999). This experience of not being believed, and at times even considered to be malingering, can in some ways be as burdensome as the illness itself (Asbring & Narvanen, 2002; Thomas & Bosch, 2005). The resultant increase in stress levels can serve to reduce overall quality of life (Van Houdenhove & Luyten, 2008) as well as impair immune function (Evengard et al., 1999).

The psychologising of their symptoms (by doctors in particular) has also been experienced by many people with CFS as stigmatising in various ways. These perspectives

include the common association that the illness results simply from stress (Asbring & Narvanen, 2002), that it is 'all in the mind' (Clark et al., 2002), or associated with depression (Shlaes et al., 1999). These all are found to contribute to sentiments that persons with CFS themselves are responsible for having the illness on account of their lifestyle choices and personality structures (Jason et al., 2004) or because they are lazy and prefer to remain ill (Shlaes et al., 1999; Thomas & Bosch, 2005).

The uncertainty surrounding the illness has also been said to add to the stigmatising potential (Asbring & Narvanen, 2002). The lack of a unified discourse for CFS leaves each suggested aetiological explanation called into question by the opposing viewpoints (Tucker, 2004). The resultant uncertainty can lead to others fearing contagion by an as yet unknown source (Ware, 1999). The effects of these stigmatising experiences on people with CFS have been found to include feelings of anxiety, shame, self-doubt, outrage, weakening self-esteem (Asbring & Narvanen, 2002; Ware, 1999), and can lead to depression (Tucker, 2004). Responses to feelings of accusation have been said to at times include the adoption of a defensive stance, with large amounts of energy being expended to be seen by others a real person (Asbring & Narvanen, 2002). Some of those affected by CFS have, in fact, described wishing that external symptoms were present so that they would be deemed credible by others (Asbring & Narvanen, 2002).

2.3.4 Effects on Sense of Self

The diminishing sense of competence stemming from reduced functional capacity in many areas of life has been said to have a significant impact on the identities of people with CFS (Schweitzer, Foran, Kelly, Terry, & Whiting, 1995, Thomas & Bosch, 2005). This was found to come about as a result of the disruption to previously assumed roles as life often ground to a gradual halt (Hilger, 1995). The constriction on the capacity to adequately fulfil roles such as that of parent, spouse or employee has been linked to a feeling that one's illness comes to dominate over all other qualities that were previously recognised (Ware, 1999). Despite endeavours to still be regarded as fully functioning members of society (Asbring & Narvanen, 2002), a strong illness identity has often been found to emerge (Moss-Morris & Petrie, 2001).

The questioning over their moral character, as outlined in terms of stigmatising reactions, has been seen to threaten the identities of many people with CFS. This threat is seen to emerge as a result of the inconsistencies between self opinions and the internalisation of the perceptions of others, indicating that one is lazy or deceitful (Asbring & Narvanen,

2002; Thomas & Bosch, 2005). Facing the possibility that one is suffering from a psychologically-, rather than physically-based illness, has been found to evoke perceptions of oneself as personally at fault and deficient, which run contrary to previous notions of self (Thomas & Bosch, 2005; Tucker, 2004). These perceived changes on a personal level have been reported as challenging to face. In a study on the possible effectiveness of group therapy as a management strategy for people with CFS, Soderberg and Evengard (2001) found that some of the participants expressed struggling with coming to accept the 'new person' they had become. In other cases, identity shifts were found to generate negative reactions from friends, which led to grief over the severance of relationships (Thomas & Bosch, 2005).

Tuck and Human (1998) have brought attention to the fact that the experience of CFS is of a holistic nature, affecting the body, mind and spirit of the person involved. Van Houdenhove et al. (2002) have outlined a further shift in self-identity emerging through the need that is generated for people with CFS to adapt to changes in their goals and aspirations in life. There were also some positive shifts in self-identity reported. These shifts included the development of a better understanding of oneself through the opportunity for reflection, re-evaluation of one's goals and priorities, and in some cases facilitation of major life-changing decisions (Thomas & Bosch, 2005).

2.3.5 Consequences for General Functioning

There seems little doubt in the literature that CFS has severely debilitating consequences (McNally, 2008; Tucker, 2004). These consequences have been associated with marked reductions in the aspects of social, occupational and personal functioning (Shlaes et al., 1999, Thomas & Bosch, 2005), resulting in substantial effects on people's lives (Moss-Morris, 2005). The extent of this disruption, however, has hardly been researched to date (Thomas & Bosch, 2005). The research that has been conducted indicates that impairment can last for many years (Fukuda et al., 1994). The overall quality of life has been found to be particularly low in people with CFS (Anderson & Ferrans, 1997) and the functional prognosis offered is poor, with reports having indicated that without treatment, less than 10% of adults return to pre-morbid levels of functioning (Moss-Morris, 2005).

In a society where productivity is deemed the golden highway to success, an illness that attacks this capacity is found to be particularly hard hitting (Tuck & Human, 1998). People with CFS experience that they are not encouraged by their bosses, doctors, friends or family to take the time that is required to recover from CFS, but instead face constant pressure to keep performing at previous levels, no matter how unrealistic these may be

(Shlaes et al., 1999). In a world that is constantly speeding up, people with CFS find themselves steadily slowing down and being left behind (Ware, 1999). The loneliness of this experience was found at times to be avoided by an attitude of 'all or nothing', which involved expending all of one's available energy on the task at hand to cope as normally as possible (Moss-Morris, 2005; Van Houdenhove & Luyten, 2008) only to suffer the consequences of this over-exertion through a sharp exacerbation of symptoms directly thereafter (Ware, 1999). A further societal expectation outlined as particularly difficult for those with CFS is the construction and adherence to a schedule of events. The unpredictability of CFS, which plays out in its fluctuating course and symptom profile, was found to frequently make scheduling of arrangements fruitless and anxiety-provoking in terms of dealing with others who are put out by unavoidable changes (Ware, 1999). The above impacts exert an influence over all aspects of functioning, whilst the sections to follow portray a more in-depth analysis of the findings particular to certain domains of functional performance.

2.3.5.1 Impacts on personal functioning

On an individual level reported impacts included a hampering of physical capacity, as many people with CFS are homebound, sometimes entirely bed-ridden and unable to complete even basic hygiene routines, let alone complete a broader spectrum of tasks that are a part of daily living (Hilger, 1995; Thomas & Bosch, 2005). Shlaes et al. (1999) described the challenges of not being able to cope with regular daily activities, such as shopping, cleaning and cooking. Van Houdenhove et al. (2002) have described this limitation as a high frequency of daily hassles for people living with CFS. An elaboration of their findings is that when such minor hassles are experienced over an extended period of time they accumulate to take on a form of chronic psychosocial stress which can be as significant as a single major negative event. This stress of daily hassles has being linked with feelings of dissatisfaction with oneself, insecurity and feelings of poor levels of social recognition (Van Houdenhove et al., 2002).

Aikman (1994) described those with CFS as experiencing that "every aspect of their lives has been affected by their disease, resulting in a loss of trust in their own ability to respond adequately to the world" (p. 1). Continual failed attempts to deliver mentally and physically, despite the limitations of CFS, can result in feelings of frustration and disappointment (Van Houdenhove et al., 2002). Individuals feel compelled to forgo their past personal goals (Shlaes et al., 1999) and, in an attempt to manage symptoms, particularly the

post-exertional malaise that is typical of the CFS experience, exercise is markedly reduced or eliminated altogether (Ottenweller et al., 2001).

2.3.5.2 Impacts on social functioning

Schweitzer et al. (1995) found that one of the most significant impacts on quality of life for people with CFS was in the domain of social functioning. It has been found that patients' perceptions of their level of social support play a significant role in their adjustment to being diagnosed with CFS (Hilger, 1995). A lack of social resources for people with CFS has been noted to lead to heightened levels of stress (DeLongis, Folkman, & Lazarus, 1988). Many people with CFS are said to be restricted to staying at home (Shlaes et al., 1999) and are often not able to engage socially with others due to their level of fatigue and difficulties in planning activities in advance (Asbring & Narvanen, 2002). Consequentially, patients' normal ways of coping are typically found to be invalidated and their support mechanisms fractured, often resulting in isolation (Thomas & Bosch, 2005). Themes of isolation and abandonment experienced by people with CFS were echoed by a number of authors (Shlaes et al., 1999; Tucker, 2004). Tucker (2004) described that illness is not only experienced on an individual level, but within the context of the social world it inhabits and the meanings that are inferred. Ware (1999) echoed these social influences, emphasising the marginalisation processes that are implicit in the experience of CFS. Marginalisation was seen to emerge through the reaction of others to the illness or through self-marginalising coping mechanisms on the part of person with CFS, to hide deficits or impairments (Ware, 1999). Over time, it was said to become increasingly more difficult to integrate into social conversations as one's world became more isolated and disconnected (Ware, 1999). Even when social contact was maintained, the cost was sometimes found to be that inner authenticity was lost, as people with CFS tended to avoid speaking about their true experiences with others for fear of being rejected or ridiculed (Ware, 1999).

There were also instances where people with CFS described supportive interactions with those around them, which generated experiences of feeling understood and trusted (Tuck & Human, 1998). These seemed to be largely in the minority, however, and were often not able to compensate for the many experiences where family members to doctors did not understand or believe their difficulties (Tuck & Human, 1998). A reaction to this widespread scepticism was sometimes found to be that greater intimacy and closeness was sought with a small, select group of people who were supportive, whilst others were either avoided or, if approached, were not made aware of the genuine experiences of living with the illness

(Asbring & Narvanen, 2002). The only time that family members were found to be initially accepting of the illness was when another family member had already been diagnosed with CFS (Thomas & Bosch, 2005). This general doubt by family members was found to be particularly challenging to cope with because of the level of practical support that was needed from them in order to deal with CFS (Thomas & Bosch, 2005). Additionally, unrealistic expectations on the part of family members who did not acknowledge CFS were found to be felt as heavy additional burdens to bear (Thomas & Bosch, 2005).

It is vital to note that CFS has been found to result in immense strain, not only for the ill individuals, but also for their families or carers (Clark et al., 2002; Hempel et al., 2008; Millen, Peterson, & Woodward, 1998). Deringer (1992) described changes in roles within households where a family member has CFS that result from the limitation in activity of the ill individual. The findings of Procter (1990) highlighted that, in families where the mother has CFS, family relations were more negative than in controls, and there were fewer activities for children to engage in outside of the home. For these mothers the worry over their ability to raise their children properly with the adequate level of care was found to be overwhelming (Procter, 1990). Family members (including spouses, children, siblings and parents) were often expected to make sacrifices and take on extra tasks to compensate for the inactivity of the ill family member, also often stirring up feelings of guilt in the sick individual (Ware, 1999). Financial strain from negative occupational impacts and medical costs incurred also resulted in people with CFS fearing for their marriage relationships, should their partners become overly burdened and frustrated (Ware, 1999). These intimate relationships, including problems in sexual relations, were a topic of concern in the group therapy sessions conducted in the study by Soderberg and Evengard (2001).

In terms of communication with others regarding their illness, Thomas and Bosch (2005) described that people with CFS at times actively seeking to spread information about CFS to others close to them in order to assist them to know and understand more about their experiences. On the other hand, there were findings by Ware (1999) that experiences of living with CFS are often actively kept secret by those that are ill. This was echoed by Asbring and Narvanen (2002) in what were termed ‘concealing strategies’, which involved resisted expression of one’s reality, instead presenting a facade through controlling information presented to others in order to diminish the perceived stigma. The typical lack of evident external signs of illness in people with CFS was seen to make this strategy particularly salient (Asbring & Narvanen, 2002).

2.3.5.3 Impacts on occupational functioning

Andersen, Permin, and Albrecht (2007) found in a nine-year follow-up study of people with CFS in Denmark that, in these individuals, the role of occupational functioning was the most adversely affected, relative to other aspects of their functioning. Moss-Morris (2005) reported on the occupational effects of CFS, commenting that 40% of persons affected become unemployed whilst ill and a further 20-30% had to significantly reduce their working hours on account of their illness. Ware (1999) concluded that cognitive impairments impact on basic communication skills required for professional interactions and chronic levels of pain are a constant distraction to professional focus. It was reported that employers do not usually appreciate the seriousness of the symptoms experienced (Shlaes et al., 1999) and whilst many people with CFS described themselves as conscientious and ambitious prior to becoming ill, they found themselves accused of purposefully avoiding work for their own gain once they fell ill (Asbring & Narvanen, 2002). Burke and Cuhna (2008) pointed out that it is important to take into account that people with CFS are not consciously choosing not to work and, on the whole, are extremely frustrated at their lack of ability to deal with both personal and professional tasks. This frustration could be said to be fuelled by the societal norm that it is often one's job that defines both position in society and how one feels about oneself. Not being able to fulfil this role, therefore, places identity and self-esteem under threat (Ware, 1999).

2.3.5.4 Financial implications

In the same vein, Reynolds, Vernon, Bouchery, and Reeves (2005) found that the reduced occupational productivity of people with CFS results in remarkable financial loss for the individual. This financial strain was recognised to be compounded by additional expenses (in the form of medical tests and treatments) increasing, whilst income is reduced (Ware, 1999). There were many findings that indicated that CFS is often not recognised by medical insurance companies as a legitimate cause for claim, causing the financial burden of cost of treatment to rest squarely on the individual (Millen et al., 1998). Dealing with medical or social insurance companies in an attempt to gain benefits was found to be particularly taxing, in facing off-hand staff, who doubted the credibility of the applicant (Asbring & Narvanen, 2002). Where financial implications were sorely felt, savings were depleted, non-essential items were eliminated, essential items were reduced (such as one participant rationing electricity and hot water), and possessions were sold off to generate extra income (Ware, 1999). Some people with CFS, faced with the threat of losing their homes, turned to family

for support (Ware, 1999). Female single wage earners were found to be most severely affected financially, followed by families who previously were sustained on two incomes (Ware, 1999). As has been referred to, the economic pressures resulting from CFS typically have a ripple effect on the entire family and can serve to cause additional stress in increasing tensions within the family unit (Millen et al., 1998).

2.3.6 Psychological Experiences

The emotional experience of facing CFS has been equated with a rollercoaster ride (Tuck & Human, 1998). This experience is seen to be induced by the many psychosocial stressors encountered in coping with and adapting to living with CFS, the lack of general awareness of CFS within the environment, and the array of uncertainties inevitably faced (Van Houdenhove et al., 2002).

2.3.6.1 Depression

One of the most common co-morbid emotional experiences discussed in the literature was that of depression (Addington et al., 2001; Afari & Buchwald, 2003; Fuller-thomson & Nimigon, 2008; Moss-Morris & Petrie, 2001; Smith et al., 2004; Soderberg & Evengard, 2001; Tuck & Human, 1998). Fuller-thomson and Nimigon (2008) concluded that 36% of their sample of 1045 persons diagnosed with CFS had co-morbid depression. The risk factors for depression in CFS were found to include being female, being younger, having a lower income and thus food security, and being limited in terms of participation in activities on account of high levels of pain (Fuller-thomson & Nimigon, 2008). It was noted that 22% of the participants with both CFS and depression had considered suicide (Fuller-thomson & Nimigon, 2008). Smith et al. (2004), on the other hand, in a comparison conducted between people with CFS and depression, found that the participants with CFS did not present a higher suicide risk than that of the general population. It was also found that those with CFS had higher self-esteem and lower feelings of worthlessness, and were more likely to report secondary symptoms of depression (such as insomnia, fatigue and reduction in pleasurable activities) rather than primary symptoms such as depressed mood (Smith et al., 2004). Caplan (1998) and Evengard et al. (1999) mentioned that despite the evident co-morbidity of depression in people with CFS, anti-depressant medication has been found to have a minimal effect in alleviating depressive symptoms in this patient group, significantly limiting the treatment options available to deal with this symptom.

Most of the postulated reasons for co-morbid depression in people with CFS have already been outlined in previous sections. These reasons include reduced levels of social support typically received and ineffectual coping and adaptation to the illness (Hilger, 1995), as well as an incapacity to engage in tasks and activities previously performed (Burke & Cunha, 2008). Afari and Buchwald (2003) have also suggested that co-morbid depression could result from changes in brain physiology or effects of infectious agents or immunological changes resulting from the illness. Further research has also listed a contributing factor to be living with a disease that is little understood and under-diagnosed (Caplan, 2001; Fossey et al., 2004). Depression is seen to be sparked through feelings of shame on account of the stigmatisation and negative self-perceptions that result from being labelled with a psychiatric syndrome (Altrows, 2006; McNally, 2008).

2.3.6.2 Anxiety

Whilst Afari and Buchwald (2003) have asserted that both anxiety and depression are the most frequently experienced psychological responses to medical illnesses in general, Van Houdenhove et al. (2002) pointed out an increase in rates of anxiety and depression in people with CFS compared with chronic illnesses that have a definitive organic aetiology. Research certainly suggests high levels of co-morbid anxiety and stress in people with CFS (Fukuda et al., 1994; Henningson, Zimmerman, & Sattel, 2003; Walsh, Zainal, Middleton, & Paykel, 2001). Anxiety and worry have been described as everyday experiences in the lives of those with CFS (Moss-Morris, 2005; Tuck & Human, 1998). Moss-Morris and Petrie (2001) found that the primary concern of people with CFS was their poor health, whilst Asbring and Narvanen (2002) emphasised that part of this anxiety at least results from enacted stigmatisation by others and concerns over social isolation. Other listed experiences seen to result in co-morbid anxiety included the restriction on one's ability to work, financial pressures, inability to care for one's children effectively, uncertainty as to whether one will ever recover, and concern as to what to do to promote recovery (CDC, 2009).

2.3.6.3 The range of other emotions

Besides the major focus on anxiety and depression, there were a range of other feelings more briefly reported on in the available literature. These feelings included helplessness (Moss-Morris, 2005; Shlaes et al., 1999), hopelessness (Moss-Morris, 2005), anger (Tuck & Human, 1998), frustration (Tuck & Human, 1998), demoralisation at the loss of previous capacities (McNally, 2008; Van Houdenhove & Luyten, 2008), loneliness (Shlaes

et al., 1999), fear (Thomas & Bosch, 2005), distress (Thomas & Bosch, 2005) and feeling overwhelmed by the extent of life hassles faced on a day-to-day basis (Van Houdenhove et al., 2002). Many people with CFS seem to be plagued by uncertainty in terms of their illness prognosis (Asbring & Narvanen, 2002), inexplicable symptom variances (Ware, 1999), and on account of a lack of accessible resources on CFS (Shlaes et al., 1999). Similarly, the vast array of theories and opinions manifest were considered to not only contribute to feelings of uncertainty, but also generate feelings of helplessness that undermine efficient coping strategies (Van Houdenhove & Luyten, 2008). On the positive side, however, some authors reported feelings of hope expressed by some participants, particularly in terms of anticipating a more optimistic future experience and a focus on what small joys were available in the present moment (Tuck & Human, 1998).

2.3.7 Coping with CFS

Facing the impacts, as described above, associated with having CFS naturally generate a set of responses on the part of the individual. Some authors, such as Moss-Morris (2005), have classified coping strategies engaged in by people with CFS as either positive or negative. Positive strategies are seen to include those that have an adaptive function, mobilise support or include positive ways of reframing experiences (Moss-Morris, 2005). Less constructive coping mechanisms have been defined to include those that promote avoidance, venting of emotions or disengaging from society (Moss-Morris, 2005). In maintaining the focus on psychosocial experiences, however, the aim of this section is to outline the various reactions to living with CFS that have been reported without adopting a particular stance as to the benefit or detriment of these ways of coping.

2.3.7.1 Adjusting to living with CFS

Perceptions as to the manageability of CFS are said to play an important role in determining one's ability to cope with the illness (Heijmans & de Ridder, 1998). One of the strategies reported to be most commonly employed to deal with the symptoms of CFS is to make adjustments that allow one to still feel able to participate in activities, but in a slightly altered way. An example of such an adaptation was one woman who still played baseball with her husband and children, but took a stool to the outfield to sit on whilst waiting for the ball to come her way (Ware, 1999). Other adjustments that were described involved planning one's activities to require the least possible effort and to take as few steps as possible (Ware, 1999). Some people with CFS explained that they had adjusted their standards to what was

'good enough' rather than ideal, thus letting go of unrealistic expectations (Moss-Morris, 2005). Other adjustment techniques included limiting stress and activity levels (Moss-Morris & Petrie, 2001) and learning to ascertain when one's limit had been reached and respond accordingly (Soderberg & Evengard, 2001).

The term 'pacing' was utilized in the literature on coping with CFS and although this term has not as yet been academically defined or evaluated within this context, it was described as establishing a balance between engaging in activities and making use of periods of rest (Clark et al., 2002). Incorporated into this approach were the practices of breaking activities into segments with intermittent rests and doing only one thing at a time (Ware, 1999). Ware (1999) also described prioritization as a coping strategy engaged in by people with CFS, this being an elimination of non-essential activities from one's schedule. Asbring and Narvanen (2002) concurred with this finding, qualifying that besides cutting down on non-essential activities, compromises were made where all available energy was poured into a certain domain, such as occupational functioning (to preserve identity, a semblance of normality, or out of financial need), in consequence of which the social domain, for example, was sacrificed entirely.

2.3.7.2 Role of social support

It was found by Clark et al. (2002) that those who were the most severely affected by CFS seemed to receive the least support from others. Some findings reflected the marked effectiveness of support groups and talking to others with CFS, these being found to offer both advice and support (Thomas & Bosch, 2005). Asbring and Narvanen (2002), however, concluded that there was ambivalence on the part of people with CFS in associating with other people who had the illness as, on the one hand, they felt and appreciated the sense of solidarity and acceptance generated and, on the other hand, felt as though it brought the illness constantly to the forefront of their minds.

Thomas and Bosch (2005) also expounded the perceived benefit of individual psychotherapy for people with CFS as a form of forging a supportive relationship in a context where such validation is hard to come by. This was only found to be beneficial, however, when the therapist had specialised knowledge on the topic of CFS, believed in CFS and was flexible in terms of accommodating the symptoms and fluctuating course of the illness by means of facilitating telephonic counselling or allowing for shorter sessions (Thomas & Bosch, 2005). Internet access was also found to generate support for people with CFS in

terms of the supportive connections that were established through this mode of communication (Thomas & Bosch, 2005).

2.3.7.3 Available resources

Whilst there are a limited number of books on CFS available on the market, by far the most significant portion of these are geared towards the individual with CFS in the form of what could be termed 'self-help' books, such as that of Bassman (2007), Collinge (1993), and Wilkinson (1988). The titles of these books include segments such as "a guide to self-empowerment" (Collinge, 1993) and "the feel good guide" (Bassman, 2007). These books have often been written by people who have had CFS themselves and struggled with the lack of synthesised information on the topic and the uncertainty and desperation that they faced during the illness (Bassman, 2007). They cover topics such as lists of the symptoms of CFS, aetiological theories, the prognosis and course of CFS, and interspersed quotes from others with the illness. For the most part, however, these books focus predominantly on the vast array of treatment options that are available to choose from, including allopathic treatments, alternative diets, cognitive training programs, therapeutic interventions, relaxation techniques and alternative healing strategies. There are typically messages of encouragement and validation embedded in these books, but for the most part they portray strong messages of developing one's capacity for being proactive and making informed decisions as to which options are most appropriate.

2.4 Summary of the Literature Reviewed

In summary, the literature reviewed has outlined the range of symptoms included within the diagnostic criteria of CFS, as well as prevalence statistics indicating that the illness is relatively common and affects a broad spectrum of the population. The level of controversy and uncertainty was highlighted through an overview of the debates pertaining to the title, aetiology and treatment approaches applied to CFS. An examination of the literature regarding psychosocial experiences of those with CFS yielded insight into positive and negative experiences around diagnosis, largely unconstructive and demoralising interactions with health care professionals, experiences of stigmatisation and invalidation, and changes generated in the individual's sense of self through living with the illness.

Some of the impacts on functioning for a person with CFS were found to include reduced productivity and hence capacity to perform personal and occupational tasks, reduced

social functioning and hence social support, changes in role functioning and family dynamics and increased financial pressures due to a loss of income and treatment costs incurred. Findings regarding associated psychological experiences were dominated by reports of depression and anxiety, but other emotions were also brought to bear, including helplessness, hopelessness, anger, frustration, loneliness, uncertainty, fear, distress and feelings of being overwhelmed. On the positive side of the spectrum, hope was highlighted as evident at times. The means of coping explored in the literature consisted mainly of adjustment techniques, as well as attitudes regarding making use of potential sources of social support.

As has been pointed out, there has been minimal literature internationally to date focussing particularly on outlining the psychosocial experiences of people with CFS, and no such literature within a South African context. Although this review of available literature has produced what seems to be a fairly comprehensive account of what these experiences might include, research with the primary aim of providing a full analysis of these psychosocial experiences both internationally and within the South African context can offer a significant contribution to this field. The information gleaned can contribute to the investigation and implementation of necessary intervention strategies that aim to reduce the evidently devastating secondary effects of living with CFS.

Chapter 3: Methodology

3.1 Aim of the study

The aim of this study is to document the experiences of those living with CFS, with a particular focus on experiences of a psychosocial nature. The motivation for this broad scope of interest is in line with the exploratory nature of the research. The study is aimed at eliciting the perspectives of South African persons living with CFS, as well as those living internationally.

3.2 Research Design

The present study was a qualitative inquiry into the experiences of people living with CFS, as described on the Internet within the form of a Facebook group discussion board and by South African participants in a focus group discussion, or through written questionnaire responses. As shall be elaborated on to follow, the response rate in gathering participants for the study was particularly low. This, as well as the exploratory nature of the study, was a significant factor in motivating for a qualitative approach. This multiple methods design was deemed appropriate, largely on account of the particularly poor participant response rate that was achieved, despite a vigorous recruitment process, which made the incorporation of the public domain data from the Facebook network a valuable addition in terms of the quantity of the data. Besides this practical expansion of the data, it is considered that the international perspective offered from the Internet data can also qualitatively enhance the study by offering a wider perspective that allows for a comparison of local and international experiences. This comparison allows for both a crystallisation of themes that emerge in the two samples, as well as the possible unearthing of thematic variances. This being said, it is not suggested that the two samples are equivalent and, whilst the variation in samples is deemed valuable in some ways, it is acknowledged that the discrepancies in data-gathering methodologies may have resulted in systematic discrepancies in the data obtained. As this research is exploratory in nature, however, it is believed that the extraction of the major themes will fulfil the aim of documenting the common experiences of people living with CFS. The results would then inform future research, which would use more controlled methodologies to unpack those experiences in more systematic and analytic ways.

The focus group method was deemed appropriate for the gathering of data for South Africans' experiences of living with CFS, due to its acclaimed effectiveness in initial or

exploratory research (Morgan, 1993). A further benefit of the focus group method is its potential for eliciting inter-subjective experience (the extraction of common trends within reported experiences), whilst simultaneously allowing for differences to emerge (Terre Blanche & Durrheim, 1999). The focus group was structured by the use of open-ended questions posed by the researcher as facilitator. Whilst it is acknowledged that by asking such questions the facilitator is guiding the discussion to some extent, the use of less structured, particularly broad questions can help to reduce this effect by allowing the group to maintain a high level of control over the choice of content, whilst remaining within the scope of the research (Morgan & Scannell, 1998; Puchta & Potter, 2004).

Further benefits of including Internet-based research are outlined by Mann and Stewart (2000). They highlighted that Internet-based research offers the potential for a diverse sample population within a particular interest group despite geographical limitations. Internet research also allows for sensitive topics and marginalised voices to be given air, on account of the physical distance and optional anonymity typically available, and provides savings in cost and time to both researcher and participant, as well as reduced transcription bias on account of the use of self-transcribed data. Some drawbacks are also listed. These revolve around participants requiring access to the Internet and proficiency using both computers and the Internet for participants and researchers, as well as ensuring participation in the study and possibly losing access to the research data (Mann & Stewart, 2000). The most pertinent of these in this study, as shall be discussed in the following section, is the access to and proficiency in Internet usage.

3.3 Participants

Two samples were used in providing the data for this research. The first sample was drawn from a public social networking medium in the form of the discussion board entries from a Facebook group entitled “Sufferers with Chronic Fatigue Syndrome Unite”. Facebook is a free-access, social networking website, that can be accessed by anyone who creates a profile (including basic demographic information), using either their real name or a pseudonym (Dwyer, Hiltz, & Passerini, 2007). Any person with a profile may join a Facebook group and participate in any available discussion topics, or begin a new topic for discussion. Discussion groups are considered to be the most common form of group interaction available on the Internet at present, at times consisting of thousands of members (Smith & Kollock, 1999). They are valued for research purposes, in terms of consisting of extensive archives that can be relatively easily searched (Dochartaigh, 2002). This particular

Facebook group was selected for its figure of 2,013 members internationally, at the time of data collection, from countries such as England, United States of America, Wales, Australia, Ireland, Canada, New Zealand and Netherlands. This sample cannot be described in any detail, on account of the privacy that the Facebook group structure provides, but is naturally limited to those with Internet access and proficiency, and seems to mostly constitute members from first world countries.

The second sample consisted of a convenience sample sought out within the geographic location of Johannesburg, South Africa. A number of avenues were explored in terms of recruitment. The first was by means of placing flyers and response boxes at the offices of a medical professional in Johannesburg who specialises in CFS. The community diary sections of past and current Caxton Newspapers were sifted through, generating contact numbers for a support helpline for CFS/Fibromyalgia, as well as for a support group for the families of persons living with CFS, both of which were contacted as potential gatekeepers. A series of online advertisements were placed on Gumtree, Johannesburg, in the 'Community' and 'Events' categories. Finally, a recruitment advertisement was broadcast on a local radio station, Talk Radio 702, in the hope of eliciting more participants.

The response rate was extremely poor, and the majority of participants in this second sample came from the recruitment box that was placed at the medical professional's office in Johannesburg. All of the 29 participants who responded were invited to attend a focus group discussion. Of these, only three participants arrived for the focus group, two of whom were male and one female with an age range of 28 to 60 years. Eight of the remaining initial responders agreed to respond to the focus group questions in questionnaire format via email. Only two participants returned completed questionnaires, one of which was male and the other female, with an age range of 28 to 53 years.

3.4 Procedure

The gatekeepers were given a poster to display, asking prospective participants to fill in response slips and place them in confidential, sealed boxes on the gatekeepers' premises if they were interested in participating in the study. Advertisements were also accompanied by an e-mail address, should the participant prefer to contact the researcher directly. All respondents were contacted by e-mail or telephone (if a contact number was offered), to provide them more information about the research and to establish a mutually convenient date, time and venue for the focus group. Prior to beginning of the focus group discussion, participants were given a participant information letter (refer to Appendix A). Participants

were asked to respect the confidentiality of what was shared by other group members and to sign informed consent (refer to Appendix B) if they were still interested in taking part. The discussion began with a broad question relating to the title of the study, and was then guided subsequently by a few open-ended questions (refer to Appendix C) to explore some of the particular themes in more detail. At the end of the focus group, participants were fully debriefed (refer to Appendix D) and asked to reflect on their experience of participation. They were then given contact numbers for free counselling centres, should they have experienced any distress during or after the discussion. The discussion was audio-taped and later transcribed verbatim for analysis. It was unfortunate that the last-minute cancellations meant that the number of participants was significantly reduced, thus making the voices of the more dominant participants more pronounced. There was an attempt through facilitation to counteract this trend. Although fewer participants meant that it would not be possible to generalise with confidence, a positive result was that for those who were present, each had more time to speak and thus fully elaborate their experiences.

Considering that a broader number of experiences of South Africans living with CFS were required and that many of the participants who failed to attend the focus group had expressed an eagerness to still participate in the research in some way, it was decided that a questionnaire would be e-mailed to these participants (refer to Appendix E). They were also asked to complete and e-mail back a consent form (refer to Appendix F) and were instructed that they could be as brief or detailed in their questionnaire responses as they wished. They, too, were provided with numbers of free resources in the event that participation had evoked some distress.

Finally, the data from the Facebook discussion board was obtained by means of sorting the 320 discussion topics relative to the number of posts elicited, as well as the number of different people that contributed to the topic discussion. Only those topics that received ten or more of either were included in the study, this being taken as an indication that they were topics that could be seen to resonate with at least a few members of the Facebook group. A total of 96 topics were selected, based on the above criteria and included in the analyses. These topics were then categorised thematically and their contents, in the form of specific discussion entries, provided the data for further analysis and elaboration on these themes.

3.5 Data Analysis

Thematic content analysis was used to generate the results and discussion sections for this qualitative research report. The structure of this form of analysis began with preliminary reading and rereading of the data, in order to become more fully immersed in the contents. This was followed by processing the data in terms of reducing its volume, by means of summarising, paraphrasing and the selecting limited quotations (Van Zyl, 2009). This reductive process was conducted on two levels, the first being within each individual text that constituted data for this research, and the second by means of a subsequent comparison between these texts to establish relations between them, this being the core of the emergence of thematic trends (Van Zyl, 2009). These themes were assessed for frequency and sub-themes identified (Willig & Stainton-Rogers, 2008). As this research was exploratory, an inductive approach to thematic emergence was adopted, in that no particular theoretical model was used in the process of isolating pertinent themes (Willig & Stainton-Rogers, 2008). The focus on people's *experiences* of living with CFS necessitated that the themes be derived from what participants had themselves experienced (Van Zyl, 2009), and the utmost effort was made to report these themes from a position of neutrality on the part of the researcher, this differing from some other qualitative methods of data analysis, whereby the researcher adopts a constructionist, interpretative, narrative or discursive approach (Willig & Stainton-Rogers, 2008). Instead, the content of the results section of this report aimed to represent the experiences of those living with CFS, who contributed to this study, in the most accurate and objective manner possible. It is in the subsequent discussion section that the researcher's own voice was given precedence, in relating the results obtained to the pertinent literature and previous research on the topic. As this research was exploratory, every theme that was found to fulfil the inclusion criteria was reported on. This might mean that the findings are fairly lengthy, but this at the same time opens up an opportunity for starting to make sense of the data.

Chapter 4: Findings

The findings of this research are presented in two separate sections, with the division situated between themes that emerged through analysis of the Facebook discussion group data and those that were found to be prominent in the data from South African participants as derived through a focus group and questionnaires. A comparison between these two sections and a discussion of these themes in relation to relevant literature will be conducted in the discussion section hereafter. The emergent themes in each section have been organised according to overarching categories, with the aim of providing structure and clarity. It is important to acknowledge, however, that these abstract categories are a construct of the researcher and although they may provide a framework which makes the data more accessible to the reader, the actual quality of people's life experiences that they serve to represent is of a complexly inter-related nature. There are thus numerous means of categorisation that could serve equally well to accurately represent the data from this study, and the chosen method is but one of these, selected in the hope that it will allow for a full exploration and integration of the multifaceted and diverse experiences of people living with CFS. Pertinent quotes from the source data have been provided where applicable in order to assist in clarifying the proposed themes for the reader.

4.1 Thematic Content Findings from the Facebook Discussion Topics

The multitude of themes that were isolated in analysis of the ninety-six Facebook discussion topics included in the study were seen to fall within four major categories. These included participants' experiences of CFS as it related to 1) their common concerns in dealing with the illness, 2) impacts on their general functioning, 3) psychological impacts and 4) coping mechanisms. Although these four categories have been expanded upon individually, there has also been an attempt at indicating where integration of the themes within these categories has been pronounced. The most prominently featured of the four categories was that of common concerns around dealing with the illness.

4.1.1 Common Concerns in Dealing with Having CFS

The controversial nature of CFS as manifested in the debate over its aetiology, symptoms, treatment approaches and even at times its very existence as an illness, was reflected in the discussion group data, as more than half of the discussion topics were

centrally related to questions posed to fellow sufferers on possible causes of CFS, diagnostic issues, clarification of symptoms, treatment options and experiences of the course of the illness itself. The creation of this category is an attempt at communicating the extent to which living with CFS seems to take up space within the individual's internal world and become integrally entwined with their existence. A major part of their daily life becomes absorbed with investigation and knowledge-seeking around the illness itself, as well as how to cope with the range and fluctuation of symptoms and the experience of being ill.

The way in which these themes were expressed indicated extremely high levels of agency in trying to investigate and cope with CFS, as many participants felt that the "only way to get something done is to become doctors and research the darn illness ourselves". There was also a particularly strong focus on information- and opinion-sharing amongst members of the group, as the following excerpt indicates, "an alkaline diet will help tremendously too... Google 'alkaline foods", as well as asking for and providing advice, for example, "im really keen to chat to anyone who has had problems with going outside and the anxiety... im keen for advise and handy tips!!" [*sic*]. In a similar vein there was a pronounced focus on establishing shared experiences through questions such as "Does anyone else have a symptom like this?" There was also some elucidation of and questioning around the negative impacts on functioning generated by various CFS symptoms such as, "Sometimes I still feel like I can't get out of bed in the morning and have to just sleep through lectures/whatever... Is this normal post recovery or could I still be ill?"

The most prominent psychological aspects associated with this category were negative feelings of uncertainty, frustration, desperation, fear, anxiety, depression and self doubt, as will be extrapolated in the category on psychological effects of CFS. These were countered to a small extent by expressions of positivity and hope-seeking entries, as shared by one participant who had tried the treatment option of the Lightening Process, "Seriously guys. Search the net. Look this up and you'll find the process. It works! I have my life back after 2 days!!!!" These entries sometimes elicited hopeful and encouraging responses such as "thanks... will be fascinated to know whether the process works for you. Good luck!" but also frequently aroused scepticism from others based on their prior experiences and understandings of the illness as the following quotes demonstrate, "I think it's one of those programme's that will work for a percentage of sufferers, like most of the treatments, but it's a lot of money to outlay if you can't guarantee it's going to work!" and "It all sounds too implausible to me".

Another theme that emerged prominently that was applicable to this category was related to participants' experiences of interactions with medical professionals. Most of the entries regarding medical professionals highlighted the feeling that CFS was not recognised by most medical professionals who suggested "it may all be in your head", "you're just going to have to set your alarm clock and get up" or general medical practitioners "who offered their delightful care 'tell me..., do you pray?'". This was coupled with being recommended medical treatments that were found to be unsuccessful, such as being put "on just about every antidepressant that was around then, none of that worked". Participants reported feeling "so frustrated" that their experiences of living with CFS were not validated by health care professionals. Although limited, there were some descriptions of positive experiences with some medical professionals, such as, "I'm very lucky to have a GP who at least is willing to learn, my illness has been a learning curve for her". This quote also indicates how this positive experience is highly valued and certainly not seen as the norm. Comments such as "I know how you feel, I've had that same experience" indicated a recognition of shared experiences, and there were repeated excerpts offering support, such as, "It's scary when a medical professional can't see where you're coming from". Provision of information and recommendations as to which medical professionals are well acquainted with the illness and are willing to learn and deal with their patients with sensitivity were also evident, one participant recommending that "we start a list of sympathetic pro-active doctors and useful treatment centers on this group?" [*sic*].

4.1.2 Impacts of CFS on Functioning

Many of the discussion topics highlighted the integral ways in which living with CFS affects participants' ability to function academically, occupationally, individually and socially. As each of these areas of functioning can be considered integral to achieving a balanced and fulfilling lifestyle, they are presented in no particular order of importance. Naturally, once again, these impacts interweave with those outlined in the alternate three categories, but are elucidated individually in this category to draw attention to their own particular contribution to the experience of living with CFS.

4.1.2.1 Academic impacts

There were some academic consequences for secondary schooling highlighted, such as having "to drop back a year in high school when I was really sick, and was homeschooled". More prominent in this data were concerns related to coping with the

demands of tertiary study. One participant, struggling through university, found himself "hoping to learn how to slowly push through each day", and another, "starting college this fall" described feeling "a bit worried about how I will survive". These anxieties were blended with feeling overwhelmed in the face of pending decisions regarding applying for college, when "having CFS as a contributing factor is more to think about than I ever could have imagined". Uncertainty was a major factor playing in the minds of young participants with CFS considering their academic opportunities, as illustrated in the following two independent excerpts, "It's all filling me up with so many questions and doubts that I could burst" and "...how am i supposed to figure out what i'm going to do for the rest of my life if i have no way to tell how i'll be feeling at any point down the road?" [*sic*].

4.1.2.2 Occupational impacts

Occupational impacts were varied. Many participants mentioned that they "cannot work at all", some being bedridden and not having been "able to work for the past few years". Others, such as this single mother, expressed having to continue with work despite their illness, due to financial necessity and commitments, "I was on short-term disability for 4 months in 2007, but have been working full time since. I'm not sure how much longer that I can last. I'm a single mom with 2 teenagers, so I have to work..." There are also numerous descriptions of finding particular working environments more conducive to living with CFS, such as being "a freelance web writer" and thus being "glad i can set my schedule for when I'm feeling the most energized" or feeling "very lucky that my company allows me the flexibility to work from home sometimes and to go to the doc's when I need as well".

As with the academic impacts, many of the entries relating occupational impacts echoed similar themes of uncertainty, because the "illness is so unpredictable". This unpredictability was noted as impacting scheduling ability, not being able to "guarantee someone i could work on any particular day...it is most frustrating, i want nothing more than to go back to work" [*sic*]. This frustration was accompanied by feelings of shame: "it always makes me feel like I'm useless and a waste just because I can't work", fear: "I'm a single person in the UK and my only income at present is just over £100 a week in benefits, so it's pretty scary", desperation: "how do you tell them [your bosses] that you have cfs and please go easy on me because really I'm struggling but I'm too scared to shout out for help?" and anxiety: "it really worries me because a previous [NHS] employer said... 18 days off in 12 months was too high and I faced disciplinary and ultimately dismissal if it didn't improve". There was also a strong focus on advice- and information-seeking as a means of coping with

the occupational impacts of CFS, with one participant “wondering what do other people do for money?”, and asking “whether other people have managed to carry on working full time... If so, how did they do it?”

Although less prominent, there were also emergent themes of the financial implications of living with CFS, particularly linked to the decreased capacity to be productive occupationally, as well as the cost of treatments and medical consultations. Some of the financial concerns, therefore, related to issues with medical or disability insurance claims. These were typically affiliated with feelings of frustration and desperation at the struggle of getting claims recognised when “since being diagnosed with CFS I have been given absolutely no support or guidance from the NHS”. There were isolated responses relating successful medical or disability insurance and National Health Service interactions, which were shared in the form of practical advice and information, such as “sorry to hear about your experience... you are protected under the disability discrimination act, and if you feel it’s worth it could seek help from citizens advice” [*sic*]. For others, the financial strain was not as marked, in that other family members assumed the role of breadwinner, as one woman commented: “luckily my husband works to support us all.”

4.1.2.3 Personal impacts

On an individual level, participants’ lives seem to have been affected in terms of coping with everyday activities, many of which were taken for granted prior to the onset of illness. These activities included housework, in that “after coming home after a full day of work + commute...I have zero energy to do house chores!” Self-care tasks and exercising also featured prominently, with sentiments that “since ...all of this came to a head, I have done very little exercise”, and feeling “so unfit as I can't go to the gym”. This stands in stark contrast to life before getting CFS for some participants, who describe having had exceedingly active lifestyles prior to becoming ill, such as having “biked 8 hours in one day with no prior training... I couldn’t do that now if my life depended on it”. The advice from others regarding adjustment to this limitation was to “take each little thing as it comes. Pace yourself, get proper rest”, as well as to “remember that person contributed to you becoming ill - its commonly thought that CFS sufferers have a certain type of high achieving personality so in some ways to move on from this point we have to address the fact we can't do what we used to”. As this excerpt indicates, one’s personality and attitude towards life was debated as having a potential interaction with the illness profile, and pacing and acceptance were held aloft as essential means of coping.

There was also an indication that life choices and goals were significantly affected by having CFS. These manifested in careful consideration by numerous participants as to whether they would still be able to have children and cope with pregnancy and parenthood. One participant expressed that her "biggest concern is whether I will be able to be a good enough mother to my children if I am still suffering from the CFS. Like, will I have the energy to carry my toddler or keep up with the house and the baby?" Career aspirations were also perceived as under threat, with anxiety and sadness expressed around "saying good bye to my career dreams". This loss sometimes sparked hopelessness and defeat, as the following illustrates, "i want to be a dancer...but at this point the most i can manage to do is take pictures of people doing these things. I could do something more mellow, that i know i can handle, but I feel like if i shut down these adventurous kinds of hopes, than there is no reason for me try and recover" [*sic*]. Simple decisions such as taking a holiday were negatively impacted for some, through having "had some problems getting the travel vaccinations, the doctor seems unsure/is leaning towards not giving me them as he's worried I'll suffer a relapse."

Many of the entries pertaining to the theme of impacts on individual functioning once again indicated a level of agency in the form of a search for shared experience, to decrease the marked uncertainty that seems to be entwined in the living with CFS. Notably, for some participants "some good things have come out of this", with regard to enhanced personal life experiences from living with CFS, in that they felt "it gives you a huge insight into the plight of other disabled and chronically ill people", saying, for instance, that "so many of my older parishioners say things that resonate with how I feel now", and affirming that it can make them "more tolerant and empathic ... of others when they struggle". A further benefit described was the learned ability to prioritize, by focussing on what is genuinely meaningful, having needed to remove the clutter of unnecessary pursuits. One participant explained, "I have had to become slower, and in doing so, there is a connection to the world I never used to have. I have the time to notice small things of beauty, and they make more of a positive impact on me".

4.1.2.4 Social impacts

The impact on life choices outlined above naturally also has social implications, in terms of determining the context of one's family environment and the ways in which one is able to engage with the world. There seems to be a strong sense, for the most part, of facing the illness and, subsequently, one's life alone, "never having any support from friends or

family". There seemed to be marked consensus that "CFS can make you feel really lonely and isolated - especially when it feels like your so called friends have run off", which goes hand-in-hand with the many expressions of relief and pleasure at connecting with others, through the discussion topics, who have had similar experiences and can both identify with and give advice. The need for validation from friends and family seemed to be key, as depicted by the comment that "real friends (and the ones that are worth keeping) will understand", whilst often feeling that "family do not fully understand my condition or the constraints it has on me" and "friends so don't understand". Others feel that they need to push their limits to try to hold onto relationships that they are afraid of losing; for instance, feeling like "I've lost some [friends] hence why I'm trying to go for a quick drink for an hour after work on a Fri" [*sic*]. There was also an expressed concern about "always letting friends and family down when i organise stuff" [*sic*], because of struggling with the unpredictability of the symptoms and the constant interruption in scheduled activities through last minute cancellations.

Besides the impact of not feeling validated by family members, interactions with family members are sometimes reported to be additionally strained by the "crazy frustration" of living with the overall experience of CFS, which can result in "taking it out on my family". For many participants the perceived impact of their illness on their family members creates guilt and anguish, as one woman describes that her children "do way more than most kids their ages... kind of makes the mom guilt kick in. Anyone else with kids know what I mean?" There are others who do feel that they get support from loved ones and are acutely aware of the sacrifices that are often entailed, for instance a mother "giving up work to help me and my husband is so supportive but as he is the only one working he has to take what hours he can."

Some participants questioned whether embarking on romantic relationships was possible in the context of living with CFS, saying that they have "decided to give up on all romantic illusions", feeling that they "seem to have nothing to offer anyone except the burden of this illness", yet wanting to reach out for hope and reassurance by hearing "from people in the group who have or are experiencing similar feelings and from those who maybe have against the odds found someone who loves them". Although some feedback responses were positive, they tended to also express realistic drawbacks, such as "my fiancé is very supportive but it really gets to him sometimes", and "romance can happen. It's tough, and a lot of people aren't willing to make the extra effort it takes to be in a relationship with someone who is as ill as we are."

4.1.3 Psychological Impacts of CFS

Besides the more practical functional impacts, a myriad of psychological correlates linked to living with CFS emerged, some of which have been briefly touched on in earlier sections. The most prominent of these, in terms of the discussion group data, were references to feelings of desperation, as one participant put it, "I am basically bedridden with pain so bad that i want to put my head thru a window...and THIS is my life? If I was a horse they'd shoot me!", linked to expressions of hopelessness and a search for hope, which one participant expressed as follows, "At least once a week I wish I was dead because I can't see any hope. Can anyone put me right?" Many participants expressed sentiments that "there is so much contradictory advice it is overwhelming" and also feeling "endlessly frustrated with being unable to do things". This frustration also extended to anger, in feeling that the experience of having CFS "makes me want to scream". Recommendations extended from others were to "Cry if you need to. Rant if you have to. Write. Punch a pillow. Scream. Let it all out." Participants also described feeling "so scared". There was a marked focus on a search for validation of the reality of the illness experience, with comment that "the majority of people don't understand" and the "worst thing about this illness is the disbelief of others". There was urging for people without CFS to remember that "when a sufferer tells you he or she is a little tired, they sometimes mean is they are so exhausted they could weep".

There were descriptions of "feeling damaged and very alone". Many experienced negative impacts on self-esteem and the loss of a former self, feeling that "the longer I have this CFS the more of my confidence, allure, intellect, reason, and sense it takes away". There also were evident battles not to blame, doubt and punish oneself, encapsulated in the expression of one participant, "if I could visibly see on the outside how bad I often feel inside my body, then maybe I would have more patience with myself and my fluctuating limitations". The illness was also described as "robbing you of friends, outings, and any type of fun and can, therefore, be very depressing". Some commented that "trying not to get down about it... is THE hardest thing" [*sic*].

Uncertainty seems to reach vast proportions in terms of whether one will ever be well again and able to resume life as it was, as one participant expressed, "Every single day with Chronic Fatigue is filled with uncertainty. Not just questions about how you'll feel tomorrow, but questions about how you'll feel five years down the road". A stark division seemed to emerge between one's life before CFS and one's life thereafter, the latter being seen for the most part as shrouded in loss, as depicted by feeling that "one day I was living, and the next I am not. The loss is too much". CFS was described as a thief that "robs you of who you used

to be", or in more detail, "it has robbed me of my career and a purpose in life". Taken to its extreme, some felt "completely overwhelmed by a sense of loss, loss of my 20's, loss of the career I should have had, loss of potential relationships, loss of friendships that have fallen by the wayside". Through this significant change and loss, there was a sense of one's identity becoming deeply entwined with the experience of living with CFS, attributed to the overwhelming life impact conjured by all of the categories combined. This identity shift was not always seen as negative, as one participant elaborates, "I'm not glad I'm sick, and I wish we would all spontaneously recover over-night, but I do have some affection for the new person I am because of it".

4.1.4 Coping Strategies Employed

Finally, in conjunction with and as a result of the impact of the categories that have already been outlined, there are a number of themes that came to light, evidencing coping mechanisms employed in living with CFS. One of the most pronounced coping mechanisms was found to be engaging in networking activities with a range of objectives. These included the already highlighted tools of advice giving, such as "give up wheat, give up alcohol" and advice seeking, for example, "It's all very confusing, and i'm just a little lost. So i guess i'm just asking if anyone has any advice to offer, because it would be sosososooo much appreciated!!!" [*sic*], as well as sharing of one's opinion, in stating "I would be careful what you declare". The most recurrent networking coping mechanism, however, was seeking and providing information on an extended range of topics. Some information-seeking excerpts included "Please keep me posted on your LP therapy", or "Can anyone suggest any supplements I can try to kick start my health back to life?", whilst information provision was evident in, "You are entitled to CBT... let me see if I can find the info" and "I use 'kool'n'soothe migraine' which is a cool gel patch... seems to work after around an hour". There were also a number of entries by those who described themselves as having "just been diagnosed" with CFS. These often centred on networking to elicit information and advice, such as "my m.e specialist has put me on an epeleptic med due to m.e being damaged receptors in the brain stem... just wonderin if ne1 else has tried this cheers!" [*sic*]. These entries typically had distinct tones of anxiety, blended with hopefulness, regarding prognosis of the illness - this hopefulness seeming understandably muted in those who had lived with CFS for a longer time.

Besides contribution to a pool of knowledge, a central aspect of the value of networking seemed to be ascertaining whether there is anyone "who's gone through the same

thing", this being valued in declaring "it's really good to hear from other people in the same boat". This shared experience was taken a step further by some, in terms of building deeper connections with others, such as suggesting being "happy to meet up, just send an email". A marked theme in terms of coping mechanisms was offering encouragement, such as "keep up the good work" and eliciting support from and offering support to others living with CFS. Many participants expressed thanks, saying that they "really appreciate and need the support" or, in anticipation, declared that "support and patience will be invaluable". Besides the support from others contributing to the discussion board, there was advice to "make sure you have a good support team around you". Similarly, in countries where ME clinics exist and are accessible, they have been found by some to be helpful in coping with CFS, as one participant explained that she has "finally managed to get into one near me (after a lot of pushing!!) but they have been more supportive and understanding than any doctor or consultant I've seen" [*sic*].

A recurrent theme integrally linked with networking strategies, was the prevalence of agency through self-investigation as to the various components of CFS and how best to deal with the experience of it, as indicated in the belief that "the key is to understand your own CFS and do what's best for you alone". For some, this agency becomes a way of life, as indicated by "This is my 20th year with CFS and I'm a research junkie, like most of us". One of the more proactive elements of coping included lobbying and petitioning activities, as demonstrated in the discussion title, "Petition to FOX about House's CFS episode", which urged others to stand up for recognition of the rights and integrity of people living with CFS.

There were also surfacing themes of increased self-reflection, some participants stating that a consequence of the illness was that "we tend to know ourselves a lot better". There was a sense portrayed by some that their peace of mind is nestled in realising that they "can live with being ill. It is possible!! It's just about accepting and not giving up, being thankful we are alive". Thus acceptance, perseverance and gratitude all featured as coping mechanisms. Some participants focussed more on perseverance, describing battling with CFS as an opponent against which "you have two choices, fight it or let it win..." This battle was encouraged by some who urged others to "keep your head up and keep fighting", whilst others felt acceptance was more integral, in that they "can't fight CFS/ME because it bites back. We have to find a way to live with it (I don't mean give up)" and that peace comes from "accepting CFS - it hasn't buggered up your life, it makes you approach it differently". A strongly emphasised aspect of this different approach to life was engaging in pacing

techniques, which were described as “trying to balance not doing too much on good days so that I feel rubbish the next day”.

There were a large contingent of posts that urged others with CFS to “try to think positively”, elaborating that “even though you have CFIDS, it doesn't mean you have to stop living your life. Do what you can, and build on it, and most of all be happy”. Strategies for achieving this positive outlook included reframing in seeing “every achievement for what it is.... an achievement” and focussing on “the bright side” by being “grateful i am not constantly bedridden like one person i know that has to be carried to the toilet even, so as frustrated as i can get i am happy that it is not worse!” [*sic*]. Other more marginal themes within the category of ways of coping included the use of humour to lighten serious anxieties, two examples being, “what I do for living? - my personal favorite is "Professional Couch Tester"” [*sic*] and a comment around having to start using a wheelchair, focussing on the benefit of getting “to run people over, though not as often as I’d like”. This extended at times to the use of irony, encapsulated in “three cheers for cfs!” There was some mention of the way in which spirituality has played a role, as one participant wrote, “the one thing that I have found that has helped me more than anything in this trial is my faith... having a relationship my Heavenly Father has made all of this bearable”. There are also some examples of ways in which creative endeavours, such as poetry writing, have been used as a medium to facilitate expression of one’s predicament in a way that it is hoped others will understand. One participant shared a poem that resonated with many other participants, which compared the experience of CFS with living “with an abusive and unpredictable partner”:

> He tells me what I spend my day doing.
> He makes me cancel on friends, and cancel appointments.
> He decides whether I can read a book, or listen to music.
> He gives me false hope; lets me think that I can achieve an unprecedented step forward, then pulls me back down to his level.
> He tells me what I can eat and drink.
> He’s indecisive, sometimes he lets me do something then changes his mind midway.
> He plays tricks on me, and punishes me when I read his mood incorrectly.
> He makes me feel sick in the same day that he let me be happy.
> He controls how long I sleep, or if I’m allowed to sleep at all.
> He makes me feel pain for no reason.
> He makes me afraid of what will happen if I defy him.
> He knows I dream of leaving him, and reminds me that I’m foolish for doing so.
> But what I don’t let him know, is that I will one day be free of him, and that his power over me will slowly diminish.

4.1.5 Brief Summary of the Findings from the Facebook Data

The findings suggest that participants in the Facebook discussion group tend to have high levels of agency in response to the many uncertainties of CFS. Feelings of intense frustration, desperation, anxiety and hopelessness were most common in dealing with the vast range of symptoms, extensive and yet generally unsuccessful treatment options, severe impacts on functioning, and negative responses from others. The responses from others that seemed to generate the most distress were not feeling their experiences were validated by medical health professionals or those responsible for allocating disability or insurance claims. Lack of understanding and belief from family members was more marginally highlighted, although strained family interactions were reported. Participants perceived their lives to have altered significantly since contracting CFS, resulting in marked identity shifts and profound themes of loss.

Functionally, CFS seemed to present significant challenges in all areas of life. The illness was often experienced as something one had to battle against, but some sought to strive as far as possible for acceptance, and highlighted the ways in which living with CFS had developed their capacity of empathy for others. Coping strategies most starkly evident were the gathering of information and advice, as well as eliciting the opinions and experiences of others with CFS. One of the commonly recommended means of dealing most effectively with CFS was adopting pacing into one's life. There were scores of encouraging entries offering support to fellow participants, as well as the use of humour to lighten the tone at times and creativity to facilitate a deeper level of expression and connection. There are naturally some aspects of these findings that could be amplified or dulled relative to this particular sample, as will be explored in the section on the limitations of this research. The combination of the data from the South African sample, however, can help to some extent in establishing which findings might be more applicable to those in the general population with CFS.

4.2 Thematic Content Findings from the SA Focus Group and Questionnaires

As has been highlighted in the methodology section, although the utmost effort was made to recruit participants to attend a focus group discussion, there was a remarkably poor response rate. For the sake of obtaining a larger sample, therefore, those who could not attend were e-mailed questionnaires to complete. For the sake of simplicity, the data from the focus group and the completed questionnaires have been jointly reported on. The same structural categories as that of the Facebook data were found to be highly applicable to this data.

However, there were slight variances nestled within the thematic foci of these categories, which shall be explored and commented on in the discussion section.

4.2.1 Common Concerns in Dealing with Having CFS

The strongest thematic focus with regard to this category was on participants' experiences of medical professionals in coping with CFS. There seemed to be consensus around having had to go "through a variety of doctors" both before arriving at a diagnosis and in searching for effective treatments for CFS. One of the strongest psychological correlates of this experience was intense frustration at not feeling that their experience was validated or understood by medical professionals, for instance, feeling one "can't get on with your life and you know what you want to do and get on with and these psychiatrists say to you, you are giving up!" and highlighting "the frustration of when you go to all of these GPs, I remember one GP saying look you've got to snap out of this, it's all in your head, we've done all of these tests and there is nothing wrong with you". There was also a distress over feeling either misdiagnosed, in being told that "you need a psychiatrist or have something wrong with your brain... most say you need more vitamins, less stress, exercise and more sleep", or dismissed by medical professionals, who suggest that they "just go home and rest, you know you are a bit run down, take some vitamin C and Vitamin B". The corollary to this frustration was a recognition of the highly positive effect of feeling validated by a medical professional, such as someone who felt a "top virologist picked up straight away that I was suffering from many viruses, could see I was very sick, had no real treatment but his sympathy and support helped enormously."

In terms of the financial implications of treatment, there was also a focus by some on the experience of feeling that many doctors do not provide the attention that is both desired and representative of the fees that they charge, thus leading one to "question that the doctor is sadly riding the money band wagon", feeling that they "just stick the drip into you and off they go, chatting around, and 'oh thank you, that will be six hundred rand'". Although the perceived receipt of inadequate medical attention by some participants was attributed to doctors being over-worked or careless in their treatment regimes, other participants commended their doctors for not trying "to hurry you up or speed you up" and expressed intense relief at having found a doctor who could assist them, exclaiming, "thank God I met Dr...".

A psychological implication of the medical concerns inherent in living with CFS was predominantly a sense of lingering uncertainty, when "for 18 months I went through 15

specialists and nobody knew what was wrong, at least they admitted they didn't have a clue". There was a sentiment expressed by those who had lived with CFS for a long time, however, that over the past decade they perceived there to be "more understanding, but in 1985... some believed you, others doubted you, creating a very difficult situation" indicting that some validation can be reassuring, in that "at least it is better now to maybe get a diagnosis".

Although it featured as less central than in the Facebook data, there was also repeated elaboration on the possible causes of CFS, the symptoms involved and the various treatment options suggested, considered and embarked on. Participants discussed possible causes for their CFS such as "I know why I probably got it, because I have always lived in old houses that have probably got lead pipes" and explained how they were "diagnosed with various things and treated for various things" and compared, clarified and shared information on their symptoms.

4.2.2 Impacts of CFS on Functioning

There were found to be impacts in all of the four areas of functioning outlined in the findings on the Facebook data. The more marginal focus on academic as opposed to occupational impacts may have been a function of the age group of the participants.

4.2.2.1 Academic impacts

There were reported negative academic impacts on a secondary and tertiary level, due to both health restraints and the financial consequences of living with CFS. One participant described having had to "cut studies short because I essentially ran out of money trying to fund all these doctors bills and all these misdiagnoses" and another related that "at school, one of the classrooms was two flights up and... when I went up that second flight I used my hands on the steps above me".

4.2.2.2 Occupational impacts

The occupational impacts of living with CFS encompassed a general consensus that "you never really reach your full potential" because when "one is often too sick to do a full time job one is not taken so seriously in the industry". Commentary was made on trying to cope with occupational demands whilst enduring the symptoms of CFS, such as having "to go to work with these headaches, I actually don't know how I managed, I felt blind". Affiliated psychological experiences made repeated reference to getting "so frustrated" by the experience of, for instance, being "at a meeting and feeling like I am about to start dribbling

out of the side of my mouth, I can't talk properly, I can't remember names". Others described struggling with "not quite getting the respect you wish you could have and probably would get if you were not a sufferer" and finding that "in the workplace... people don't necessarily understand and it is difficult to relay exactly what it is like and why I am not really working to my full capacity".

There were financial implications embedded in these occupational impacts in that some participants felt that they earned "a lot less than I would have been able to demand had I felt able to move on and upwards", but it was pointed out that "It effects many people in a whole lot of different ways, if you are a house wife who's got a husband who is earning lots of money it effects you in a different way". Some described ways in which they felt they were fortunate in being able to accommodate their symptoms, one participant saying "I am lucky that I run my own practise but I mean I used to have to go and sleep under my drawing board", whilst others explained financial adjustments that were necessary, explaining "we did go through a bit of a rough patch with interest rates going up and we were both pretty sick and ran out of medical, they went pretty quickly with all the blood tests, you learn to cut back and move things around and focus on getting better rather than focus on how much money you have." There was also fairly extensive discussion around the stress of dealing with endless hassles related to medical and occupational insurance, with commentary that "when you are ill, all of these things, you don't have the energy to do". This feeling also extended to more general occupational demands, as one participant explained he couldn't "confront a problem that I have with a client or a contractor, so I let things slip rather than confront them".

4.2.2.3 Personal impacts

On a personal level, CFS was seen to affect participants' lives with regard to their capacity to perform basic tasks of daily living, in that "some days when you are really feeling ill you don't even feel like getting in your car to go and get a bottle of milk, you feel like it is too daunting" and "I used to have to actually stop my car because I couldn't drive". There was also frustration at the lack of a capacity to exercise, feeling that "the more I exercised the sicker I became, any physical activity made me worse", which was hard to accept for those who were "very active" before having CFS, feeling "Always healthy, hardly EVER sick" [*sic*]. The theme of an old 'productive' self that is lost to the experience of CFS also emerged, with feelings of "frustrations and the anger when you can't do what you want to do and you know you can work at a certain level on a good day but today is not a good day and I just

wish I could push myself a little bit further, I don't have it in me to do it". There were also perceived personal benefits mentioned, in terms of an "ability to understand people better and not to judge so quickly based on pre-defined thoughts", as well as the capacity to "be more empathic towards people that have it" and having "more understanding for other sick people". A reported existential insight gained was that "we are not immortal".

4.2.2.4 Social impacts

In terms of the social impacts of CFS for SA participants, some reported "difficulty interacting with other people and with explaining to them why you feel this way and what is wrong with you". These interactions were often laced with anxiety and fear in that "it is really scary, trying to explain it to people because they all go blank, or get so bored with you". This resulted in some participants feeling that they just "couldn't go out... I became almost like a hermit" and when they did go "out sometimes feeling really ill and tired, like I can hardly talk to these people". A large part of the "extreme difficulty" in interacting with friends and strangers was described as being "because people don't really understand and can't relate and most think you just being funny or got physiological issues" [*sic*]. Thus relationships were seen to change "completely... family, friends, work, strangers". Some expressed concern regarding the impact their illness has had on their family life, for instance, wondering "if my relationships would have been different (better?) with my spouse and children had I not had CFS". A much more desperate version of these concerns was "just truly feeling that my family would be better off if I was dead". There was sentiment that CFS puts "a lot of stress on family life and personal relationships. I have read that many CFS sufferers end up getting divorced". There were also descriptions, however, of how romantic relationships with an understanding partner (this particular partner also having CFS) can lend support, with one participant feeling "it was fortuitous meeting my wife".

4.2.3 Psychological Impacts of CFS

A perceived lack of empathy, understanding and validation from others seemed to be one of the most challenging psychological aspects of coping with CFS that the participants experienced. These factors were described as being "very important" in combating situations where one tries to explain what one is going through to others and they "sort of look at you as though you are mad and say, oh well, try this grape seed diet and it will cure you!" There was also a sense that "with other diseases that are far more obvious and easily treatable, if you break your leg and it's in a cast, it's clear, everybody sympathises, they can see you have a

broken leg and they can identify with what it must be like to only walk with one leg, but to say I am tired, people think, oh well, hypochondriac, have an apple, get your blood sugar up, or have a nap, they don't know how to react to you, or say, you are depressed just snap out of it, don't be so melodramatic". Thus most participants described feeling "mostly misunderstood" and as though "very little sympathy is given". This seemed to be particularly challenging in light of the desperation that was so evident in the experience of living with CFS, with participants expressing that they would "try anything to get better", for example, one participant feeling that he must "always be trying things, if someone says 'here's this can of dirt, eat that and it'll make it better', I'll do that". There were also intense feelings at times of being overwhelmed, in that things "just feel insurmountable at times and you try to deal with things by saying, 'if I just get through these two things today'."

The fluctuating course of the illness and its significant impact on functioning was described as bringing one to the "point where you do start getting a bit depressed and almost suicidal, like I thought I actually wouldn't mind if I just died in my sleep because I can't live like this, I am not a functioning human being". These depressive feelings were explained by some in considering it to be really the "frustration that is the key... the absolute frustration", reasoning that "the depression that one's goes through sometimes, was not so much depression as frustration with myself, and thinking that I can't do what I used to do". There was also shame in feeling, for instance, that the "lack of memory can make one look and feel quite ridiculous at times" and dealing with situations such as "people who used to laugh in my office, I had barrels loads of different types of pills, vitamin B injections...". Many of the aforementioned impacts contributed to one feeling "very much alone coping with this problem". There also seemed to be level of continual uncertainty faced, manifesting most prominently in the lingering question of "am I going to have a relapse?" These lingering concerns and consequences fed into identity shifts, as one participant described, "it is such a long term illness, that you become the person". For some, although diagnosis introduced many uncertainties of its own, there was immense reassurance and relief in feeling that one "wasn't losing my mind anymore."

4.2.4 Coping Strategies Employed

Due to the method of data gathering used, the opportunity for engaging in networking as a coping strategy within this sample was naturally limited to the focus group rather than the questionnaire responses, diminishing its overall emergence as a prominent theme. Based on the extent to which it did feature in this context alone, however, connecting with others

who have had a similar experience and sharing of advice, opinions and information were still considered to be major emergent themes. There was a sense that it was "good to speak with other people... who have gone through different experiences related to the same problem, and it is comforting and it gives you a sort of hope that you are not completely alone". Some declared that even "finding one person who also shares the exact same experience and symptoms... makes you feel like you not going crazy – like people largely imply, because they don't understand what you are really going through". There was a strong level of importance placed on having "someone who understands it... who can empathise and know exactly what you are going through". Thus utilizing the support of friends and family was considered an "imperative" and valued coping strategy, but at the same time it was considered "difficult as it is only human nature that they get fed up hearing you are always sick and unable to fully participate in normal living". In the light of this challenge, two types of support groups were suggested as potentially valuable, the one for people with CFS to have a network of people that one "can phone up when you are feeling blue", and the other suggestion being "support groups with family involvement". This was reiterated by mention of the fact that the family relationships that were found to be particularly nurturing to participants were those where the other person has had CFS themselves. One participant who's wife also has CFS described that "having her in my life has made things a lot easier" and another described that he can't do without phoning his sister every day "because she understands, my younger sister doesn't understand because she hasn't had anything wrong with her... I feel a lot stronger after having spoken to my sister than I do after speaking to anybody else". A linked theme that surfaced was the simple act of expression itself, in that "talking about something that is a huge problem in one's life is always useful" and having "a safe place where you can just let the emotions out... is terribly necessary".

As emerged from the Facebook data, a theme of engaging in agency-related coping strategies was discovered to be prominent. This extended to include agency with regard to investigating and speculating on the aetiology of CFS, having, for instance, done "my own research and I decided all these nutrients and things they had been giving me, it wasn't getting better, I must have a parasite". Similarly, participants became actively involved in discovering treatment options, as one described, that he "used the worthy alternative below when my doctor didn't help me out". Part of the reason for becoming so actively involved in one's illness experience seemed to be linked to the anxiety around facing the many uncertainties of living with CFS and the lack of control that this implies. Thus a growing self-reflection and monitoring has developed for some participants, including vigilance regarding

symptom fluctuations, such as "recognising when my body's reaching a low and I should go back on another treatment", and being aware of the consequences of certain behaviours, and responding accordingly, such as knowing "when not to go out because I know when I will feel ill". This also indicates some engagement in pacing techniques, although this particular term did not feature in this data. There was a linked focus on "learning to prioritize" and "learning to have to differentiate between personal wishes and financial necessities, and you have to make the decision, sometimes forced upon you, but we all have to realise that we've got a soul and a person that has to survive and it can survive without all the material things".

An additional means of coping raised was embracing solitude, this being embraced in a "safe place" which can constitute "a walk in the zoo, just to get away" at times when "going out with friends or interacting with people was extremely difficult" and "one became withdrawn". Some participants felt compelled to become "very private and personal and in that space I was forced to become strong and support myself". Some participants also included references to spiritual means of support, listing church as a supportive structure in their lives, or feeling that they were "going through their destiny". There was also a strong focus on meaning-making around having CFS, feeling that there must be "an active reason, that before you die you will know why it happened", whether it is to "pass on what I have learnt, or even just holding somebody's hand through an experience is something you can do with more dignity and empathy". The illness experience was considered to "reinforce your own strength in your own self, and at the same time, the importance of giving", which was related to a newfound ability to be a "support for my wife, a support for my parents... I see myself developing into this role". There was an emphasis on focussing on positive outcomes, as one participant phrased it, "I appreciate and am thankful that I've gone through something so amazing and roller coasting as this. It was extremely tough, extremely challenging and took one to your low or lows. I have learnt an amazing amount, have become more understanding of people and myself. I don't wish this on anybody, but if you ever have it – you have a great lesson coming to you, if you don't go crazy first. There is so much good out of this!" [*sic*].

4.2.5 Brief Summary of the Findings from the Focus Group and Questionnaires

There was an emphasis in these findings on the struggle with medical practitioners for recognition, either feeling misdiagnosed or dismissed. The consequential high financial cost of medical care and tests was raised. Experiences with health professionals often generated marked frustration as well as self-doubt, with concerns that one might be going mad. There

were many questions to fellow participants in the focus group clarifying symptom experiences and treatment options and the value of this opportunity to establish shared experiences was affirmed through a stated longing for support groups. Negative occupational and social impacts were given primary focus functionally, with the loss of previous capacity for productivity sorely felt. Difficulty interacting with others led to social isolation. Personal functional impacts were interwoven within these narratives, but there was a noteworthy positive emphasis on the personal development that can emerge from the illness experience. These linked with meaning-making strategies, striving to maintain optimism and finding spiritual fulfilment. There was also a focus on adopting agency techniques in researching around the illness, being aware of consequences of actions and prioritising to control one's symptoms. On the whole, participants reported experiencing feelings of desperation, uncertainty, frustration, anxiety, shame and depression.

Chapter 5: Discussion

The aim of this research was to explore the psychosocial experiences of living with CFS. The findings generated shall now be evaluated relative to the literature reviewed. As the reader may have already concluded, there was a significant amount of resonance between the results gathered from various previous studies and the psychosocial experiences that surfaced in this research. Thus, rather than reporting on all that was confirmed, the focus of this section will be on highlighting areas of experience that were either found to be particularly salient to participants or were less accentuated. New aspects of experience brought to the fore through this study will also be outlined. Although many of the experiences of participants in the two samples were found to be similar, a comparison between the separate findings will be applied throughout this discussion in order to highlight psychosocial experiences that might be more unique to South Africans with CFS in 2009. It is important to acknowledge in this exploration of variance and concord, however, that the samples are not entirely comparable on account of the different methodologies applied and the relatively small South African sample. Any hypotheses that are suggested from this comparison should therefore be considered as potential focus areas that future research on CFS in South Africa can either confirm or negate.

The parallels between the literature and the two samples of this study seem to indicate a largely generalised psychosocial range of experience of CFS. Four central challenges were identified within this range of experience. It is evident that the experience of living with CFS was felt to be an overwhelming challenge to those who face it. The first challenge arose in connection with the symptoms of CFS, which can be incapacitating and painful to endure. The second challenging aspect revolved around the nature of the perceptions and responses of others to the illness, particularly many health care professionals, but also family members, friends and colleagues. A third aspect to the overall challenge seemed to be facing the uncertainties generated by the lack of a commonly agreed upon understanding of CFS. This controversial discourse of CFS was outlined in the literature describing the disagreements over the concept of CFS as an illness and the associated aetiological understandings and treatment approaches. The challenge over these uncertainties came across in the amount of space that was taken up for participants in dealing with questions of how to understand their illness and how best to go about engaging in healing or managing their symptoms. A fourth

and final challenge which seemed to derive from a combination of the above three was the emotional component of living with CFS.

Overall, it seemed that these four combined influences confronted participants with an experience that was primarily negative, reducing both their physical and mental health quality of life, as had been previously asserted by Van Houdenhove and Luyten (2008). As with many challenges, however, a marginal redeeming feature reported by some was that living with CFS had also offered them opportunities for growth and self-development that served to construct meaning around the experience and facilitate a level of acceptance. Whilst these positive correlates may indeed be cherished by some, for others they are either absent, or do not in any way make the experience worthwhile. At this point in time, the literature suggests that there is no conclusive means of alleviating the symptoms of CFS (Asbring & Narvanen, 2002; Clark et al., 2002; Ware, 1999). There was confirmation that much of the distress evoked through living with CFS seems to arise through aspects of the illness experience quite aside from the symptoms. This offers a window of opportunity for exploration of the ways in which the mental health quality of life for this population can be improved. A benefit of this research was that a more thorough understanding has emerged of what the experiences are that either burdened participants further or allowed them some relief, comfort and inspiration. Whether these additional stressors, left unacknowledged and unresolved, serve to perpetuate the illness itself, is not within the scope of this report to conclude. What is relevant is that, based on this more holistic understanding of the illness experience, recommendations can be made as to potential ways of improving the quality of life of people with CFS. As this exploratory report constitutes one of the first steps in this process, some of the recommendations outlined may naturally need to be explored through further, more systematic research on the topic, as shall be discussed.

5.1 The Challenge of the Symptoms of CFS

5.1.1 The Physical Experience of the Symptoms

The symptoms of CFS reported to be experienced fell on a spectrum from unpleasant or mildly irritating, to excruciating or unbearable. The position on the spectrum hinged on either the symptom type or the level of intensity, the latter often subject to extreme fluctuations. Whilst there have been many management approaches explored to date, as described by Afari and Buchwald (2003), success in generating reliable means of alleviation for many of the symptoms has been remarkably poor. This is therefore an area of research that should continue to be grappled with until a more comprehensive understanding emerges.

5.1.2 The Functional Impact of the Symptoms

Besides the discomfort or pain associated with the experience of the symptoms, many were also found to be remarkably incapacitating. The findings of this report corroborated the literature reviewed, with regard to the significant impacts on all aspects of functioning for people living with CFS (Shlaes et al., 1999, Thomas & Bosch, 2005). Functioning was found to be impaired on a social, personal, academic, and occupational level in both samples of participants. Areas of occupational, social, and personal functioning were seen to be equally profoundly negatively affected. Whilst there was somewhat less focus on academic impairment of functioning, the age group of the participants was likely to have been a mitigating factor in accentuating occupational over academic concerns. Academic impairments that were raised related primarily to tertiary education. Besides the physical and mental challenges described in the Facebook data, the South African sample brought financial limitations to the fore in terms of medical expenses having reduced available funding for studies.

This theme of financial impediment was significant for both samples in terms of occupational limitations, although there was confirmation of the findings by Ware (1999) that these effects were mediated by whether one was a single wage earner prior to becoming ill or relied on income from other sources. A sense of having to 'make do without' financially and shifting focus to other aspects of fulfilment (such as spirituality) was salient for South African participants. This discrepancy could be linked to a dearth of public services in South Africa that provide either suitable free health care or financial disability support. The agency and information seeking approaches applicable to accessing these potentially available services in the Facebook sample, may have been the more active correlates of the acceptance strategies engaged in by South African participants who do not have this structure as a potential buffer. Thus the financial strain of medical expenses for South African participants was also a major theme and difficulty accessing financial support was limited to conflict with medical insurance companies and occasionally private occupational insurance companies who refused to recognise CFS as a valid basis for claims.

Both samples in this study evidenced levels of frustration linked to occupational limitations that went beyond the scope of what was evidenced in the literature. Although present in both samples, for South African participants this frustration was tinged to a deeper degree with feelings of anxiety, desperation, and shame. The greater anxiety and desperation can be understood in light of the lack of public services as described above, whilst the deeper shame seemed to be centrally related to the self-doubt emerging from a remarkable lack of

knowledge and validation of CFS by co-workers and bosses, as well as feeling ridiculed for not performing up to standard on account of 'being tired'.

Social implications indicated a profound sense of isolation for all participants, as described by Thomas and Bosch (2005). This was particularly related to not feeling understood or validated by friends and family members. There was also a focus on the strain CFS puts on social relationships, particularly between family members, resulting in feelings of guilt and depression for participants. South African participants seemed to place particular emphasis on the intense drain on their energy resources that interacting with others exacted and thus seemed to more actively seek solitude. This could be linked to the strain, as described by Ware (1999), on inner authenticity that results from trying to conceal one's reality, whilst interacting with others who are entirely ignorant of CFS or discredit its validity.

5.1.3 Changes in Roles and Identities

There was coherence between the findings of this research and the perspective of Schweitzer et al. (1995) that the experience of CFS is decidedly challenging in terms of shifting identities. The strongest determinant of changes in identity was found to be the shift in roles dictated by the functional impairments of CFS. Whilst these changes were typically considered extremely hard to adapt to and accept, there was often also a strong focus on evolving positive aspects of identity, as found by Thomas and Bosch (2005). Most predominantly identified was a shift in priorities and perspectives in life, as well as the development of a more empathic nature.

5.1.4 All That is Lost

Themes of loss emerged strongly in the findings, and were either felt to conjure frustration and fury, or were mourned with sadness. Although the theme of having lost the person one was before the illness was briefly explored by Tuck and Human (1998), the findings of this study accentuated the range and texture of the losses experienced. Those most sorely felt included the loss of general functionality, relationships, careers, financial security, control, and previous assumptions of health. There was an overarching theme in both samples that the illness came to dictate and control one's life in endless ways, implying an additional loss of independence. This echoes the finding of Thomas and Bosch (2005) that the ways in which patterns of living are disrupted leaves those with CFS often feeling that they are constantly held hostage by the illness and are under its volatile control. This experience is not

only linked to the impact of the symptoms of CFS, but also resonates with the challenge of facing the uncertainties that are borne through a perceived loss of control.

5.1.5 Adjustments and Pacing as Coping Techniques

Strategies such as making physical and attitudinal adjustments were common responses to the illness experience, as suggested by Ware (1999). Prioritization and elimination of superfluous activities were accentuated in the findings, as was allegiance to one particular domain of functioning at the cost of another. Becoming well-attuned to one's limits (Soderberg & Evengard, 2001) and working within these limits was also given marked attention. The term 'pacing' was particularly prevalent in the data from the Facebook participants, being used to describe paying attention to one's limits, and the incorporation of rests whenever necessary. Although not extensively researched, this term has frequently been used in literature regarding coping with CFS both academically (Clark et al., 2002) and in most self-help books (for example Collinge, 1993). Although the South African participants did report the use of pacing in exercising self-awareness and making adjustments, the fact that not one of the participants used this precise term could point to the extent to which they are disconnected from the international discourse of CFS and the silence that surrounds the illness in this country.

5.2 The Challenge of Perceptions and Responses of Others

5.2.1 Stigmatisation and Invalidation

Both the findings and previous literature (Asbring & Narvanen, 2002; Thomas and Bosch, 2005) have confirmed that the challenge of one's experience either being regarded as invented, non-existent or exaggerated, is almost as hard to bear as the symptoms themselves. The findings indicated that many participants felt quite strongly that their veracity was doubted by others, as suggested by Thomas and Bosch (2005). Although the focus of this challenge was primarily related to the attitudes of health care professionals, there were certainly equally profound feelings of one's experience not being validated or understood by family, friends, co-workers and others, as reported by Ware (1999). Not being supported by one's family was reported to be particularly challenging, as well as the loss of valued friendships. There was evident gratitude and relief expressed regarding having at times received recognition, compassion, and patience from loved ones. Experiences of stigmatisation were found to generate feelings of anger, frustration, depression, loneliness, and self-doubt, concurring with Van Houdenhove and Luyten's (2008) assertion that these

experiences serve to significantly decrease overall quality of life. Interestingly, the issue of changing the name of CFS did not expressly emerge in the data of this study, although others' reactions to the name, that they were 'also tired', were often described as highly frustrating. It could be that, whilst the name was considered to produce additional challenges, the intense debate and fluctuation over the name of CFS over the past decade has not generated suitable shifts, and a level of resignation has grown in this regard.

5.2.2 Responses from Health Care Professionals

Deserving of a separate section on account of its ubiquitous mention, invalidation from health care professionals shone through as the major source of distress generated within this particular challenge. Negative experiences of not being believed by these professionals, or one's experience confined to being 'all in the mind' or labelled as depression, were pointed out in the literature (Clark et al., 2002; Shlaes et al., 1999; Thomas & Bosch, 2005), as well as being strongly confirmed by both samples in this study. What emerged of particular interest through this study was that, even if health care professionals were not able to offer helpful advice and treatment options, simply believing that symptoms were real and offering verbal understanding was vastly appreciated and determined a 'positive interaction'. This emphasises the supportive power of recognition and the immense struggle that many people with CFS face in seeking treatment. South African participants who had been living with CFS for a long time expressed gratitude for increased recognition of their CFS by health care professionals over the past twenty years, indicating that there have been some positive shifts underway, however gradual.

5.2.3 Issues Around Diagnosis

Although the issue of diagnosis certainly also has links to feelings of uncertainty, it has been situated here because of its powerful dependence on health care professionals. The relief diagnosis instilled was apparent, as previously documented by Huibers and Wessely (2006) and Thomas and Bosch (2005). This relief seemed to be particularly linked with being offered a vocabulary to express one's experience, as well as the recognition that was implied in being given a diagnosis from a health care professional. Diagnosis with CFS was indeed found to be pre-empted by endless misdiagnoses, as had been affirmed by Harrigan (1998), generally creating a long waiting period between appearance of symptoms and diagnosis. Despite diagnosis implying having to deal with the many complexities of facing a poorly recognised and understood illness, it seemed that most often any diagnosis was considered

better than none, disconfirming the ambivalence reported by Asbring and Narvanen (2002). Being diagnosed with CFS was also generally considered immeasurably better than being diagnosed with a psychological illness and, for the most part, participants were emphatic that their distress was physically-based and resented the self-doubt that at times emerged from being told otherwise.

5.2.4 Support as a Means of Coping

The topic of utilization of support was not extensively covered in the literature, the focus having been largely on the converse experience of the perceived lack thereof from medical professionals and others reported seldom to understand and validate one's experience. Although participants often felt they had to cope with CFS alone without the desired support, the converse availability of support was highlighted in this research to be a cherished aspect of experience. Sources of such support included family members, friends, medical professionals, others with CFS, or any other avenue that offered validation, physical or financial assistance. The value of obtaining emotional support from other people with CFS was made particularly clear in statements of appreciation for establishing shared experiences and obtaining advice and information. This resonates with the findings of Soderberg and Evengard (2001) regarding a group therapy approach that was found to be supportive by participants, with a rich information-sharing process underway, covering topics such as emerging medical information, symptom management and alternative treatment options. The findings on the benefits of shared experience in the current study were considered valid, as these benefits were not only highly praised by Facebook participants (as might be expected through their continued participation in the group), but also by the focus group participants, for whom this was a new experience. Furthermore, the utilisation of the Facebook discussion board medium for this supportive purpose affirms the suggestion of Thomas and Bosch (2005) that Internet access can indeed offer valuable support to persons with an illness that limits their mobility and functionality.

South African participants also brought attention to a need for support structures for family members of people with CFS. This may link with a lack of recognition and accessible resources on CFS in this country. Offering support to family members may be perceived as an opportunity to create a platform for recognition within one's family at least. This kind of support could also be needed to mediate the additional stressors that the general public perceptions of the illness may be injecting into family dynamics.

5.2.5 Advocacy as a Coping Response

The only lobbying activities mentioned in the literature reviewed revolved around trying to affect changes in the name of CFS in order to alter experiences associated with the current title (McNally, 2008). Whilst this particular form of lobbying did not emerge in the current study, there were petitions for changes in perceptions of CFS within the Facebook data. There were no such reported activities from South African participants. It is speculated that whilst a generalised lack of acknowledgement of CFS seemed prevalent internationally, the absence of any evident supportive backing organisations in South Africa may leave people with CFS even less united, more marginalised and silenced.

5.3 The Challenge of Facing the Uncertainties of CFS

5.3.1 Core Aspects of Uncertainty

The trail of uncertainty for those with CFS was typically found in both samples of participants to start at the emergence of the first symptoms and continue with growing unrest, until a diagnosis was obtained and beyond. The diagnosis, although reported to provide relief, was an introduction into a host of new questions with contrasting answers. The largest looming question for participants seemed to be regarding their prognosis and what the hope for recovery might be, this having been pin-pointed as a pertinent issue by Asbring and Narvanen (2002). As mentioned by Ware (1999), even those who had achieved a reasonable level of recovery at some point were left with lingering uncertainty as to whether they would once again relapse without apparent rhyme or reason. As was suggested by the CDC (2009), uncertainty regarding prognosis was found to negatively affect all domains of functioning.

The reduced ability to move forward with one's current life or plan for the future was a commonly perceived loss, as previously outlined by Thomas and Bosch (2005). Participants engaged in both soliciting and sharing questions, opinions, experiences, advice and information in a way that quite clearly evidenced the well of uncertainty that surrounds the illness. The general foci of these debates included which symptoms were common, which treatments were effective and how other people had dealt with challenging life issues that arose through the illness experience, such as financial pressures, caring for one's children, relationships with significant others, how to keep oneself positive, and so forth. Living with this level of uncertainty was found to potentially generate immense anxiety, hopelessness, feelings of being overwhelmed, or a commitment to assuming as much personal control as possible.

5.3.2 Agency as an Antidote to Unanswered Questions

By their very choice to participate in either the Facebook discussion group, the focus group or to answer the questionnaires of this study, all of the participants by definition evidenced a certain level of motivation and agency. The apparent buzz that emerged, however, of exploring endless options and researching countless avenues of treatment, seemed to speak of a wider trend of people with CFS devoting a large amount of time and effort to investigating aspects of the illness. In the absence of a commonly subscribed-to explanation from health care professionals as to why this illness had come about and what the most effective means for curing it was, participants seemed to gain some sense of control from becoming very active participants in trying to figure out their particular illness precipitants, perpetuating factors and options for alleviation. Although the vast amount of contradictory information pertaining to the treatment of CFS implies that consultation with health care professionals could be helpful in sifting through what might prove effective, the negative experiences already described with such professionals can leave the individual feeling that the only solution is to tackle these options themselves. This level of agency could also be linked to a finding by Sontag (1989, as cited in Shlaes et al., 1999) that there is a perceived onus on the individual with CFS to take responsibility for healing themselves when the illness is attributed to a psychological cause.

Whilst the Facebook participants have clearly adopted networking with others with CFS as one means of exercising their agency, this was not a common theme with South African participants. The different methodological approaches of this study, however, prevent solid conclusions from being drawn as to why this might be the case, as it can be decently argued that there are most likely persons with CFS in other countries who have also not networked in this way. Similarly, taking into account the small sample size of South African participants in this study, it is also possible that there may be a portion of South Africans who have, in fact, participated on an Internet forum besides the one analysed in this research.

5.4 The Challenge of the Emotional Component

The three central challenges discussed thus far of the symptoms of CFS, dealing with the responses of others and facing marked uncertainty, feed into what in itself becomes a fourth challenge to living with CFS. This challenge is how to acknowledge, cope with and understand the emotions that are aroused within the illness experience.

5.4.1 Emotions Foreground in This Study

On the whole, participants expressed immense frustration at being labelled as depressed or simply overworked or stressed. It seemed that some participants had tried anti-depressant medications, but, as found by Moss-Morris and Petrie (2001), these did not seem to improve their symptoms. Participants commented on feeling extremely depressed at times, supporting the realms of research asserting this co-morbidity. This was generally explained, however, as a consequence of frustration or hopelessness at not being able to live life and accomplish tasks that had been previously possible, as discussed by Burke and Cunha (2008). Depressive feelings were also seen to result from the isolation that was generated in living with an illness that was poorly understood.

Fear and anxiety were also evident in these findings, as suggested by Tuck and Human (1998). These emotions were located mainly in the occupational impact that CFS implies, as well as the uncertainty regarding the prognosis of the illness. It seems that there has been a predominant focus on depression and anxiety in previous literature, possibly due to the psychiatric relevance that these two emotions are endowed with. This seems to have come at the expense of adequately recognising the powerful blend of emotions that are evident besides these two, as were quite strongly highlighted in this study. These emotions include frustration, anger, loneliness, self-blame, self-doubt, desperation and feeling overwhelmed (as have all been raised in the preceding three sections of this chapter). Besides these difficult emotions, more positive feelings of hopefulness and optimism were also evident, as will be discussed shortly.

5.4.2 Positivity and Meaning-Making

Some participants in both samples of the current research expressed elements of striving to maintain a positive focus and recognition of what were considered to be valuable outcomes of the illness experience. Although not covered in-depth, there was brief mention by Ware (1999) of the 'unmaking of one's life' through the experience of CFS, and how this needed to be repaired through the attribution of meaning to the overall event. The use of positivity and meaning-making by some participants in the current research seemed to provide an understanding that the experience had not been entirely without purpose, in that some good was derived. This benefit-finding, however, was not evident for all participants. The fact that there are so many unknowns and challenges to face for a person diagnosed with CFS may make it hard to reach a place of emotional safety within the illness experience. Those with CFS are found to live with a chronic illness that is often stigmatising and offers

no guarantee as to how long one might be affected and what treatments might work. In this context, the focus often seems to remain on devising ways of surviving the experience and coping, rather than reaching a place of emotional safety, where the experience can be explained through meaning-making. There is a possibility that finding some kind of doctor who demonstrates an understanding of one's experience with CFS may allow for a sense of control over the experience, which could allow for a shift towards emotional safety. A further possibility is that those participants who have reached a more optimum level of health have been more able to reflect back on their experiences, and isolate what it may have meant for them, drawing existential links.

Some of the participants in the South African sample emphasised benefits of becoming more supportive and understanding of others, deepening their spiritual connection, or being able to pass on what they had learnt. The focus in the Facebook sample was on adopting an attitude of 'looking on the bright side', using humour to lighten the tone of communication and engaging in spiritual practices. Spirituality featured briefly in the research of Aikman (1994) and Tuck and Human (1998) as valuable in enhancing coping ability in CFS in lending strength through prayer. The focus on providing support for others within the South African sample may have again been illustrative of a distinct scarcity of such support available to South Africans living with CFS. This focus could be seen as a function of an attempt to fulfil this need to some extent.

5.4.3 Expression in Dealing with Emotions

An area that came to light in this research that was not specifically evident in the literature reviewed was the value of expression as a means of coping with CFS. Expression came to light as a way of coping in a more traditional sense for South African participants who valued communication with others as a means of getting by. Whilst this was echoed by Facebook participants, there was also an emerging theme of engaging in creative activities to release pent up emotions and more effectively communicate one's experiences to others. Although Thomas and Bosch (2005) mentioned that people with CFS engage in actively spreading information about CFS to others around them to generate understanding, the particular slant of trying to portray one's experience through creative investment does not seem to have been previously highlighted.

5.5 Implications of the Study

The following section outlines the implications of the themes found to be particularly salient and the nuances of varying focus between the two samples. One of the prominent messages that emerged from these findings is the evident level of distress for people living with CFS that originates from stigmatisation and the lack of understanding from other people, especially medical professionals. Increased understanding from others regarding the implications of CFS for one's life would possibly facilitate recognition that, although symptoms may be invisible, practical support and validation are most valued. Advocacy regarding the existence of CFS and the experience of living with the illness could help to minimise the reportedly high levels of associated distress. The finding that recognition from health care practitioners on the whole is sorely lacking and that people with CFS highly value simply being affirmed and believed within this context, suggests that advocacy and training for these professionals can provide significant benefits to people with CFS.

The emotional strain of living with CFS evident in these findings could be improved through further investigation, such as that of Thomas and Bosch (2005), into the possible effectiveness of individual and group therapy, support groups, and the use of tools such as the Internet to facilitate easier access. As has been highlighted in previous studies and the present findings, however, the beneficial aspects to this form of support seem only to emerge when persons with CFS feel that their experiences are validated, which is felt to be undermined by therapists who express a belief that CFS is caused by psychological phenomena. Therapeutic input has been suggested to be beneficial as a supportive framework to assist with the emotions evoked through uncertainty, the responses of others, and symptom experiences and consequences. Linked to this finding is the powerful stigma that seems to prevail with regard to even the possibility of having a psychosomatic illness. The level of distress and frustration evoked in this possibility alone is an indication of what might emerge if psychosomatic processes did happen to be definitively linked to CFS in the future, as well as what is likely to already be experienced by persons who are currently living with illnesses that are psychosomatically defined. Advocacy directed at the general public perception regarding psychosomatic illness is therefore sorely needed to deconstruct this stigma and reduce the associated distress.

Overall, the call by people with CFS seemed to be for a more sensitive understanding of their experiences. They asked for acceptance of the fact that they cannot simply cure themselves through will and extra effort, and recognition that their experiences are real and valid, whatever the cause and however invisible. There is speculation as to whether the use of

creative expression can be further facilitated as a possible means of allowing persons with CFS expression of their experiences in a way that achieves emotional connection with others. Developing capacity for the agency of those with CFS may also assist in combating the uncertainty of the illness. Means of achieving this agency could be through making information and resources easily accessible, particularly for those who do not have available Internet access. Material in libraries could be reviewed and updated and organisations that function as central ports of call for queries and service provision could either be established or more effectively marketed. There seems to be a particular lack of these organisations and resources in the South African context. CFS seems to have remained under the radar in this country, particularly the diagnostic radar of health care professionals. Financial stressors of living with an illness that requires extensive exclusionary tests and various continual treatment approaches were found to be significant, particularly in a country such as South Africa, that lacks reasonable health care services at an affordable cost.

5.6 Limitations of the Study

The limitations of this study need to be evaluated as fully as possible, in order to acknowledge any factors which may have compromised the validity and generalisability of these findings. Firstly, as already mentioned, the agency implicit in participating in a Facebook group discussion or a research study may skew the findings toward amplification of this trait. This being said, eliciting the experience of others who are less proactive is extremely challenging for any type of research. Also unfortunate is the fact that for some people with CFS, the lack of participation may have been determined instead by levels of severe incapacity. Thus, the experiences of those most severely affected have not been documented, except insofar as through recollection of those who have previously experienced being bedridden and entirely immobilized. As the illness is characterised by marked levels of fluctuating health, although subject to retrospective bias, these contributions have hopefully been able to represent the experiences of those severely affected to some extent at least. Similarly, this study deals essentially with the experiences of those already diagnosed with CFS. Experiences of those who have CFS, but have never been given a diagnostic term to describe their experiences, are also only represented in terms of the recollections of those now already diagnosed. Whilst this is a valid limitation, there are realistic practical impediments to recruiting participants who have not as yet been diagnosed. Furthermore, there is an associated acknowledgement that it was not possible to establish definitively whether all of those participating on the discussion board in the Facebook sample had been

diagnosed with CFS, although the general impression gathered from the content of the discussions was such that most participants had, in fact, been diagnosed.

One of the limitations that does need serious consideration in terms of its impact on the accuracy and generalisability of the findings, was the size (and subsequent characteristics) of the sample of South African participants, despite extensive recruitment efforts. Due to the varied methodological approaches, it is not possible to conclude whether difficulty recruiting participants is an international challenge in research on CFS, a function of CFS being less prevalent in South Africa, or CFS being under-diagnosed in this country (due to a general lack of recognition by health care practitioners). The costly tests required in diagnostic procedures also determines that only those with sufficient economic resources can be diagnosed and hence participate in this research, excluding those of a lower socioeconomic bracket and limiting the study pool. The result of this poor response rate was that only one focus group was held, which did not allow for corroboration of the prevalent themes, except through the questionnaires received from those who could not attend the focus group. This, however, does not undermine the possible benefits of the findings of this research, as they do pertain to the population sample recruited and further studies with a larger scope can examine possible effects in a wider population.

The fact that the forum of the Facebook discussion group was not intended for research purposes functions both as a limitation and a benefit. Those participating in the focus group were well aware that what they said was to be used for research purposes, which may have resulted in them exerting more control over what they contributed. Those participating on the Facebook forum, however, had no idea that their contribution was going to be used for research purposes and were thus less likely to control what they said. The benefit of this was the provision of raw, unscripted experiences, which were offered in a context of relative anonymity. One of the drawbacks was that it was not possible to offer a demographic description of this sample and thus effectively assess generalisability. Thus, even though the Facebook group consists of over 2,000 members contributing to over 300 discussion topics, these participants derive from all different parts of the world. Experiences of CFS may vary significantly according to the level of acceptance and resources available in each particular country and, as such, it is difficult to ascertain which aspects of their experience are related to dominant views of CFS within their particular milieu. Furthermore, there were some participants who were significantly more active than others, which also impacts on generalisability, as their experiences may have at times dominated the discussions. Since some of the discussion topics included in the study had been active over

the past two years, there are also potential cohort effects, on account of possible dramatic developments in the field of CFS throughout this period. Naturally, participation for this sample was limited to those with computer and Internet access and savvy, which in turn dictates a certain level of economic security. Whilst the above limitations could impact negatively on generalisability, it should be recognised that this study aimed to bring to the fore some of the experiences of those living with CFS, in order that further research might unpack these in a preferably quantitative and more systematic paradigm.

Finally, the variances between the methodologies utilized may also have lent to systematic differences that could not be controlled for, as have been highlighted in the method and discussion chapters. There are distinct limitations in using the word "compare" for what has been done in this study. A true comparison between the focus group data and that derived from what took place up to two years ago in a combination of other countries in a public space is not possible. The distinct difference between the quantities of data available for analysis, on account of the small sample size of South African participants and the vast number of discussions accessible in the Facebook group, also made comparison less appropriate. Hence the present study's aim was more focussed on picking up themes in the two samples, rather than demonstrating relationships. As such, any speculative comparisons discussed in the present study should be interpreted with caution, and are better conceptualized as extremely tentative hypotheses that should be further explored by more systematic research.

Chapter 6: Conclusion and Recommendations

There was found to be a paucity of literature addressing the psychosocial experiences of people living with CFS, especially literature examining the experiences of a broad number of people with this particular focus in mind. An in-depth review of various academic texts that reported on different aspects of psychosocial experience provided a fairly comprehensive summary of what might be experienced. This qualitative study was an exploratory attempt at offering these persons a voice in academic literature. The ultimate objective was that, through as full a description of their experiences as possible, conclusions could be drawn as to what might be of benefit to this population group and recommendations suggested for future relevant research. The two samples for this study consisted of international members of a Facebook group who posted entries on discussion board topics and South African participants who attended either a focus group, or answered questionnaires regarding their experiences of living with CFS. Thus, two separate sets of data were analysed for relevant themes of experience, using thematic content analysis, and reported on individually. These two sets of findings were then compared with the literature reviewed and particularly salient features were highlighted. Seemingly discrepant experiences between the two sets of findings were also pointed out, with cognizance as to the limitations of their validity based on methodological constraints.

The findings brought attention to four major categories of challenges for people living with CFS and some of the resultant coping strategies that seem applicable to each. The first was the challenge of the symptoms themselves and their impact on one's physical sensations and ability to function, with subsequent consequences for roles, identities and experiences of loss. Coping strategies aligned to this were seen to be making necessary adjustments and pacing one's activities. The second challenge that was addressed related to the perceptions that others have of CFS and how they respond to persons affected. Instances of feeling stigmatised and invalidated were apparent, particularly in association with health care professionals, this having implications in terms of experiences of diagnosis. Fostering support and advocacy were seen to be the primary coping responses in dealing with this challenge. The third challenging aspect of the illness experience was identified to be facing the uncertainties that were found to be rife. Uncertainty was often tackled by becoming an active agent in one's own healing process. Finally, the emotional rollercoaster that the above three challenges evoked became the fourth aspect of experience seen to be challenging to endure.

The central means of reducing this particular challenge seemed to be through focussing as much as possible on positivity, meaning-making and utilising various avenues of expression.

These findings can offer valuable insight into the ways in which those with CFS can be more effectively supported, which appropriate future research can further explore. In order to achieve this, future studies should strive for increased sample sizes to guarantee that a variety of experiences are gleaned. A focus on the perspectives of health care professionals and their awareness of CFS would also be of value, with the inclusion of unpacking aspects that may prompt or inhibit diagnosis. It is recommended that current prevalence rates of CFS should be established, particularly in South Africa where no such rates seem to have been ascertained thus far. What came across as seemingly effective coping mechanisms in this study (such as utilizing support groups, online support, agency techniques and creative means of expression) need to be further researched in terms of their impact on quality of life. The findings of the current study also suggest that there is room for exploration as to the differentiation between those with CFS who move into a process of meaning-making from those who do not. Furthermore, it goes without saying that, despite the realms of research on the topic thus far, additional research that can provide some definitive evidence as to the aetiology and treatment of CFS would be remarkably beneficial. Whilst it was beyond the scope of the present study to discuss, it is also suggested that future research focus on the experiences of family members living with a person with CFS. Adolescents and children with CFS could also be benefited by further research documenting their experiences of living with CFS in particular.

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Appendices

Appendix A

- Participant Information Letter

Appendix B

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Appendix A: Participant Information Letter

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4 August 2009

Dear Prospective Participant

My name is Bronwen Lee and I am conducting research for the purposes of obtaining a Masters in Clinical Psychology at the University of the Witwatersrand. My area of focus is that of **the experiences of people living with Chronic Fatigue Syndrome (CFS) in a South African context and internationally.** There is extensive debate internationally as to the cause, title and treatment of CFS, but what seems clear is how CFS significantly affects the lives and functioning of those people who experience it. We would like to invite you to participate in this study.

Participation in this study involves partaking in a one and a half hour focus group of 6-10 people at a location, date and time that is convenient. In the focus group, open-ended questions about your experiences of living with CFS will be put to the group by the facilitator, but the discussion will be guided for the most part by the topics that emerge as significant through the group dialogue. After the session there will be a short debriefing to offer containment to all members of the group.

All participants will be asked to sign a confidentiality form stating that they will agree to refrain from discussing the views expressed by others in the focus group after the session. Whilst themes that emerged from the focus group will be reported on, no names will be mentioned in the final report. The session will be audio-taped and transcribed for research analysis, but will not be seen or heard by any person besides myself and my supervisor. Participation in this study is voluntary and you may decide at any point to stop participating. No individual will be advantaged or disadvantaged in any way for choosing to participate or not to participate in this research. The results of the study will appear in a final research report and may also be presented at a conference or reported in a journal article. A summarised version of the results can be e-mailed to you on request after April 2010. Your participation in this study would be greatly appreciated. This research will contribute to a larger body of knowledge on the experiences of people living with CFS. If you consent to participate in the study **please complete the form attached.** Should you wish to contact me please do so on bron10@hotmail.com or 082 5843848. The supervisor for this research is Dr. Esther Price and she can be contacted on (011) 717 4517.

Kind regards

Bronwen Lee

Appendix B: Consent Form (Focus Group)

I _____ consent to participating in this research project designed by Bronwen Lee for her study on the experiences of people living with CFS for the purposes of obtaining a Masters in Clinical Psychology at the University of the Witwatersrand.

I understand that:

- I will be participating in a one hour focus group discussion on my experiences of living with CFS.
- I am invited to participate in this study and participation in this study is voluntary and there will be no negative consequences should I decide not to participate.
- I may refuse to answer any questions I would prefer not to.
- I may withdraw from the study at any time.
- The audio-tape and transcript will be kept confidential and all participants in the focus group will be asked to sign agreement of confidentiality.
- No names of participants will be mentioned in the report, as data will be reported as a reflection of themes that emerge through the group discussion.

Please indicate whether you would like a summary of the results to be e-mailed or posted to you: *Tick the appropriate box*

☐ YES

☐ NO

Date: _____

Signed: _____

Appendix C: Focus Group Questions

1. We are here to talk about your experiences with CFS. What has been your experience of living with CFS from the time you were diagnosed?
2. What makes your life easier and what makes it harder?
3. What has your interaction been like with medical/treatment professionals?
4. How has living with CFS changed your life, if at all?
5. How do you feel having CFS has influenced your relationships with significant others in your life?
6. What have the occupational consequences been for you?
7. What support mechanisms, if any, are valuable for you?
8. Do you feel that there is anything that you have gained from the experience of living with CFS?

Appendix D: Participant Debriefing Form

Dear Participant

Thank you taking part in this focus group. Your participation will contribute to the body of knowledge on the experiences of people with CFS within a South African context as compared with the experiences of people living with CFS internationally. Should you experience any residual distress, these are some resources that you might like to consult.

- **Lifeline Norwood** (24 hour counselling service) **011 728 1347**
- **Lifeline National Share Call** (24 hour counselling service) **0861 322 322**

Kind regards

Bronwen Lee

Appendix E: Questionnaire to South African participants

Instructions:

Please read and complete the consent form attached and return it with your questionnaire responses. There is no required length for your response entries. You may be as brief or detailed as you wish for each question.

1. What has been your experience of living with CFS from the time you were diagnosed?

Response:

2. What makes your life easier?

Response:

3. What makes your life harder?

Response:

4. How do you feel having CFS has influenced your relationships with other people in your life?

Response:

5. What support mechanisms, if any, are valuable for you?

Response:

6. How has living with CFS changed your life, if at all?

Response:

7. What has your interaction been like with medical/treatment professionals?

Response:

8. What have the occupational consequences been for you?

Response:

9. Do you feel that there is anything that you have gained or lost from the experience of living with CFS?

Response:

10. These questions have been to guide an elaboration of your experiences of living with CFS. What other areas that have not been touched on are relevant for you in living with CFS?

Response:

Appendix F: Consent Form (Questionnaire)

I _____ consent to participating in this research project designed by Bronwen Lee for her study on the experiences of people living with CFS for the purposes of obtaining a Masters in Clinical Psychology at the University of the Witwatersrand.

I understand that:

- I will be completing a questionnaire on my experiences of living with CFS.
- I am invited to participate in this study and participation in this study is voluntary and there will be no negative consequences should I decide not to participate.
- I may refuse to answer any questions I would prefer not to.
- I may withdraw from the study at any time.
- The questionnaire response forms will be kept confidential.
- No names of participants will be mentioned in the report, as data will be reported as a reflection of themes that emerge through the group discussion.

Please indicate whether you would like a summary of the results to be e-mailed to you:

Mark the appropriate option

☐ YES

☐ NO

Date: _____

Signed: _____

Please could you also provide the following demographic information:

1. Age:
2. Gender:

Appendix G: Ethics Clearance Certificate