Well-Being in Chronic Fatigue Syndrome:

Relationship to Symptoms and Psychological Distress

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Abstract

There is growing recognition in psychology that wellness is more than the absence of disease and distress. Well-being has been defined in numerous ways. Two dominant models include Diener, Eunkook, Suh, Lucas & Smith's (1999) Hedonic model of Subjective Well-Being (SWB) and Ryff's (1989) Eudiamonic model of Psychological Well-Being (PWB). There has been insufficient research into positive mental processes and well-being in Chronic Fatigue Syndrome (CFS), in contrast to the abundance of research emphasising psychopathology and dysfunction. This study's first aim was to examine PWB and SWB and their relationship to symptoms in individuals with CFS (N = 60). Participants completed self-report scales of PWB, SWB, fatigue, pain, anxiety and depression. The second aim was to compare PWB scores in a subgroup of the CFS sample (N = 42) to a matched non-clinical control group (N = 42). Correlations between scales of symptoms and well-being were found to be complex. Well-being dimensions were largely independent of physical symptoms (Pain intensity, Physical Fatigue, Reduced Activity and General Fatigue) but strongly related to psychological components of fatigue (Mental Fatigue and Reduced Motivation) and psychological distress (Depression and Anxiety). Multiple regression analyses indicated that five dimensions of well-being uniquely predicted symptomatology in CFS. Compared to the control group, the CFS group scored significantly lower on five of Ryff 's six PWB dimensions, with particularly marked deficits in Personal Growth, Environmental Mastery and Self-Acceptance. No significant difference was found between the CFS and control groups on the Autonomy subscale. This multi-dimensional assessment of well-being advances our understanding of CFS; it highlights the burden of CFS beyond symptoms, challenges the over emphasis on maladaptive cognitive and personality traits in previous research

and offers several new treatment targets. Future research must investigate whether interventions targeting theses well-being deficits can boost the efficacy of symptom-focused treatments, which currently produce unsatisfactory recovery rates in this client group.

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Chapter 1: Introduction

1.1 Purpose of Research

There has been an abundance of psychological research investigating psychopathology and dysfunction in Chronic Fatigue Syndrome (CFS), whilst very few studies have examined positive attributes. A positive psychology approach suggests that well-being and recovery from illness are more than just the absence of symptoms and should also include the restoration of strengths, happiness and meaning in a person's life (Seligman & Csikszentmihalyi, 2000). Given the unsatisfactory recovery rates following symptom-focused treatments in CFS, research identifying alternative treatment targets is a clinical priority (Price et al., 2008). The present study aims to investigate various aspects of well-being in adults with CFS. A positive psychology approach could help us better understand the experience of individuals with CFS and challenge the emphasis on maladaptive cognitive and personality traits in previous research. A greater understanding of the relationships between symptoms and well-being in CFS could help identify new, positive treatment targets that could inform the development of less pathologising psychological interventions.

1.2 Chapter Overview

This chapter will begin by providing an overview of CFS, its diagnostic criteria and a critique of previous psychological research into the condition. It will then highlight the inadequacy of symptom focused treatment like Cognitive Behavioural Therapy, which produce unsatisfactory recovery rates in physical symptoms, psychological

distress and quality of life. An argument for the necessity of a positive psychology approach in CFS will be given, before defining the constructs of Hedonic and Eudiamonic well-being. Given the striking absence of research examining psychological well-being in CFS, literature investigating its relationship to symptoms in co-morbid conditions of CFS will be discussed. The chapter concludes with a description of the present study and the research questions it aims to answer.

1.3 Chronic Fatigue Syndrome

1.3.1 Classification

CFS is characterised by a range of symptoms including profound and disabling fatigue, sleep difficulties, pain and cognitive impairment (Fukuda et al., 1994). With a population prevalence of at least 0.2-2%, depending on the diagnostic criteria and study design used, CFS is a relatively common condition, (Bates et al., 1993; Wessely, Chalder, Hirsch, Wallace, & Wright, 1997). It affects four times more women than men and the average age of onset is 30 years (Ranjith, 2005). Recovery is rare (5–10% achieving total remission) and only palliative treatments exist (Cairns & Hotopf, 2005). As a result, most people with the condition experience a chronic course of symptoms, which fluctuate in intensity and severity and pose a significant challenge to them, their families and the medical profession.

The World Health Organisation (1992) classifies CFS as a neurological illness, although its medical aetiology is unknown and no diagnostic test exists. A recent

systematic review identified 20 different case definitions of CFS (Brurberg, Fønhus, Larun, Flottorp, Malterud, 2014), exposing the lack of medical consensus and significant controversy surrounding the condition. The most frequently applied and extensively validated diagnostic criteria are that of the Centres for Disease Control (CDC; Fukuda et al., 1994), listed in Figure 1. The CDC states that symptoms must have been present for six consecutive months, before a diagnosis can be given. In comparison, The National Institute of Clinical Excellence (NICE, 2007) recommends a diagnostic waiting period of four consecutive months, whilst the International Consensus Criteria (Carruthers et al., 2011) asserts that any waiting period is unnecessary and potentially damaging.

Centres for Disease Control Criteria:

A case of the chronic fatigue syndrome is defined by the presence of the following:

1) Clinically evaluated, un- explained, persistent or relapsing chronic fatigue that is of new or definite onset (has not been lifelong); is not the result of ongoing exertion; is not substantially alleviated by rest; and results in substantial reduction in previous levels of occupational, educational, social, or personal activities

2) The concurrent occurrence of four or more of the following symptoms, all of which must have persisted or recurred during 6 or more consecutive months of illness and must not have predated the fatigue:

Self-reported impairment in
- Short-term memory or concentration severe enough to cause substantial reduction in previous levels of occupational, educational, social, or personal activities
- Sore throat
- Tender cervical or axillary lymph nodes
- Muscle pain
- Multi-joint pain without joint swelling or redness
- Headaches of a new type, pattern, or severity
- Unrefreshing sleep
- Post-exertional malaise lasting more than 24 hours.

3) No clinical evidence of other causes of fatigue: i) organ failure; ii) chronic infections; iii) rheumatic and chronic inflammatory diseases; iv) major neurological diseases; v) systemic treatment for neoplasms; vi) untreated endocrine diseases; vii) primary sleep disorders; viii) obesity (BMI > 40); ix) alcohol/ substance abuse; x) reversible causes of fatigue such as medications, infections or major surgery; xi) psychiatric conditions e.g. melancholic depression, bipolar disorder, psychosis, eating disorder.)

4) Routine investigations do not suggest a cause for fatigue: FBC, ESR, U&E, LFTs, calcium, phosphate, random glucose, thyroid function, celiac serology, urinalysis.

Figure 1: CDC Criteria for a Diagnosis of Chronic Fatigue Syndrome (Fuduka et al., 1994).

A plethora of diagnostic criteria and disparate terminology (Myalgic Encephalopathy ME; post-viral fatigue) has hindered CFS research and rendered studies incomparable. For patients the effect of medical uncertainty is devastating. Many encounter extensive, yet fruitless medical examinations, inconsistent advice, treatment delays and skepticism from healthcare providers (Deale & Wessely, 2001). The diagnostic label given to patients may even determine their prognosis. After controlling for baseline differences, a longitudinal survey found that ME patients showed the worse prognosis, followed by CFS patients and then post-viral fatigue patients, who showed the most favourable outcomes (Hamilton, Gallagher, Thomas & White, 2005). Authors concluded that having a diagnostic label that infers an untreatable pathological process (ME) or an unknown cause (CFS) may somehow render the patients more helpless in combating their symptoms and disability, as opposed to a label that implies a triggering illness (post-viral fatigue). Historically, many physicians have not believed in CFS and accused patients of malingering or attributed their symptoms to a psychiatric disorder. Reports have since been issued warning health professionals that CFS is a genuine illness (Sharpe, 2002) and that inaction due to denial or ignorance of the condition is not acceptable (Royal Colleges of Physicians, Psychiatrists and General Practitioners, 1996).

1.3.2 Co-Morbidity In CFS

High rates of co-morbidity exist between CFS and other functional disorders. Approximately 35%- 75% of individuals with CFS also have fibromyalgia, a chronic widespread pain condition (Buchwald & Garrity, 1994; Goldenberg, Simms, Geiger & Komaroff, 1990), whilst 63% have irritable bowel syndrome (IBS;

Gomborone, Gorard, Dewsnap Libby & Farthing, 1996). Having an additional functional syndrome puts a patient at increased risk of depression and psychiatric morbidity. Ciccone and Natelson (2003) found that rates of lifetime depression increased from 27.4% in the CFS only group to 52.3% in the comorbid CFS and fibromyalgia group. There has been some debate as to whether CFS, fibromyalgia and IBS are simply different expression of the same thing and it is widely accepted that they share many similar clinical features (e.g., they all have an unknown aetiology and are frequently accompanied by a significant psychological sequelae). According to Wessely, Nimnuan and Sharpe (1999) the "similarities between them outweigh the differences" (p. 936); however, a more recent review of the biological literature suggests that there are significant differences in their underlying pathophysiology (Abbi & Natelson, 2013). Based on current evidence, grouping them together as the same illness is inappropriate and further exploration of the similarities and differences between them is required. Having the three discrete case definitions (CFS, FM, IBS) arguably advances the study of medically unexplained illness. It permits comparisons to be made of treatment outcomes, prevalence rates and the effects of illness on quality of life (Ciccone & Natelson, 2003). Ultimately, there may be important differences in the experience and psychological impact of living with chronic fatigue (CFS) versus chronic widespread pain (fibromyalgia) versus chronic abdominal pain (IBS).

1.3.3 Theories of CFS

Many potential causal factors of CFS, including immunological, genetic, infectious, endocrine, neurological, and psychological, have been examined yet none fully explain the diverse array of symptoms reported by patients. Mounting evidence

suggests that a complex disease mechanism underlies the condition (Brurberg et al., 2014). This has been operationalised in the Cognitive Behavioural Therapy (CBT) model of CFS, which outlines a plethora of predisposing, precipitating and perpetuating factors (Surawy, Hackmann, Hawton & Sharpe, 1995). Factors thought to predispose a person to CFS are typically psychological in nature and include a history of depression (Abbey, 1996), somatisation (Manu, Matthews & Lane, 1988), maladaptive personality traits (Sáez-Francàs et al., 2014) an over active lifestyle (Van Houdenhove, Neerinckx, Onghena, Lysens & Vertommen, 2001), parental physical abuse (Clark, Goodwin, Stansfield, Hotopf & White, 2011) and an insecure attachment style (Noyes et al., 2003; Taylor, Mann, White, & Goldberg, 2000; Wearden, Lamberton, Crook, & Walsh, 2004). Common precipitants include viral infections and stressful life events (Hatcher & House, 2003; White et al., 2001), whereas avoidance of activity, excessive resting, selective attention to symptoms, maladaptive illness beliefs and changes to the functioning of the hypothalamus pituitary adrenal axis, are hypothesised to maintain CFS (Ray, Jefferies, & Weir, 1997; Deale, Chalder, & Wessely, 1998; Deary & Chalder, 2010).

1.3.4 Overview of psychological research into CFS

Previous psychological research into CFS has focused almost exclusively on identifying the presence of negative constructs, with a particular emphasis on psychological distress, maladaptive personality traits and social dysfunction.

Psychological Distress

Surveys and systematic reviews reveal a high prevalence of psychiatric disorders, amongst individuals with CFS. Up to 85% of CFS patients identify depressed mood as

a primary symptom (Komaroff & Buchwald, 1991) and approximately 65% meet lifetime criteria for depression (Abbey & Garfinkel, 1991). Furthermore, 20-56% meet criteria for Generalised Anxiety Disorder (GAD; Fischler et al., 1997). Studies comparing CFS patients to patients with explainable chronic illnesses, including multiple sclerosis, arthritis, and myopathies, consistently document higher rates of depression in CFS (Wood, Bentall, Gopfert, & Edwards, 1991; Johnson, DeLuca, & Natelson, 1996; Pepper, Krupp, Friedberg, Doscher, & Coyle, 1993). This has led some researchers to argue that CFS is an atypical manifestation or somatised expression of psychiatric illness (Katon, 1984; Manu, et al., 1988). Biological evidence contests this view. Compared to depression, CFS is accompanied by distinct abnormalities such as immune system dysfunction (Cho & Stollerman, 1992; Gurwitt et al., 1992), brain abnormalities (Gurwitt et al., 1992) and limbic system dysfunction (Goldstein, 1992). There is also no strong evidence to suggest that anti-depressant medications facilitate recovery in CFS. Rimes & Chalder (2005) reviewed three Randomised Controlled Trials (RCTs) of antidepressants (Serotonin and Phenelzine). Two of the RCTs (Natelson Cheu, Pareja, Ellis, Policastro & Findley, 1996; Vercoulen et al., 1996) revealed no significant effects for any outcomes measured. The third trial showed that fluoxetine produced modest improvements in depression but had no effect on fatigue (Wearden et al., 1998).

Psychological research suggests that CFS patients can be distinguished from depressed patients according to their cognitive style; depressed patients' self schemas are dominated by a negative view of the self, whereas CFS patients are principally concerned with their ill health (Moss-Morris & Petrie, 2001). According to Abbey and

Garfinkel (1991) depression in individuals with CFS is better understood as an adjustment reaction to living with a controversial, chronic condition. It is typical for individuals with a chronic health condition to grieve about their predicament before adapting to it and inevitably some sufferers will go on to experience prolonged distress that meets criteria for a psychiatric disorder (Turner & Kelly, 2000). A study by Lehman, Lehman, Hemphill, Mandel and Cooper (2002) found that levels of depression and anxiety were highest amongst CFS patients whose physician failed to legitimatise their illness, suggesting negative responses from medical professionals may exacerbate distress and adjustment problems in this population. The majority of participants in Lehman et al.'s (2002) study were opportunistically recruited from patient-led organisations, raising issues concerning the generalisability of findings. Such a sample could be biased in favour of those having had a poor relationship with their physician.

Personality Traits

Neuroticism is one of the big five personality traits, characterised by emotional instability - including feelings of anxiety, depression, anger and envy (Goldberg, 1990). It is associated with increased stress vulnerability, a dysfunctional, helpless coping style and in those with chronic health conditions, greater adjustment problems (Flett, Baricza, Gupta, Hewitt, & Endler, 2011; Vollrath & Torgersen, 2000). Several studies have documented high levels of neuroticism and low levels of extraversion in individuals with CFS, (Blakely et al., 1991; Buckley et al., 1999; Sáez-Francàs et al., 2014; Taillefer, Kirmayer, Robbins, & Lasry, 2003). As a trait, Watson and Pennebaker, (1989) suggest neuroticism predisposes a person to somatopsychic distress, which in turn contributes to the likelihood of them experiencing a range of

medically unexplained symptoms (De Gucht, Fischler, & Heiser, 2004). Another popular hypothesis is that perfectionism is a risk factor for fatigue and CFS. Deary and Chalder (2010) highlight that the prevailing stereotype of a CFS patient is one of a "burnt-out perfectionist" (p.466). In support of this Ware and Kleinman (1992) found that CFS patients described working tirelessly to achieve the excessively high standards they set for themselves. Compared to healthy controls, women with CFS have also been documented to have high levels of unhealthy perfectionism, defined as excessive concern over mistakes, doubts about actions, parental expectations and parental criticism (Deary & Chalder, 2010).

There is some limited evidence suggesting that DSM-IV personality disorders (Courjaret, Schotte, Wijnants, Morrkens & Cosyns, 2009; Nater et al., 2010), self-sacrificing schema (Hambrook, et al., 2011) alexithmyia (conveying difficulties with recognising, labelling, and describing emotion; Friedberg & Quick, 2007) and negative beliefs about the acceptability of experiencing and expressing negative emotions (Hambrook et al., 2011; Rimes & Chalder, 2010), are more prevalent in CFS patients compared to the general population; attributes associated with disability and poor treatment outcomes. The majority of studies investigating psychopathology in CFS samples however have used cross-sectional designs and non-clinical control groups (as opposed to other patient groups). As a result, it is not possible to conclude that the abnormalities documented are specific to CFS, or that they play a causal role in predisposing or perpetuating the condition. Two studies suggest that the personality profiles of CFS patients are equivalent if not more favourable than those of patients with multiple sclerosis and rheumatoid arthritis, as demonstrated by their scores on

measures of perfectionism, attitudes towards mental illness, defensiveness, social desirability, alexithymia and harm avoidance (Christodoulou, Deluca, Johnson, Lange, Gaudino, & Natelson, 1999; Wood & Wesseley, 1999). Furthermore, Chubb et al. (1999) found no differences between healthy controls and non-depressed CFS patients on measures of neuroticism and social desirability. One prospective population study conducted in the UK strengthens the evidence base for the aetiological role of premorbid psychopathology in CFS, however authors acknowledged that this association was partly confounded by comorbid psychopathology (Clark et al., 2011). In sum, there is little robust evidence to suggest that CFS patients possess an unusually high level of maladaptive personality traits that would predispose them to developing their illness.

Impact of CFS on the individual

The impact of CFS on a person's social functioning has been documented by both quantitative and qualitative research. Findings reveal a sad itinerary of losses, including, friendships, support systems and ultimately, a lifestyle, (Anderson & Ferrans, 1997; Schoofs, Bambini, Ronning, Bielak & Woehl, 2004). An informative mixed-methods study assessed perceived quality of life in CFS using structured interviews and questionnaires (Anderson et al., 1997). Findings revealed that 100% of participants felt CFS had devastated their social activities and relationships, whilst 32% stated they had lost most, if not all, of their previous friends. Participants described having to frequently cancel social plans due to the unpredictable nature of their symptoms and consequently, most remaining friendships were strained or

distant. Ninety-five percent of participants described friends' responses to their illness as hurtful and reactions ranged from outright disbelief, to lack of understanding and fear of transmission. In terms of participants' families, all of woman and half of the men felt that CFS had negatively impacted on their family life and 55% of the women expressed feelings of shame, guilt, or sadness over their dependency on family members. The strengths of this study were its high response rate (75%) and mixed methods triangulation design, allowing the authors to obtained a rich and robust data set. Nevertheless, statements of causality cannot be made, owing to the cross-sectional nature of the data. A study by Mayer (2000) found that CFS patients reported receiving significantly less social support than healthy controls in the year prior to their illness onset. Although retrospective, this implies that individuals' with CFS may have premorbid difficulties with social relationships.

Persons with CFS differ not only in the frequency of their social interactions but also in the types of interactions they have. A large study compared 270 individuals with CFS to disease-free breast cancer patients, fatigued employees on sick-leave and healthy controls (Prins et al., 2004). Findings revealed that individuals with CFS reported significantly more negative and problem-focused interactions. Poor relationships with family/ friends and negative social interactions predicted fatigue severity in CFS participants at baseline and one year follow-up. The majority of participants in this study however, had a relatively short illness duration (< 2 years) and so findings may not be representative of people who have had CFS for longer.

Finally, high levels of unemployment have been documented in individuals with CFS. In a systematic review investigating disability, 35 studies (containing 2652 patients) reported employment status (Ross, Estok, Frame, Stone, Ludensky, & Levine, 2004). Findings revealed that just 42% of participants with CFS were employed, compared to 90% of controls. Employment was subdivided into full and part-time hours by 16 studies, illustrating that only 19% of CFS participants were in full-time employment, compared to 75% controls. A strength of this review was that the majority of included studies (81%) required patients to fulfil CDC (1994) diagnostic criteria for CFS, increasing the homogeneity of samples and comparability of results. However, based on cross-sectional data one cannot infer causality. A more recent study using data from National Outcome Database (N= 2170) found that 50.1% of CFS patients reported discontinuing employment because of fatigue-related symptoms (Collin, Crawley, May, Sterne, & Hollingworth, 2011).

In sum, individuals who have CFS tend to be markedly disabled. Many are unable to work, engage in social activities or maintain relationships. The consequence of this is that they feel isolated, alienated, misunderstood and unsupported.

Investigations of positive constructs in CFS

In comparison to the abundance of research examining negative mental processes in CFS, only three studies have quantitatively assessed positive mental processes and their relationship to functioning. Jason, Witter and Harding (2003) examined

dispositional optimism, referring to a generalised expectation that good things will happen. They found that individuals with CFS (N= 32) had lower levels of optimism than healthy controls and that higher levels of optimism were predictive of better mental and physical functioning. Findley, Kerns, and Weinberg (1998) examined self-efficacy (a person's perceived ability to control their illness or achieve a specific outcome) in participants with CFS (N= 68) and found that higher levels of self-efficacy predicted lower levels of symptoms, disability and distress, even after controlling for demographic variables. Similarly, Van-Damme, Crombeza, Van Houdenhove, Mariman and Michielsen (2006) examined participants' (N= 110) degree of acceptance of their illness and functional limitations and found that higher levels of acceptance were related to lower levels of psychological distress, beyond the effects of demographic variables and fatigue severity.

In conclusion, although the evidence is sparse and more methodologically rigorous research is required, the findings do suggest that i) individuals with CFS can continue to flourish in life despite unremitting physical symptom and ii) that positive factors may play a key role in moderating fatigue and distress in this population. A significant weakness of these studies is that they have investigated singular concepts, in the absence of a theoretical framework of optimal psychological functioning or well-being.

1.3.5 Interventions for CFS

According to NICE (2007) all patients should have access to a specialist CFS service. The reality however, is that over two million people in England don't. Within the National Health Service, CFS service provision is "patchy and inconsistent" and in areas where specialist services are available, significant social inequalities in access exist (All-Party Parliamentary Group, 2010, p.15; Collin, Sterne, Hollingworth, May & Crawley, 2012).

The primary goal of specialist CFS services is early diagnosis and symptom management. No specific pharmalogical treatments for CFS exist and drugs are simply prescribed for the purpose of managing symptoms. Non-pharmalogical, rehabilitative inventions such as Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) have shown some promise as treatments for CFS (NICE, 2007). However, several meta-analyses highlight that only a paucity of randomised control trials, often containing small sample sizes and non-active comparators, have been conducted (Price, Mitchell, Tidy, & Hunot, 2008; NICE, 2007; Whiting et al., 2001). Dropout rates in GET are also higher than in CBT, suggesting that it may not be an acceptable intervention to this client group (Ridsdale, Darbishire & Seed, 2004; Wearden et al., 1998).

CBT for CFS targets particular patterns of maladaptive thinking and behaving (such as avoidance, rumination and thinking biases) with the aim of reducing their impact on physiological processes in the body (Surawy, et al., 1995). It has been shown to reduce levels of fatigue and disability in CFS; however only a minority of patients go on to make a full recovery after treatment (Price et al., 2008). Quarmby, Rimes,

Deale, Wessely and Chalder, (2007) examined CBT in routine clinical practice and reported that post-treatment, 70% of patients still met criteria for excessive fatigue. Similarly, in a more recent randomised controlled trials (RCT; N= 641) just 30% of participants receiving CBT ceased to meet Oxford diagnostic criteria for CFS and had ratings of fatigue and physical function in the normal range, at 52 weeks post-randomisation (White et al., 2011).

The benefit of CBT for psychiatric symptoms in CFS is questionable too. A systematic review of 15 studies with a total of 1043 CFS patients, suggests that CBT's effectiveness at reducing depression, anxiety and psychological distress is uncertain (Price et al., 2008). Compared to treatment as usual, CBT was found to have no significant effect on depression post-treatment, but did show an advantage at short-term follow-up. For anxiety, the opposite effect was seen, CBT was significantly better than treatment as usual at reducing anxiety at post-treatment but this difference was lost at follow up. CBT showed no advantage over treatment as usual at reducing overall psychological distress at post-treatment or follow-up. Evidence from a single RCT signifies that CBT yields no improvement in cognitive functioning or quality of life in CFS patients (O'Dowd et al., 2006). Given the complexity of CFS, coupled with the evidence that CBT alone produces unsatisfactory recovery rates in symptoms (physical and psychiatric) and quality of life, Price et al. (2008) conclude that studies investigating other interventions that can be used alone or in conjunction with CBT to increase its efficacy, should be a major research priority.

1.4 Positive Psychology and Well-Being

In the last few decades, positive psychology research has exponentially grown. It is shifting the paradigm of psychology away from a preoccupation with illness and the worst parts of existence, towards more positive aspects and the question of what it is that makes life good. Positive psychology researchers assert that psychology should not concern itself solely with the amelioration of psychopathology, weakness and dysfunction but also the promotion of strengths, happiness and well-being (Seligman & Csikszentmihalyi, 2000). This reflects the growing recognition that just as positive affect is not the opposite of negative affect (Cacioppo & Berntson, 1999) well-being is not the absence of illness (Ryan & Deci, 2001). In accordance with this view the World Health Organisation, defines health as:

‘”A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (1946, p. 1).

With an aging population and increasing prevalence of chronic, disabling conditions, health care providers are being forced to expand their focus, from an out-dated, narrow emphasis on cure and quantity of life, to include the promotion of quality of life and well-being (The Institute of Medicine, 2012). When a return to premorbid functioning is no longer possible (or very rare as in the case of CFS), the question of how to conceive recovery as a treatment objective is pivotal. The Recovery Model Approach endorsed by The National Institute for Mental Health England (2005) focuses on reducing the *impact* of chronic illness, as opposed to illness *per se*. This is achieved through the provision of holistic interventions that cultivate self-efficacy, hope, empowerment, a positive self-image, self-management skills, social inclusion and meaning in life.

CBT can be conceptualised as an illness or symptom-focused treatment in that it specifically aims to reduce negative mental processes and behaviours. Clinical investigations signify however, that the elimination of negative functioning and illness does not necessarily give rise to positive functioning and wellness. A study investigating the effects of internet-delivered CBT for major depression on future thinking found that despite being effective at reducing negative future thinking, CBT failed to increase positive future thinking (Andersson, Sarkohi, Karlsson, Bjarehed, & Hesser, 2013). This is significant given that depressed individuals differ from healthy controls predominantly in their failure to anticipate positive events, as opposed to their propensity to anticipate negative events (Bjarehed, Sarkohi & Andersson, 2010). Brown (2007) examined affectivity in 606 patients undergoing CBT treatment for a variety of axis I disorders, including GAD, social phobia, panic disorder, specific phobia and obsessive compulsive disorder. Findings revealed that negative affect demonstrated a large treatment effect, whilst positive affect remained remarkably stable. Together, these studies suggest that CBT may not target the whole problem and provide further support for a positive psychology approach that promotes positive functioning in CFS, alongside a reduction of negative functioning.

A question central to the field of positive psychology is what constitutes well-being or optimal psychological functioning? Ultimately, the way we define well-being determines what research variables we measure and how we practice therapeutically. To date, there is no consensus on what well-being is. Following a review of the literature Ryan and Deci (2001) concluded that it can be broadly categorised according to two distinct, yet overlapping theories, one concerned with happiness

(Hedonic well-being/ subjective well-being; SWB) and the other concerned with human potentials and meaning in life (Eudiamonic well-being/ psychological well-being; PWB). There is some debate over the usefulness and validity of splitting well-being into two distinct constructs and mounting evidence suggests that they are highly intertwined and reciprocally related. King and Napa (1998) asked participants to rate the components of a good life and found that happiness and meaning were both pivotal. The discriminant validity between Hedonic and Eudiamonic measures is large enough for them to be considered separate constructs (Waterman, Schwartz, & Conti, 2008). According to Ryan and Deci (2001) our understanding of well-being will be enhanced by measuring it in different ways. Both aspects likely represent assets that play an important role in restoring and protecting our mental and physical health. Therefore, to provide a holistic, unconstrained understanding of well-being in CFS, the present study will utilise SWB and PWB indicators.

1.4.1 Hedonic Theory and Subjective Well-being

Well-being has long been equated with happiness. Greek philosophers described happiness as the highest of all goods and the ultimate motivation for human action (Aristotle 350 B.C/ 1925). Hedonic theory suggests that a person has well-being to the extent that they feel pleasure, enjoyment and happiness in their life (Kahneman, Diener & Schwarz, 1999). The most prolific model of hedonia is Diener, Eunkook, Suh, Lucas & Smith's (1999) tripartite model of subjective well-being (SWB). It is concerned with how and why people experience their lives as positive and includes affective reactions and cognitive evaluations. SWB defines happiness as a

combination of three components: A global evaluation of satisfaction with one's life, the presence of positive affect and the absence of negative affect (Diener, Lucas, Oishi & Shuh, 2002). Diener et al., (1999) argue that the components of SWB, although closely related, represent three distinct constructs that need to be individually understood and researched. SWB can therefore be considered "a general area of scientific interest rather than a single specific construct" (Diener et al., 1999; p. 257).

Viewed as the cognitive component of SWB, life satisfaction involves judgments regarding fulfilments of one's goals, expectations, standards and desires. In Diener et al.'s (1999) model it is defined as a comparative judgment of one's circumstances against what is deemed to be an appropriate standard; the bigger the discrepancy between one's circumstances and the appropriate standard, the lower one's life satisfaction. Bottom up models stipulate that life satisfaction judgements are domain dependent, meaning that they are based on external events, situations and demographic variables such as income, health and marriage (Shea, 2013). In contrast, top down models infer that a person's personality and values determine how they evaluate their life. Evidence for both models has been found however; a full review of this research is beyond the scope of this thesis (see Shea, 2013).

In CFS, appraisals of life satisfaction have received considerable attention. One study specifically examined global life satisfaction in a sample of 75 CFS patients, using The Manchester Short Assessment of Quality of Life (MANSA; Rakib et al., 2005). Findings revealed that CFS patients expressed lower levels of satisfaction with their

life as a whole, their financial situation and their leisure activities, than medical students, first admission schizophrenia patients and female patients with alcoholism. A further seven studies have examined patients' satisfaction ratings in the domains of health and physical, occupational and social functioning (Anderson & Ferrans, 1997; Buchwald, Pearlman, Umali, Schmaling & Katon, 1996; Hardt, Buchwald, Wilks, Sharpe, Nix & Egle, 2001; Lowry & Pakenham, 2008; Komaroff et al., 1996; Priebe, Huxley, Knight & Evans, 1999; Schweitzer, Kelly, Foran, Terry & Whiting, 1995). Findings confirm that CFS patients are highly dissatisfied with the quality of their lives and the scale of their impairments, which spans a range of physical and mental activities, and is equal to, if not greater than that seen in other chronic illness. In sum, whilst these studies suggest that life satisfaction is significantly and uniquely affected by the experience of CFS, they do not assess affective well-being or several other psychological domains that have been implicated in positive functioning and will therefore, form the focus of the present study.

Bradburn (1969) was the first to establish positive affect and negative affect as two distinct dimensions that vary independently and ought to be measured separately. Today they are considered the "dominant dimensions of emotional experience" (Watson & Clark, 1994, p.1). Positive affect reflects the extent to which a person feels pleasant emotions or moods such as joy, pride contentment and happiness (Diener et al., 1999). In contrast, negative affect reflects the extent to which a person feels unpleasant emotions such as guilt, anger, sadness and fear (Diener et al., 1999). To assess the full range of emotions and feelings that a person might be experiencing, Diener et al. (2010) developed a 12-item questionnaire, the Scale of Positive and

Negative Experience (SPANE). It includes specific emotions (sad, afraid, joyful, angry, happy, contented) and general feelings (positive, negative, good, bad, pleasant, unpleasant). Three subscales are calculated from participants' scores: a scale of positive affect (SPANE-P), negative affect (SPANE-N) and balanced affect (SPANE-B), which is calculated by subtracting the negative score from the positive score. According to Diener et al. (2010) the SPANE offers several advantages over the Positive and Negative Affect Schedule (PANAS), which has been the most widely used measure of affective well-being to date (Watson, Clark, & Tellegen, 1988). Firstly, the SPANE reflects all levels of emotional arousal, in comparison to the PANAS, which focuses exclusively on high arousal states and also includes items such as "strong" and "alert", which are more akin to physical states than affective ones. Secondly, the inclusion of general words allows the SPANE to assess all positive and negative feelings, regardless of their specific label, which is more in keeping with SWB theory. By listing specific emotions and weighting them all identically, the PANAS overlooks the fact that a person may actually feel reasonably positive or negative despite not experiencing the full range of emotions listed on the scale. Correlational research suggests that the frequency with which a person experiences positive affect is more strongly related to other well-being measures such as life satisfaction, than intensity with which they feel them (Diener, Sandvik, & Pavot, 1991). A third advantage of the SPANE over the PANAS is that it asks respondents to report on the frequency with which they experience each feeling (e.g. "always", "sometimes", "never"), opposed to the intensity of feelings (e.g. "not at all", "extremely"). Finally, by asking the respondent to report on their emotional experience in the past four weeks the SPANE avoids capturing short-term mood states and incites the respondent to answer based on actual experiences (bottom-up

appraisal), as opposed to relying on general self-concept (top-down appraisal). Internal consistency for all three scales is good (ranging from 0.81-0.89 across the scales), as is temporal stability over a one-month period (0.62-0.68; Diener et al., 2010) and convergence validity with other measures of happiness (including Fordyce's (1988) single item measure of happiness) and satisfaction with life (the Satisfaction with Life Scale; Diener, Emmons, Larsen, & Griffin, 1985). Despite its promising psychometric properties, a criticism of the SPANE is that it is yet to be validated across cultures and in clinical samples. Normative scores have been produced from studies using samples of western college students (N= 468) and further research is needed. In defence, Diener et al. (2010) argue that the scale should perform well across cultures and societies. It assesses a respondent's personal appraisal of their own feelings based on their own experiences, opposed to pre-defined external criteria, which are typically more vulnerable to cultural bias.

Compared to negative affect, namely depression and anxiety, positive affect has been grossly under researched in CFS. Three UK studies have previously assessed it but as a secondary outcome measure. Using visual analogue scales Wood and Magnello (1992) measured diurnal changes in perceptions of energy in a small sample of 36 participants who had CFS or had recently recovered from it. Findings revealed a strong positive correlation ($r = 0.70$ to 0.80) between high levels of positive affect and high levels of mental and physical energy, whilst negative affect was independent of energy levels. Wood, Magnello & Sharpe (1992) verified these findings in second study (N=37) that employed a modified version of the PANAS (Watson, et al., 1988) to measure affect. Finally, Marshall et al. (1996) assessed cognitive function and

mood in CFS (N= 27) using the PANAS and found that compared to a large sample of college students reported in the literature, CFS patients had extremely low levels of positive affect, but relatively normal levels of negative affect. Authors suggest that this profile distinguishes CFS patients from those with major depression, who show depleted levels of positive affect and elevated levels of negative affect. The relationships between symptoms of cognitive impairment and affect were not reported. Although these studies provide preliminary evidence for the importance of assessing positive affect in CFS, they have several limitations that the present study aims to overcome. Specifically, they can be criticised for using small sample sizes, flawed measures of affect and for failing to comprehensively assess the relationship between affect and symptomatology in CFS.

1.4.2 Eudiamonic Theory and Psychological Well-being

According to Eudiamonic theory, happiness is not the primary goal of life but rather the by-product of a life well lived (Ryff & Singer, 1998). Eudiamonic theorists concern themselves with examining what a person is doing in their life, as opposed to how it makes them feel. They propose that a person will flourish if they are striving to achieve their true potential and engaging themself in purposeful activities. Eudiamonic researchers have criticised SWB for simplifying what it means to live a good life (Ryff & Singer, 1998) and for not objectifying the types of activities, goals and achievements necessary to create happiness (Ryan & Deci, 2001). On the contrary, by creating a list of criteria, Eudiamonic researchers can be accused of constraining individual definitions of wellness. Sumner (1996) reminds us that well-

being is only achieved when a life is deemed good by the person living it. In clinical psychology, Eudiamonic well-being tends to be privileged, as its focus on life processes, as opposed to specific outcomes, offers clearer implications for the development of treatments (Fava & Ruini, 2003).

Many theorists have formulated perspectives on Eudiamonic well-being, for instance Maslow's (1968) conception of self-actualization, Allport's (1961) formulation of maturity and Rogers' (1961) depiction of the fully functioning person. However, few plausible assessment procedures have been put forward. Historically, atheoretical measures of Eudiamonic well-being have hindered research into the field. To address this, Ryff (1989) generated a new, multi-dimensional model of psychological well-being, which consolidates convergence points in existing Eudiamonic theories from several psychological arenas (developmental, humanistic and clinical). According to Ryff's (1989) taxonomy there are six dimensions of positive functioning: Autonomy (the ability to be independent and self-determining and not look to others for approval); Self-Acceptance (having positive self-regard and acceptance of one's strengths and weaknesses); Environmental Mastery (the ability to choose, control and create environments that fit with one's personal needs and values); Positive Relationships with Others (the ability to form warm and trusting interpersonal relationships and display empathy and intimacy, towards others); Purpose in Life (having goals and a direction in life that contribute to the belief that one's life is purposefully and meaningful); Personal Growth (an openness to new experience and sense that one is continuing to grow and develop over time). To quantify each

dimension, Ryff (1989) devised a 20-item scale (120 items in total) and tested it in a large sample (n= 320) of relatively healthy, well-educated respondents. Findings indicated that the Psychological Wellbeing Scale had good internal consistency (0.87-0.93) and re-test reliability coefficients over a 6-week period (0.81-0.88; Ryff, 1989). Since then, several more rigorous tests have validated the six-factor model (Cheng & Chan, 2005; Ryff & Weaton, 2001; van Dierendonck, 2004; van Dierendonck, Diaz, Rodriguez-Carvajal, Blanco & Moreno-Jimenez, 2008), including a study containing a large national probability sample of 1108 adults (Ryff & Keyes, 1995).

Critics of the six-factor model of PWB have questioned its multidimensionality, by claiming that there is substantial conceptual overlap between the dimensions. In an assessment of the scales construct validity Spring and Hausser (2005) analysed data from three large surverys —Midlife in the United States, National Survey of Families and Households II, and the Wisconsin Longitudinal Study. Findings revealed a very strong correlation ($r = 0.85$) between participants' scores on the Self-Acceptance and Environmental Mastery subscales, leading authors to conclude that they are largely measuring the same concept. Further strong correlations have been documented between the dimensions of Self-Acceptance and Purpose in Life (0.72) and Purpose in Life and Personal Growth (0.72; Ryff, 1989). This raises doubts about the factorial validity of the instrument but also Ryff's theoretical framework. In defence of such criticism, there are several sources of evidence championing distinctiveness. Ryff and Keyes (1995) highlight that the six dimensions have distinct age and gender profiles, whilst the original validation study (Ryff, 1989) confirms that the subscales have

differential patterns of association with other well-being measures. Specifically, Affect Balance shows a moderate correlation with Self-Acceptance but much weaker links with Purpose in Life. There is also growing evidence that the scales show unique profiles in clinical populations and different relationships with symptom measures (Mangelli, Gribbin, Büchi, Allard & Sensky, 2002; Nierenberg et al., 2010). Ultimately, despite the criticism, Ryff's work has been ground breaking in the field of well-being and highly influential in wider psychology. Her seminal paper has been cited in 5114 publications (Ryff, 1989; retrieved from Google Scholar, 07th April 2015), and the Psychological Well-Being Scale itself, used in more than 500 studies.

1.4.3 Factors Related to Well-Being

The relationship between several socio-demographic variables has been examined and findings suggest that subjective and psychological well-being dimensions vary in meaningful ways according to personal characteristics including age, gender, marital status and educational attainment. Controlling for these factors in clinical research is imperative, as DeNeve (1999) found that individual's demographics account for 3% of the variance in well-being outcomes.

Three cross-sectional, cohort studies suggest the life course trajectory of PWB is diverse: Autonomy and Environmental mastery increase from adulthood to old age, whilst Purpose in Life and Personal Growth decrease and Positive Relationships with Others and Self-Acceptance remain the same (Ryff, 1989; Ryff & Keyes, 1995; Ryff

& Singer, 2008). Studies using nationally representative data have verified these life course patterns (Ryff, Keyes & Hughes, 2004). A criticism of cross-sectional studies however, is that they are confounded by inter- and intra-cohort variation. Springer, Pudrovska and Hauser (2011) examined age-related patterns in PWB using data from two large longitudinal surveys, each containing three life-course transitions: Adulthood to early midlife (aged 32-51 years), early midlife to late midlife (aged 50-59 years) and late midlife to old age (aged 57-75 years). Findings revealed that with the exception of Environmental Mastery, age trends in PWB were not consistent across samples or life-course transitions. More variation was observed within age periods than between subscales across age or time, thus suggesting that previous findings of life course patterns might be best explained by cohort differences. In terms of SWB, the average older age profile of SWB is generally positive, with several studies indicating that life satisfaction increases with age (Diener & Suh 1998; Shmotkin 1990;). Cross-sectional and longitudinal research examining positive affect evidences both gains and losses with age, whilst negative affect appears to decline for some and stabilise for others (Diener & Suh 1998; Mroczek & Kolarz 1998; Shmotkin 1990).

Gender differences have been reported across multiple sets of data, with women consistently scoring higher than men on Positive Relations with Others and Personal Growth, (Ryff, 1995). In terms of educational attainment a strong positive correlation has been documented with all six dimensions of Ryff's PWB, but most strikingly so for Purpose in Life and Personal Growth (Ryff & Singer, 2008). There is now robust

evidence to suggest that unemployment leads to a significant deterioration in an individual's well-being, not simply because of the incurred financial losses but also because of the loss of the psychological benefits that are associated with work. A job is a source of social status and recognition that provides self-respect and self-worth. It creates a structure for one's day, increases opportunities for social interaction, and supports and maintains one's sense of purpose (Darity & Goldsmith, 1996; Shields & Wheatley, 2005). Longitudinal and cross-sectional research has linked employment to lower mortality, lower psychological distress, higher self-esteem and higher life satisfaction (Winefield, Tiggemann, Winefield, 1991; Winefield, Winefield, Tiggemann, & Goldney, 1991). In addition to psychological well-being, research has also looked at life satisfaction as an indicator of well-being. Relationship status, such as being married or being in a stable relationship, has been associated with increased life satisfaction (Argle & Martin, 1991; Diener et al., 1999). Burns and Machin (2013) speculate that this is due to the increased social support that a partner provides. In addition, it is the quality opposed to the quantity of relationships that has been found to be most the important factor, with those who have more intimate or high quality relationships demonstrating the greatest well-being. In both clinical populations and the general population, loneliness has been negatively associated with markers of well-being (positive affect and life satisfaction) and positively associated with depression (Ames & Roitzsch, 2000; Falcón, Todorova, & Tucker, 2009; Heinrich & Gullone, 2006; Lee & Ishii-Kuntz 1987). Importantly in CFS samples, social support has been found to moderate health outcomes and reduce illness burden (Saltzstein et al., 1998).

Research also suggests that evaluations of well-being are influenced by one's personality. In an investigation of the big 5 personality traits, Schmutte and Ryff (1997) found that all six PWB dimensions have distinctive personality correlates: Self-Acceptance, Environmental Mastery and Purpose in Life were negatively linked with Neuroticism and positively linked with Extraversion and Conscientiousness; Personal Growth was positively linked with Openness to Experience and Extraversion; Positive Relations with Others was positively linked with Agreeableness and Extraversion; and Autonomy was negatively linked with Neuroticism. Similarly, DeNeve and Cooper (1998) conducted a meta-analysis and reported that extraversion and agreeableness were consistently positively associated with SWB, whereas neuroticism was consistently negatively associated with it. Diener and Lucas (1999) state such findings are intuitive given that extraversion is largely characterised by positive affect and neuroticism by negative affect. Other researchers argue that affectivity is better conceptualised as a stable trait (individual predispositions to certain states) rather than a transient state (fluctuations in mood; Tellegen, 1985; Watson & Clark, 1984).

Finally, research has identified biological correlates of well-being. Ryff, Keyes and Hughes (2004) found that higher levels of Personal Growth and Purpose in Life were associated with better endocrine regulation and lower inflammatory markers in a sample of older women. They also documented that higher levels of Environmental Mastery were associated with longer periods of REM sleep. Other studies have linked higher Purpose in Life to lower levels of cortisol, cardiovascular risk and

musculoskeletal symptoms (Lindfors & Lundberg, 2002; Ryff, Singer & Love, 2004). Increased social support has been associated with lower blood pressure and stress hormones (Uchino, Cacioppo, & Kiecolt-Glaser, 1996), whilst self-enhancing thoughts have been linked to lower salivary cortisol and cardiovascular response to a laboratory stressor (Taylor, Lerner, Sherman, Sage, & McDowell, 2003). Although it is not possible to draw causal conclusions, just as psychological stress has a biopsychosocial interaction, these findings infer that psychological well-being could enhance the functioning of a number of biological systems that protect against disease and promote physical recovery.

1.4.4 Psychological Wellbeing Links With Depression and Chronic Illness

A broad, multidimensional investigation of well-being has yet to be conducted in individuals with CFS, despite mounting evidence that this is a valuable approach in healthy individuals and those with depression and other chronic physical health conditions such as Fibromyalgia and Rheumatoid Arthritis. Rheumatoid Arthritis is an autoimmune disease that causes swelling, stiffness and pain in the joints. Fatigue is a frequent and severe complaint of patients, with prevalence rates ranging between 42% and 80% depending on the measure used (Repping-Wuts, van Reil & van Achterberg, 2009). Given the significant diagnostic overlap and high comorbidity between these conditions, the well-being profile of these patient-groups may provide a useful parallel. Comparing wellbeing in individuals with CFS to individuals with depression and fibromyalgia could further add to the debate about whether or not they are a single

syndrome. If the well-being profile of CFS were found to be distinct, then it would suggest that these conditions have important psychological differences.

Within the well-being literature depression is the most researched mental health disorder and there is now robust evidence to suggest that depression arises not only from "the presence of the negative", but also from "the absence of the positive" (Ryff & Singer, 1996, p. 21). Several studies have profiled Ryff's model of PWB in depression using clinical and non-clinical samples and findings indicate that depression correlates negatively with all six dimensions. In a comparison of depressed patients to general population norms, Nierenberg et al., (2010) found that depressed individuals scored significantly lower in the domains of Environmental Mastery and Self-Acceptance (two standard deviations below the population mean), and lower in Purpose in Life and Positive Relations with Others than norms (one standard deviation below the mean). In the domains of Personal Growth and Autonomy however, they scored within the normal range. In an attempt to control for extraneous variables Edmondson and MacLeod (2014) repeated this study but this time comparing clinically depressed participants (N= 26) to matched controls. Findings confirmed that well-being in depressed individuals is most depleted in the domains of Environmental Mastery and Self-Acceptance. Overall, PWB research highlights the need for depression treatments that focus not only on alleviating psychopathology but also on promoting well-being; in particular, rebuilding individuals' sense of control over their environment and fostering a more positive self-attitude (Edmondson & MacLeod, 2014).

Mangelli et al. (2002) examined Ryff's psychological well-being dimensions in patients with rheumatoid arthritis. Findings revealed that well-being was largely independent of disease variables (disease activity, pain and functioning) and more closely related to psychological distress. Compared to a large American community sample (Ryff, Lee, Essex & Schmutte, 1994) patients reported significantly lower well-being scores across all six dimensions and showed the most marked impairment in Personal Growth and Purpose in Life. This is a distinctly different pattern of deficits to that observed in depressed samples. Schleicher, Alonso, & Shirtcliff (2005) investigated Ryff's model of PWB in a sample of 57 women with fibromyalgia. Findings showed psychological well-being was independent of pain but strongly related to self-reported disability. Unfortunately, psychological distress was not measured. Compared to two matched groups, one of healthy controls and the other of women with rheumatoid arthritis, the fibromyalgia group reported the lowest overall PWB and demonstrated significantly greater deficits from the control group mean in Environmental Mastery, Self-Acceptance, Positive Relations with Others and Purpose in Life, and to a lesser extent Personal Growth. Their level of Autonomy fell within the normal range. Due to the cross-sectional nature of these studies it is not possible to draw causal conclusions and the relationship between well-being, disability and psychological distress is most likely bidirectional. Findings do however, allude to the presence of condition-specific deficits in PWB. They also concur that increasing meaningful activity and promoting well-being should be the focus of treatments for chronic physical conditions, opposed to reducing physical symptoms *per se*.

1.5 The Present Study

CFS is a poorly understood condition, with no known cure and only palliative treatment options. Previous psychological research into CFS has focused almost exclusively on the identification of negative criteria. Yet, therapies such as CBT, which focus on reducing negative constructs, produce unsatisfactory recovery rates in physical and psychiatric symptoms in this patient group. Finding ways to enhance the efficacy of existing treatments is a clinical priority. Previous research examining psychological well-being in other mental and physical health disorders signifies that it could equally advance our understanding of CFS. The present study addressed a major gap in the literature described above by conducting a theoretically informed, multi-dimensional investigation of well-being in adults with CFS. Building such a profile helps us better understand the experiences of people with CFS, identify new treatment targets and distinguish CFS from its co-morbid partners.

The present study firstly examined the relationship between measures of well-being and measures of physical symptoms and psychological distress in a sample of adults with CFS. Where significant relationships were found, the study then went on to investigate whether well-being scores predicted symptoms scores in CFS. No previous research has considered CFS's relationship to Ryff's dimensions of PWB. Secondly, it examined Ryff's (1989) six domains of PWB in a group of CFS participants, by directly comparing their scores to that of a matched, non-clinical control group. More information is needed about the profile of well-being in individuals currently suffering from CFS so that treatments can be specifically tailored to their needs. Control group data was not available for the SPANE, as the two previous studies from which the

control data was taken did not include the measure. CFS participants SPANE scores were therefore, compared to Diener et al.'s (2010) normative sample. It was predicted that well-being dimensions would be related to symptom measures in CFS participants and that, compared to non-clinical controls, CFS participants would score lower on all measures of well-being. There were however, no grounds for making strong predictions.

To summarise the study had two hypotheses:

Hypothesis 1: CFS participants' self-reported scores on two measures of wellbeing (SPANE and PWB) will be significantly related to their self-reported scores on measures of symptoms (the Multi-dimensional Fatigue Inventory and the Pain Visual Analogue Scale) and psychological distress (the Hospital Anxiety and Depression Scale). Differential relationships between different aspects of well-being and different aspects of CFS were of major interest but there was no basis for making strong predictions.

Hypothesis 2: Self-reported ratings of current PWB will be significantly lower in the CFS group than the Control group. Differential impairments on the different psychological well-being scales were of significant interest; however again there was no basis for making strong predictions.

Chapter 2: Method

2.1 Ethical Approval

Ethical approval was obtained from the East of Scotland Research Ethics Committee in April 2014 (Appendix I and II). This study was also reviewed and approved by the Royal Holloway, University of London Ethics Committee. Permission was gained from the Research and Development (R&D) departments at Lincolnshire Partnership NHS Foundation Trust and University College London Hospitals NHS Foundation Trust (see Appendices III and IV for letters confirming ethical approval).

2.2 Design

A cross sectional, correlational design was used for hypothesis one. Participants were administered self-report questionnaires, which assessed symptoms and several domains of well-being. The independent variables were symptoms of fatigue, pain, anxiety and depression. The dependent variables were the dimensions of PWB (Ryff, 1989), Positive Affect and Negative Affect. An independent samples design was used for hypothesis two, to compare the CFS group to a normative community sample on self-reported PWB. On self-reported Positive Affect and Negative Affect

2.3 Power Calculation

The number of participants required was calculated by taking the smallest (0.29) and largest (0.61) effect sizes found in a correlational study examining the relationships between Ryff's six dimensions of PWB and fatigue interference in daily activities, in

females with fibromyalgia (Schleicher et al., 2005). In order to conduct correlations coefficients, with alpha set to 0.05 and power set to 0.8 (Cohen, 1988), it was calculated that the current study required a sample of 29 participants to detect a large effect size and 84 for a medium effect size. The total number of CFS participants included in this study was 60; therefore a large effect size was attained for hypothesis one.

A medium effect size was predicted based on previous findings showing a medium to large effect size between clinically depressed and non-clinical participants for self-reported psychological well-being (Edmondson & MacLeod, 2014). With alpha set to 0.05 and power set to 0.8 (Cohen, 1988) the current study required a sample of 26 participants in each group for independent t-tests. The aim however, was not only to test significance of difference but the varying magnitude of differences for the different subscales; therefore a substantially larger sample was recruited. The total number of participants included in each group in this study was 42; therefore, a small effect size was attained for hypothesis two.

2.4 Sample

2.4.1 Clinical Participants

Sixty-two participants with a diagnosis of Chronic Fatigue Syndrome were recruited to this study: 39 participants were recruited from two CFS services (one based in Lincolnshire and one based in London) and 23 participants were recruited from either CFS/ ME support groups, online forums or because they approached the researcher directly having seen the study registration on clinicaltrial.gov. Two participants did

not meet threshold for severe fatigue, as defined by having a score of 13 or above on the General Fatigue subscale or a score of 10 or above on the Reduced Activity subscale of the Multidimensional Fatigue Inventory (Reeves et al., 2005). They were therefore, excluded from the study leaving a final sample of 60 participants for analysis.

The CFS Group consisted of 12 males and 48 females. The mean age was 40.50 years (SD = 14.94) with an age range of 18 to 70 years old. Fifty-eight participants identified as White British, one participant identified as White Irish and one participant identified as Black British. Twenty-two percent stated they had a co-morbid diagnosis of fibromyalgia. The mean number of years with CFS was 8.08 (SD = 7.38; minimum = 0.5, maximum = 30) and the mean time taken to receive a diagnosis of CFS from the onset of symptoms was 3.83 years (SD = 4.39). 37.6% of participants had previously received treatment for CFS, whilst 63.3% had no history of previous treatment. Of the 38 included participants recruited from CFS services, 23 had been assessed by the service and were on the waiting list to start treatment. The other 15 were currently receiving treatment and the mean number of treatment sessions received was 7.52 (SD = 4.32; minimum = 1, maximum = 20).

Inclusion criteria for the CFS group were participants must have been over 18 years old, living in the United Kingdom and able to read and write fluent English. CFS participants recruited from services were required to have a diagnosis of CFS confirmed by a physician and a clinical assessment at their current CFS service. CFS

participants at all stages of treatment were invited to take part. Participants not recruited from a service were asked to confirm that a physician or general practioner had given them a diagnosis of CFS. Co-morbid disorders (other than fibromyalgia) were not recorded or controlled for. Scores on the Multi-Dimensional Fatigue Inventory (MFI-20; Smets, Garssen, Bonke & Haes, 1995) confirmed that all 60 participants in the final sample were currently experiencing severe fatigue.

2.4.2 Control Participants

Data for non-clinical, control participants were obtained from two previous doctoral thesis studies into psychological well-being (Blackburn, 2014; Edmondson, 2012). There were a total of 25 control participants in each study, who were recruited from Gumtree, online forums and community settings, such as libraries, community centres and job centres. All control participants completed a demographics questionnaire and the 54-item Ryff Scale of Psychological Well-Being (Ryff, 1989; Sewell, Hauser, Springer, & Hauser, 2004).

Inclusion criteria for controls in Edmondson's (2012) study were (1) not currently experiencing or seeking treatment for any mental health difficulties; (2) being aged between 18 and 65; (3) at the time of testing scoring below the clinical cut off (< 10) on the Patient Health Questionnaire (PHQ-9; Spitzer, Kroenke & Williams, 1999); (4) at the time of testing scoring below the clinical cut-off (< 8) on the Generalised Anxiety Disorder Scale, a self-report measure of anxiety symptoms (GAD-7; Spitzer, Kroenke, Williams & Lowe, 2006). Inclusion criteria for controls in Blackburn's (2014) study were (1) not currently experiencing or seeking treatment for any mental

health difficulties and (2) at the time of testing scoring below the cut-off (<7) for Borderline Personality Disorder symptoms on the McLean Screening Instrument for BPD (MSI-BPD, Zanarini, Frankenburg, Hennen & Silk, 2003). Control group mean scores were in the non-clinical range on the PHQ-9 (<5) and the GAD-7 (<5), indicating no difficulties with depression or anxiety.

The Control group for the current study contained a total of 42 participants, 23 from Blackburn's (2014) study and 19 from Edmondson's (2012) study. Starting with CFS Participant 1 and working consecutively through the list, each CFS participant was matched to a Control participant by finding the closest age (within 5 years), gender (female vs. male), ethnicity (white vs. non-white), employment status (unemployed vs. not unemployed) and marital status (in a relationship vs. not in a relationship) match from either sample. The 12 CFS participants that could not be matched were either older, in a relationship or unemployed. The eight Control participants that could not be matched were either male or non-white. All participants that could not be matched were excluded. The mean age of the Control group was 34.93 (SD = 11.26); 69% of Control participants were female and 31% male. Statistical analyses (reported in the results section) indicated that there were no significant differences between the two groups on any of the matched demographic variables.

2.5 Measures

2.5.1 Demographics Questionnaire

A questionnaire was designed specifically for this study to gather data about participants' age, gender, ethnicity, level of education, employment status, relationship status, number of years with CFS, time taken (from onset of symptoms) to receive a diagnosis, previous treatment, number of treatment sessions with current CFS service and comorbid fibromyalgia (see Appendix VII for full scale).

2.5.2 The Multidimensional Fatigue Inventory (MFI-20; Smets, et al., 1995)

The MFI-20 was first developed by a Dutch research group as a tool to comprehensively assess the impact of fatigue (see Appendix VII for full scale). It has been translated into many languages and validated in patients with CFS, cancer and depression (Smets, et al., 1995; Chung, Yu, Yung, Yeung, Ng & Ho, 2014). It is comprised of 20-items, divided equally into five scales: General Fatigue, Physical Fatigue, Mental Fatigue, Reduced Activity, and Reduced Motivation. General Fatigue includes generalised statements about fatigue and decreased functioning for example, "I feel tired" and "I feel fit". Physical Fatigue concerns physical sensations related to fatigue, for example "Physically I can take on a lot" and "Physically I feel I am in a bad condition". Mental Fatigue refers to cognitive functioning, including concentration difficulties, for example "I can concentrate well" and "My thoughts easily wander". Reduced Activity describes the influence of fatigue on activity levels, for example "I feel very active" and "I get little done". Reduced Motivation relates to lack of motivation for initiating activity, for example "I dread having to do things" and "I have a lot of plans". Participants rate each statement according to how they

have been feeling recently, using a five-point Likert scale running from agreement with the accompanying statement "yes, that is true" to disagreement "no, that is not true". Positively worded items are reverse scored. Higher scores indicate more fatigue. The MFI-20 has been shown to have good internal consistency in a large CFS sample (N= 357), with relatively good Cronbach's alpha coefficients for General Fatigue (0.83), Physical Fatigue (0.85), Mental Fatigue (0.91) and Reduced Motivation (0.82) and an adequate alpha coefficient for Reduced Activity (0.79; Smets et al., 1995). The author does not recommend summarising the five subscales to produce a total fatigue score.

The Centre for Disease Control and Prevention's (CDC; Fuduka et al., 1994) case definition of Chronic Fatigue Syndrome uses the MFI-20 to assess fatigue. Severe fatigue is defined either as a score of 13 or greater on the MFI general fatigue subscale or a score of 10 or greater on the reduced activity subscale (Reeves et al., 2005).

2.5.3 The Pain Visual Analog Scale (VAS; McCormack, Horne & Sheather, 1988)

This widely used questionnaire assesses subjective perception of pain based on a 10 cm horizontal line (0 cm= no pain, 10 cm= pain as bad as it could be; see Appendix VII for full scale). Participants mark the line at the point they feel represents their current pain intensity. The VAS score is determined by measuring in millimetres from the left hand end of the line to the point that the patient marks. It is quick, concise and easy to administer and score. Bigatti and Cronan (2002) evaluated several pain instruments and concluded that in patients with Fibromyalgia the VAS is the most useful. It also showed the highest correlation with measures of physical function, fatigue and stiffness. In Fibromyalgia patients, a cut-off score of 48.5 mm has been

found to give a sensitivity of 80% and a specificity of 80% (Marques, Assumpção, Matsutani, Pereira & Lage, 2008).

Cut-off scores were not specifically used in the present study. However, based on the distribution of VAS pain scores in a sample of postsurgical patients (knee replacement, hysterectomy, or laparoscopic myomectomy) the following cut points have been recommended: No pain (0 – 4 mm), mild pain (5– 44 mm), moderate pain (45–74 mm) and severe pain (75–100 mm; Jensen, Chen & Brugger 2003).

2.5.4 The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)

The HADS is a brief clinical measure used as a screening tool and severity measure for anxiety and depression in medical and surgical outpatients (see Appendix VII for full scale). All items referring to symptoms that may have a physical cause such as dizziness, headaches, insomnia and fatigue, have been excluded. For each statement participants must select one out of four possible answers, which best reflects how they are currently feeling. The HADS contains two 7-item scales, one for anxiety (HADS-A) and one for depression (HADS-D), both with scores ranging from 0 to 21. A higher score indicates higher anxiety or depression and scores for each subscale can be categorised as follows: Normal (0-7), mild (8-10), moderate (11-15), and severe (16-21; Snaith & Zigmond, 1994). Example anxiety items include: “I feel tense or wound up” and “I get sudden feelings of panic”. Example depression items include: “I have lost interest in my appearance” and “I feel cheerful”. HADS has been used extensively and has demonstrated good reliability and validity. In a review of 71 papers using the HADS, Bjelland, Dahl, Haug and Neckelmann (2002) concluded it has good internal

consistency with a mean alpha of 0.83 for HADS-A and 0.82 for HADS-D. It also has good test-retest reliability over a three-week period (HADS-A = 0.89, HADS-D = 0.86; Spinhoven, Ormel, Sloekers, & Kempen, 1997) and good validity (Bjelland et al., 2002). As a screening instrument, a cut-off score of 8 on both scales has been found to achieve the optimal balance between sensitivity (80%) and specificity (80%; Bjelland et al., 2002).

2.5.5 Ryff Psychological Well-Being Scale (PWB; Ryff, 1989)

The PWB scale is a theoretically grounded instrument designed to measure six dimensions of psychological well-being: Autonomy, environmental mastery, personal growth, purpose in life, positive relations with others, and self-acceptance. Participants are required to read positively and negatively worded statements and rate them on a scale of 1 to 6 (1 = strong disagreement; 6 = strong agreement) according to how accurately they reflect their current life (see Appendix VII for full scale). A total is calculated for each dimension with a score range of 9 to 54. Table 1 provides Ryff and Keyes's (1995) definition of a high and low score in each dimension. Self-acceptance concerns having a positive self-regard. Example items include "In general, I feel confident and positive about myself" and "I like most aspects of my personality". Positive relations with others refers to whether one has warm, satisfying, trusting relationships with others. Example items include "Most people see me as loving and affectionate" and "I enjoy personal and mutual conversations with family members or friends". Environmental mastery refers to having a sense of competence over one's environment and day-to-day tasks. Example items include "In general, I feel I am in charge of the situation in which I live" and "I am quite good at managing the many responsibilities of my daily life". Autonomy refers to the ability to be

independent and self-determining and not look to others for approval. Example items include “I tend to worry about what other people think of me” and “Being happy with myself is more important to me than having others approve of me”. Personal growth refers to an openness to new experiences and having a sense that one is expanding over time. Example items include “I don’t want to try new ways of doing things - my life is fine the way it was” and “I think it was important to have new experiences that challenge how you think about yourself and the world”. Lastly, purpose in life refers to having aims and goals in life and example items include “I don’t have a good sense of what it is I’m trying to accomplish in life” and “I enjoy making plans for the future and working to make them a reality”.

Table 1.

Categories of Psychological Well-Being as described by Ryff and Keyes (1995, p.1072)

Self-acceptance

High scorer: Possesses a positive attitude toward the self; acknowledges and accepts multiple aspects of self, including good and bad qualities; feels positive about past life.

Low scorer: Feels dissatisfied with self; is disappointed with what has occurred with past life; is troubled about certain personal qualities; wishes to be different than what he or she is.

Positive relations with others

High scorer: Has warm, satisfying, trusting relationships with others; is concerned about the welfare of others; capable of strong empathy, affection, and intimacy; understands give and take of human relationships.

Low scorer: Has few close, trusting relationships with others; finds it difficult to be warm, open, and concerned about others; is isolated and frustrated in interpersonal relationships; not willing to make compromises to sustain important ties with others.

Autonomy

High scorer: Is self-determining and independent; able to resist social pressures to think and act in certain ways; regulates behavior from within; evaluates self by personal standards.

Low scorer: Is concerned about the expectations and evaluations of others; relies on judgments of others to make important decisions; conforms to social pressures to think and act in certain ways.

Environmental mastery

High scorer: Has a sense of mastery and competence in managing the environment; controls complex array of external activities; makes effective use of surrounding opportunities; able to choose or create contexts suitable to personal needs and values.

Low scorer: Has difficulty managing everyday affairs; feels unable to change or improve surrounding context; is unaware of surrounding opportunities; lacks sense of control over external world.

Purpose in life

High scorer: Has goals in life and a sense of directedness; feels there is meaning to present and past life; holds beliefs that give life purpose; has aims and objectives for living.

Low scorer: Lacks a sense of meaning in life; has few goals or aims, lacks sense of direction; does not see purpose of past life; has no outlook or beliefs that give life meaning.

Personal growth

High scorer: Has a feeling of continued development; sees self as growing and expanding; is open to new experiences; has sense of realizing his or her potential; sees improvement in self and behavior over time; is changing in ways that reflect more self-knowledge and effectiveness.

Low scorer: Has a sense of personal stagnation; lacks sense of improvement or expansion over time; feels bored and uninterested with life; feels unable to develop new attitudes or behaviors.

The PWB scale has demonstrated good internal consistency across all six scales (alpha range = 0.86–0.93), and good test-retest reliability over a 6-week period (range = 0.81–0.88; Ryff, 1989). In terms of its convergent validity the PWB scale has been found to correlate positively with other measures of positive functioning (i.e., life satisfaction, affect balance, self-esteem, the belief that you have control over events in your life, internal control and morale), with coefficients ranging from 0.25 to 0.73 (Ryff, 1989). Similarly, significant negative correlations have been found between the PWB scale and measures of negative functioning (i.e. negative affect, depression, the belief that other people have control over events in your life and the belief that chance affects your experiences or outcomes) with coefficients ranging from -0.30 to -0.60 (Ryff, 1989).

The present study used the 54-item version of the scale. This version is a very widely used alternative to the original 78-item scale and demonstrates good psychometric properties (Sewell, Hauser, Springer & Hauser, 2004). The 54-item version was used for this study because the original version was deemed to long to administer to severely fatigued participants and the 18-item version is not recommended for research, owing to its poorer internal consistency of subscales (Springer & Hauser, 2006).

2.5.6 The Scale of Positive and Negative Experience (SPANE; Diener et al., 2010)

The SPANE is a brief 12-item scale (see Appendix VII for full scale). It has six items corresponding to positive emotions including “joyful”, “good”, “pleasant” and

"contented" and six items corresponding to negative emotions including "afraid", "angry", "bad" and "negative". Participants must rate how much they have experienced each emotion in the past four weeks using a 5-point scale ranging from "very rarely or never" and to "very often or always". The positive and negative scales are scored separately and each range from 6 to 30. The two scores can also be combined as a scale of balanced affect by subtracting the negative emotion score from the positive emotion score. Internal consistency is good (ranging from 0.81-0.89 across the scales), as is temporal stability (0.62-0.68; Diener et al., 2010). The SPANE has performed well in terms of convergent validity with other measures of emotion, well-being, happiness and life satisfaction (Diener et al., 2010).

2.6 Recruitment

Participants were recruited from two CFS services, one based in Lincolnshire and one based in London. The Lincolnshire service consists of a small multi-disciplinary team of five clinicians (psychologist, occupational therapy, physiotherapist, rehabilitation worker and assistant psychologist). The team serves the entire county, providing a range of evidenced based therapies to children and adults with CFS. All referrals must have been medically screened for differential diagnosis and the referrer assumes that the patient fulfils the criteria for CFS in line with NICE (2007) guidance. All clinicians were involved in recruiting participants for the current study.

The Royal London Hospital for Integrated Medicine (RLHIM) is the largest public-sector provider of integrated medicine in Europe and offers conventional and complementary treatments for a wide range of conditions. The CFS service consists of

a small multi-disciplinary team of five conventionally trained clinicians (a consultant physician, an occupational therapist, a physiotherapist, a dietician and a CBT therapist). The consultant physician carries out all initial assessments and a diagnosis of CFS is made on the basis of a detailed clinical assessment and tests excluding other possible causes of fatigue. The consultant physician and occupational therapist were involved in recruiting participants for the current study.

Through outpatient clinics, both services offer therapeutic groups and individual therapy including components of activity management, stress management, relaxation techniques, sleep hygiene, dietary advice, Graded Exercise Therapy and CBT. In addition to this, the RLHIM offers acupuncture and homeopathy.

CFS/ ME support groups were identified through social media sites and the ME Association website (www.meassociation.org.uk).

2.7 Procedure

Recruitment took place between June 2014 and January 2015. Clinicians in both services were informed of the study inclusion criteria and asked to identify and approach patients who met the criteria to take part. Eligible CFS participants were given a written information sheet (see Appendix V) and clinicians verbally explained the study to them, using a statement written by the researcher. Those interested in taking part were given a consent form (see Appendix VI) and questionnaire pack to take away and complete (see Appendix VII). It was stressed that participation was voluntary and that they could leave the study at any time. Participants returned the

completed questionnaire and consent form to the researcher using a prepaid, self-addressed envelope.

CFS participants from support groups were recruited by advertising the study on social media sites and emailing support groups listed on the ME Association's website. Participants were asked to email the researcher if they were interested in finding out more about the study or taking part. Those who contacted the researcher either in response to seeing the study posted on a support group or registered on clinicaltrials.gov, were then emailed an information sheet (see Appendix V) and asked to provide a postal address if they wished to take part, so that a questionnaire pack and consent form could be sent to them. Consent forms and completed questionnaires were returned to the researcher using prepaid, self-addressed envelopes. If participants wanted further information or had any concerns, the information sheet contained the researchers contact details. It also contained the contact details of their trust's Patient Advice and Liaison Service (if recruited from a service) and the Samaritans, if they were distressed. On the consent form participants were asked if they would like to receive a summary of the results and their contact details were obtained for this purpose.

All CFS participants completed the measures in the following order: Demographics questionnaire, SPANE, VAS, MFI-20, HADS, and PWB scale. All control participants had completed a demographics questionnaire and the PWB scale and these were used in the current study.

Chapter 3. Results

Chapter Overview

This chapter is divided into the sections listed below. Because the correlational analyses were the main part of this study they will be presented first, followed by the group comparison. Section A examines the relationship between symptomatology and wellbeing in CFS, using data from the whole CFS sample (N= 60). Regression analysis is used to examine how multiple facets of well-being correlate jointly and independently with a particular symptom measure. Section B examines the profile of psychological well-being (PWB) in CFS and compares data from a subgroup of the CFS sample (N= 42) to a matched, non-clinical Control group (N= 42).

3.1 Data Entry

3.2 Section A

3.2.1 Data screening

3.2.2 Participant demographics

3.2.3 Analyses of self-reported symptoms

3.2.4 Analyses of self-reported wellbeing

3.2.5 Hypothesis 1

3.2.6 Regression Analyses

3.3 Section B

3.3.1 Data screening

3.3.2 Participant demographics

3.3.3 Hypothesis 2

Throughout the chapter, where Levene's test of homogeneity of variance was significant on t-tests, appropriate alternatives were reported. Similarly, where Mauchley's test of sphericity was significant on repeated measure ANOVAs, Huynh-Feldt values were reported. To control for Type 1 error when conducting multiple correlations, a conservative significance value of .01 was used.

3.1 Data Entry

Participants' data were entered into spreadsheets and analysed using IBM SPSS Statistical Data Editor version 21. All data were explored for missing data and normal distribution. Data were missing for two CFS participants on the single item VAS pain scale and for one CFS participant on the entire SPANE scale; this missing data was treated as missing. Two CFS participants missed a single item on the Self-Acceptance subscale of The Ryff Psychological Well-being categories; their mean scores across this subscale were used as substitutions. Skewness and Kurtosis were calculated and considered within normal distribution if z-scores were below 2.58 (Field, 2013). Outliers that were more than three standard deviations from the mean were Winsorised.

3.2 Section A

3.2.1 Data Screening for the CFS Sample (N = 60)

The HADS-A, HADS-D, VAS, SPANE-POS, SPANE-NEG and participant age for the CFS sample were within normal distribution limits and there were no outliers. Internal consistencies were calculated for all the scales listed above (except the single-item VAS) and were shown to be good (Cohen $\alpha > 0.8$; see Table 2).

The Ryff Psychological Well-being categories (Positive Relationships with Others, Environmental Mastery, Personal Growth, Self-Acceptance, Purpose in Life and Autonomy) were all within normal distribution limits; one outlier was winsorised in the Positive Relationships with Others category. Internal consistencies were tested for the six subscales and were all shown to be good (Cohen $\alpha > 0.8$; see Table 2).

Three subscales on the Multi-dimensional Fatigue Scale (MFI-20) were all significantly negatively skewed: General Fatigue ($z = -3.69$), Physical Fatigue ($z = -4.25$) and Mental Fatigue ($z = -3.71$). Transformations were performed, which brought the data into normal distribution limits and there were no outliers. The Reduced Activity and the Reduced Motivation subscales were within normal distribution limits and there were no outliers. Internal consistencies were tested for the five MFI-20 subscales (see Table 2). General Fatigue was below .7 suggesting weaker internal consistency than the other subscales; however, at .66 it was close enough to the standard cut-off to be used with caution. Previous research based on larger sample of

adults with CFS (N=357; Smets et al., 1995) suggests that the internal consistency of the General Fatigue subscale is good (0.83).

Table 2.

Cronbach alphas for the internal consistency of all scales in the CFS sample (N= 60)

Scale	Subscale	Cronbach alpha
MFI-20	General Fatigue	.66
	Physical Fatigue	.79
	Mental Fatigue	.85
	Reduced Activity	.85
	Reduced Motivation	.71
HADS	Anxiety	.88
	Depression	.83
PWB	Autonomy	.87
	Environmental Mastery	.82
	Positive Relationships with Others	.86
	Personal Growth	.82
	Purpose in Life	.81
	Self Acceptance	.85
SPANE	Positive Affect	.91
	Negative Affect	.85

3.2.2 Participants' Demographics

Participants' demographics are reported in Table 3. The majority of participants were White British females. The mean number of years with CFS was 8.08 (SD = 7.38; minimum = 0.5, maximum = 30) and the mean time taken to receive a diagnosis of CFS from the onset of symptoms was 3.83 years (SD = 4.39). Only 21.7% of participants had a co-morbid diagnosis of fibromyalgia, which is lower than reported in previous studies (35%- 75%; Buchwald & Garrity, 1994; Goldenberg, et al., 1990).

Table 3.

Participant characteristics for the CFS sample

Demographic Variables	CFS (N= 60)
Gender	
N Female (%)	48 (80%)
N Male (%)	12 (20 %)
Age (years)	
Mean (SD)	40.50 (18.81)
Ethnicity	
N White British (%)	58 (96.7%)
N White Irish (%)	1 (1.7%)
N Black British (%)	1 (1.7%)
Relationship Status	
N Single (%)	22 (36.7%)
N In a relationship (%)	4 (6.7%)
N Married/ Living with a partner (%)	29 (48.3%)
N Divorced (%)	5 (8.3%)
Employment Status	
N Unemployed (%)	25 (41.7%)
N Student (%)	6 (10.0%)
N Employed Full-time (%)	8 (13.3%)
N Employed Part-time (%)	14 (23.3%)
N Retired (%)	7 (11.7%)
Number of hours worked (of those in employment)	
Mean (SD)	26.98 (11.15)
Highest Educational Attainment	
N University degree/ professional qualification (%)	24 (40.0%)
N College/ vocational training (%)	11 (18.3%)
N A levels (%)	7 (11.7%)
N GCSEs (%)	14 (23.3%)
N No qualifications (%)	3 (5.0%)
N Missing (%)	1 (1.7%)
Treatment Stage	
N In a service: Assessment stage (%)	23 (38.3%)
N In a service: In treatment (%)	23 (38.3%)
N Not in a service (%)	14 (23.3%)
Number of treatment sessions (of those in treatment)	
Mean SD	7.52 (4.32)

3.2.3 Analyses of Self-Reported Symptoms

The mean scores on the three symptoms measures (MFI-20, VAS, HADS) are displayed in Table 4. On the General Fatigue subscale 98.3% of participants scored above the cut off score (12) for severe fatigue. On the Reduced Activity subscale 78.3% participants scored above the cut off score (9) for severe fatigue. Participants' mean Mental Fatigue score was comparable to that reported in a previous study by Capuron et al. (2006), which found CFS patients exhibited significantly greater MFI Mental Fatigue scores (Mean= 14.1, SD= 4.2) than a matched, non-fatigued control group (Mean= 6.0, SD= 2.0; $t=12.5$, $p < 0.0001$). The mean score on the VAS was 4.63 cm (SD = 2.60). This was below the cut-off score for fibromyalgia patients (4.85) and indicates mild pain (Jensen et al., 2003). However, 44.8% of participants scored above this cut-off score. The mean scores on the two HADS subscales were above the clinical cut-off scores (7) indicating that the CFS sample on the whole had mild depression and anxiety (Bjelland et al., 2002; Snaith & Zigmond, 1994). This finding was consistent with HADS depression and anxiety scores reported in previous CFS research (Rimes & Chalder, 2010). The proportion of participants scoring above the HADS anxiety cut-off score (7) was 65%. The proportion of participants scoring above the HADS depression cut-off score (7) was also 65%.

Table 4.

Mean Symptom scores for the CFS sample (N= 60)

Scale	Subscale	Mean	SD
MFI-20	General Fatigue	17.98	2.12
	Physical Fatigue	16.95	3.37
	Mental Fatigue	15.45	3.85
	Reduced Activity	14.38	4.28
	Reduced motivation	12.92	3.74
VAS[1]	Pain	4.63	2.60
HADS	Anxiety	9.65	4.75
	Depression	9.02	4.10

[1]N= 58

A series of Pearson correlations were utilised to evaluate bivariate relationships between symptom variables. Given the number of correlations being performed, a conservative significance value of .01 was used to reduce the risk of Type I error.

Correlations between physical symptoms for the CFS sample are shown in Table 5. A high level of inter-correlation was found between the five fatigue subscales, with the exception of General Fatigue and Mental Fatigue, which showed no significant relationship. The strongest correlations were between Physical Fatigue and Reduced Activity and General Fatigue and Physical Fatigue. Pain was not significantly related to any of the fatigue subscales.

Table 5

Correlations between physical symptoms for the CFS sample (N = 60)

	General Fatigue	Physical Fatigue	Mental Fatigue	Reduced Activity	Reduced Motivation	Pain[1]
General Fatigue	-	.665* (p< .001)	.239 (p= .066)	.425** (p= .001)	.492** (p< .001)	.299* (p= .022)
Physical Fatigue		-	.345** (p= .007)	.716** (p< .001)	.411** (p= .001)	.200 (p= .132)
Mental Fatigue			-	.455** (p< .001)	.364** (p= .004)	.223 (p= .092)
Reduced Activity				-	.515** (p< .001)	.297* (p = .024)
Reduced Motivation					-	.131 (p= .327)

[1] N= 58

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

Correlations between physical symptoms and symptoms of psychological distress for the CFS sample are shown in Table 6. Depression showed a very high degree of correlation with all five fatigue subscales, which was especially pronounced for Reduced Motivation and Mental Fatigue. No significant relationship was found between Depression and Pain. Anxiety was not significantly related to any measures of physical symptoms. However, high levels of Anxiety were associated with high levels of Depression ($r(58) = .340$, $p= .008$).

Table 6

Pearson correlations between physical and psychiatric symptoms for the CFS sample (N= 60)

HADS	General Fatigue	Physical Fatigue	Mental Fatigue	Reduced Activity	Reduced Motivation	Pain[1]
Anxiety	0.134 (p = .306)	-0.045 (p = .735)	0.291 (p = .024)*	-0.022 (p = .870)	0.179 (p = .170)	0.183 (p = .168)
Depression	0.347** (p = .007)	0.343** (p = .007)	0.579** (p < .001)	0.435** (p = .001)	0.727** (p < .001)	0.323* (p = .014)

[1] N= 58
* Correlation is significant at the 0.05 level (2-tailed)
** Correlation is significant at the 0.01 level (2-tailed)

3.2.4 Analyses of Self-Reported Well-Being

The mean scores on the two well-being measures (PWB and SPANE) are displayed in Table 7. According to Diener et al.'s (2009) normative data, the CFS sample mean for Positive Affect fell on the 18th percentile, indicating that 82% of the normed sample scored above this. For Negative Affect, the CFS sample mean fell on 85th percentile, indicating that only 15% of the normed sample scored above this. Therefore, on the whole the CFS sample scored low in Positive Affect and high in Negative Affect. There are no published norms for the PWB scale, as it is known to vary by age and culture, hence the rationale of creating a matched control group constructed from previous studies.

Table 7.

Total well-being scores for the CFS sample (N= 60)

Wellbeing Subscale		Mean	SD
PWB	Autonomy	37.48	9.54
	Environmental Mastery	30.72	8.68
	Positive Relationships with Others	39.18	7.14
	Personal Growth	34.48	8.34
	Purpose in Life	36.20	9.33
	Self Acceptance	31.29	9.59
SPANE[1]	Positive Affect	17.71	4.72
	Negative Affect	18.75	4.33

[1] N= 59

Correlations between well-being variables for the CFS sample are shown in Table 8. On the whole, PWB variables and SWB variables were highly inter-correlated. The most striking correlations found were between Environmental Mastery and Self-Acceptance; Environmental Mastery and Personal Growth; and Purpose in Life and Personal Growth. Autonomy showed the weakest correlations with the other PWB variables, with only one reaching significance: Autonomy and Self-Acceptance. There were also some small to moderate correlations across the SWB and PWB variables, the most striking being between Negative Affect and Self Acceptance; Negative Affect and Environmental Mastery; and Positive Affect and Self-Acceptance. No significant relationship was found between Autonomy and Positive Affect; Positive Relations with Others and Positive Affect; and Positive Relations with Others and

Negative Affect. The relationships between SWB and PWB dimensions supports previous research suggesting they are highly intertwined and reciprocally related. The partial overlap nevertheless suggests that they are not synonymous and measuring both therefore enhances the broad understanding of wellbeing in CFS.

Table 8

Correlations between the dimensions of well-being for the CFS sample (N = 60)

	EM	PR	PG	PL	SA	PA[1]	NA[1]
AU	.311* (p = .016)	.277* (p = .032)	.221 (p = .089)	.182 (p = .164)	.436** (p < .001)	.145 (p = .272)	-.405** (p = .001)
EM	-	.337** (p = .008)	.681** (p < .001)	.542** (p < .001)	.768** (p < .001)	.556** (p < .001)	-.572** (p < .001)
PR		-	.592** (p < .001)	.504** (p < .001)	.405** (p = .001)	.271* (p = .038)	-.244 (p = .063)
PG			-	.741** (p <.001)	.620** (p < .001)	.409** (p = .001)	-.340** (p = .009)
PL				-	.675** (p < .001)	.438** (p < .001)	-.357** (p < .001)
SA					-	.571** (p < .001)	-.579** (p < .001)
PA[1]						-	-.614** (p < .001)
NA[1]							-

Notes: AU = Autonomy, EM = Environmental Mastery, PR = Positive Relations with Others, PL = Purpose in Life, PG = Personal Growth, SA = Self-Acceptance, PA = Positive Affect, NA = Negative Affect, [1] N= 59, * Correlation is significant at the 0.05 level (2-tailed), ** Correlation is significant at the 0.01 level (2-tailed)

Pearson r correlations indicated that well-being variables were not significantly related to participants' age, number of years with CFS and time (years) taken to receive a diagnosis of CFS from the onset of symptoms (see Table 9). To examine the influence of participants' stage of treatment, a Group (Assessment vs. in treatment vs. not in a service) X well-being (Positive Affect, Negative Affect, Environmental Mastery, Positive Relations with Others, Purpose in Life, Personal Growth, Autonomy and Self-Acceptance) MANOVA was carried out. No main effect of stage of treatment was found at the .05 significant level ($F(14, 102) = 1.264$, $p = .243$).

Table 9

Correlations between the dimensions of well-being and demographic variables for the CFS sample (N = 60)

	Age	Years with CFS	Years taken to receive a diagnosis of CFS from the onset of symptoms
AU	.330* (p = .016)	.061 (p = .644)	.013 (p = .924)
EM	.104 (p = .429)	.036 (p = .787)	.203 (p = .120)
PR	.025 (p = .849)	.010 (p = .938)	.038 (p = .774)
PG	-.020 (p = .878)	-.006 (p = .962)	.102 (p = .438)
PL	.019 (p = .887)	-.021 (p = .874)	.131 (p = .318)
SA	.147 (p = .261)	.139 (p = .288)	.284* (p = .028)
PA[1]	-.145 (p = .275)	.057 (p = .668)	.137 (p = .302)
NA[1]	-.114 (p = .389)	-.032 (p = .809)	-.107 (p = .422)

Notes: AU = Autonomy, EM = Environmental Mastery, PR = Positive Relations with Others, PL = Purpose in Life, PG = Personal Growth, SA = Self-Acceptance, PA = Positive Affect, NA = Negative Affect, [1] N= 59, * Correlation is significant at the 0.05 level (2-tailed)

3.2.5 Hypothesis 1: CFS participants' self-reported scores on the two measures of wellbeing (SPANE and PWB) will be significantly related to their scores on measures of symptoms (MFI-20 and VAS) and psychological distress (HADS).

A series of Pearson correlations were utilised to evaluate bivariate relationships between wellbeing variables and symptom variables (see Tables 10 and 11). Given the number of correlations being performed, a conservative significance value of .01 was used to reduce the risk of Type I error. No significant correlations were found between Autonomy and the eight symptom measures. In contrast, a high score on Environmental Mastery was significantly associated with a low score of all symptom measures, particularly psychological distress (Anxiety and Depression). High levels of Positive Relations with Others were associated with low levels of Reduced Motivation and Depression. High levels of Personal Growth were associated with low levels of Mental Fatigue, Reduced Motivation, and Depression. Lastly, high levels of Purpose in Life were associated with low levels of Reduced Motivation and Depression, whilst high levels of Self-Acceptance were associated with low levels of Mental Fatigue, Reduced Motivation, Anxiety and Depression.

In terms of SWB, those high in Positive Affect scored low in General Fatigue, Reduced Motivation, Anxiety and most strikingly Depression; whilst those high in Negative Affect scored high in Reduced Motivation, Depression and particularly Anxiety.

Table 10

Pearson correlations between symptoms and PWB for the CFS sample (N= 60)

	AU	EM	PR	PG	PL	SA
Physical Symptoms						
GF	-.124 (p = .346)	**-.380**** (p = .003)	-.273* (p = .035)	-.191 (p = .144)	-.194 (p = .137)	-.281* (p = .031)
PF	.023 (p = .864)	**-.440**** (p < .001)	-.225 (p = .084)	-.180 (p = .168)	-.198 (p = .129)	-.252 (p = .052)
MF	-.306* (p = .017)	**-.464**** (p < .001)	-.282* (p = .029)	**-.456**** (p < .001)	-.314* (p = .014)	**-.466**** (p < .001)
RA	-.022 (p = .867)	**-.497**** (p < .001)	-.148 (p = .259)	-.308* (p = .017)	-.163 (p = .212)	-.292* (p = .024)
RM	-.260* (p = .045)	**-.423**** (p = .001)	**-.464**** (p < .001)	**-.491**** (p < .001)	**-.433**** (p = .001)	**-.415**** (p = .001)
Pain[1]	-.231 (p = .081)	-.**349**** (p = .007)	-.155 (p = .247)	-.244 (p = .065)	-.239 (p = .071)	-.214 (p = .107)
Psychological Distress						
Anx	**-.538**** (p < .001)	**-.505**** (p < .001)	-.180 (p = .169)	-.261* (p = .044)	-.241 (p = .063)	**-.595**** (p < .001)
Dep	-.317* (p = .013)	**-.594**** (p < .001)	**-.363**** (p = .004)	**-.581**** (p < .001)	**-.614**** (p < .001)	**-.643**** (p < .001)

Notes: AU = Autonomy, EM = Environmental Mastery, PR = Positive Relations with Others, PL = Purpose in Life, PG = Personal Growth, SA = Self-Acceptance, Anx = Anxiety, Dep = Depression, GF = General Fatigue, PF = Physical Fatigue, MF = Mental Fatigue, RA = Reduced Activity, RM = Reduced Motivation,
[1] N= 58, * Correlation is significant at the 0.05 level (2-tailed), ** Correlation is significant at the 0.01 level (2-tailed)

Table 11

Pearson correlations between symptoms and SWB for the CFS sample (N= 60)

	Positive Affect[2]	Negative Affect[2]
Physical Symptoms		
General Fatigue	**-0.405**** **(p = .007)**	0.251 (p = .055)
Physical Fatigue	-0.308* (p = .018)	0.156 (p = .237)
Mental Fatigue	-0.279* (p = .032)	0.286* (p = .028)
Reduced Activity	-0.317* (p = .014)	0.151 (p = .254)
Reduced Motivation	**-0.448**** **(p < .001)**	**0.386**** **(p = .003)**
Pain[1]	-0.115 (p = .392)	0.208 (p = .117)
Psychological Distress		
Anxiety	**-0.400**** **(p = .002)**	**0.724**** **(p < .001)**
Depression	**-0.622**** **(p < .001)**	**0.457**** **(p < .001)**

Notes: [1] N= 58, [2] N= 59, * Correlation is significant at the 0.05 level (2-tailed), ** Correlation is significant at the 0.01 level (2-tailed)

3.2.6. Regression Analyses

Do CFS Participants' Scores on Well-Being Measures Predict Their Scores on Symptoms Measures?

Regression analyses examine relationships between variables and cannot establish causality. Multiple regression was utilised in the present study to examine 1) the relationship between different facets of well-being together and a specific symptom and 2) how the different facets of well-being related to a particular symptom when they were controlled for each other.

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3.2.6.1 Demographic Predictors

Before examining the predictive power of the well-being variables, the predictive power of several demographics variables were computed to check whether they would need to be taken into account. A conservative significance value of .01 was used for consistency.

Pearson r correlations indicated that participant age, number of years with CFS and years taken (from onset of symptoms) to receive a diagnosis of CFS, were not significantly related to any of the symptom measures (General Fatigue, Physical Fatigue, Mental Fatigue, Reduced Activity, Reduced Motivation, Pain, Anxiety and Depression; see Appendix VIII). Relationship status was collapsed to two categories: In a relationship vs. not in a relationship. Independent sample t-tests revealed no significant difference in symptom severity between groups (see Appendix IX). Employment status was also collapsed into two categories: unemployed vs. not

unemployed. Independent sample t-tests revealed no significant difference in symptom severity between groups (see Appendix X).

To examine the influence of participants' stage of treatment, a Group (Assessment vs. in treatment vs. not in a service) X Symptom (General Fatigue, Physical Fatigue, Mental Fatigue, Reduced Activity, Reduced Motivation, Pain, Anxiety and Depression) MANOVA was carried out. A main effect of stage of treatment was found at the .05 significance level ($F(16, 98) = 1.792$, $p = .043$). All univariate ANOVAs were non-significant at the .05 level with the exception of Reduced Activity ($F(2, 55) = 4.017$, $p = .024$; see Appendix XI for non-significant results). Post hoc t-tests revealed that CFS participants currently receiving treatment were significantly more active (Mean = 12.35, SD = 3.601) than those recruited at the assessment stage (Mean = 15.43, SD = 4.315; $t(44) = 2.634$, $p = .012$) and those not in services (Mean = 16.00, SD = 4.169; $t(35) = 2.819$, $p = .008$). No significant difference in activity levels was found between participants at the assessment stage and those not in services ($t(35) = .391$, $p = .698$).

3.2.6.2 Well-being Predictors

A series of multiple regression analyses were conducted to establish whether well-being variables predicted physical symptoms and symptoms of psychological distress in CFS participants. All correlations between well-being dimensions and symptoms found to be significant at the .01 level were included in the regression. All symptoms were examined independently; however, the researcher was aware that they were highly correlated and therefore, dependent.

Three diagnostic tests were completed for each regression model. All assumptions were met and the models were considered to be generalisable and a good fit of the observed data. Cook's distances were all less than one, indicating that there were no significant outliers (Cook & Weisberg, 1982). Variance Inflation Factors were all less than 10, indicating acceptable multicollinearity (Myers, 1990). Standardised residuals indicated that the models were an acceptable fit of the sample data (95% of z scores were between -1.96 and +1.96, 99% of scores were between -2.58 and +2.58 and 99.9% were between -3.29 and +3.29).

3.2.6.3 General Fatigue

A standard multiple regression was performed with General Fatigue as the dependent variable and Environmental Mastery and Positive Affect, as independent variables. The model accounted for a significant amount of variance in General Fatigue (R^2 = .219, Adjusted R^2 = .191, $F(2, 56) = 7.857$, $p = .001$). The partial regression coefficients showed that none of predictors made a unique contribution to General Fatigue: Environmental Mastery ($t(58) = 1.995$, $p = .051$) and Positive Affect ($t(58) = 1.740$, $p = .087$). Therefore, although the model showed a significant relationship to General Fatigue, this was not carried uniquely by either of the wellbeing predictors.

3.2.6.4 Mental Fatigue

A standard multiple regression was performed with Mental Fatigue as the dependent variable and Environmental Mastery, Personal Growth, and Self Acceptance, as independent variables. The model accounted for a significant amount of variance in Mental Fatigue (R^2 = .270, Adjusted R^2 = .231, $F(3, 56) = 6.915$, $p < .001$). However, the partial regression coefficients showed that none of predictors made a unique

contribution to Mental Fatigue: Environmental Mastery (t(58) = .757, p = .452), Personal Growth (t(58) = 1.398, p = .168) and Self Acceptance (t(58) = 1.180, p = .243).

3.2.6.5 Reduced Activity

A hierarchical multiple regression was performed with Reduced Activity as the dependent variable and treatment stage and Environmental Mastery as independent variables. Treatment stage was collapsed from three levels (assessment vs. in treatment vs. not in a service) into two levels (in treatment vs. not in treatment). The aim was to see what the combined predictive power of these variables was and also to determine the extent to which Environmental Mastery accounted for variance in Reduced Activity Levels, after the effects of treatment stage had been accounted for. Therefore, treatment stage was entered as the first step in a hierarchical regression in order to partial out any contribution to Reduced Activity levels. Treatment stage explained a significant amount of variance in Reduced Activity Levels (R^2 = .143, Adjusted R^2 = .129, F(1, 58) = 9.704, p =.003). More importantly the predictor variable at step 2 (Environmental Mastery) contributed to a significant increase in variance from 14.3% to 30.3%, adjusted R^2 = 0.279, a change that was highly significant (F(1, 57) = 13.083, p < .001). In the final equation, Environmental Mastery (B = -.207, β = -.420, t(58) = 3.617, p = .001) and to a lesser extent treatment stage (B = 2.169, β = .249, t(58) = 2.140, p = .037) made significant unique contributions to explaining Reduced Activity levels.

3.2.6.6 Reduced Motivation

A standard multiple regression was performed with Reduced Motivation as the dependent variable and Environmental Mastery, Positive Relations with Others, Personal Growth, Purpose in Life, Self Acceptance, Positive Affect and Negative Affect as independent variables. The model accounted for a significant amount of variance in Reduced Motivation (R^2 = .371, Adjusted R^2 = .285, F(7, 51) = 4.296, p = .001). The partial regression coefficients showed that only Positive Relations with Others (B = -.157, β = -.299, t(58) = 2.026, p = .048) made an independent contribution to Reduced Motivation. Environmental Mastery (t(53) = .206, p = .837), Personal Growth (t(53) = .725, p = .472), Purpose in Life (t(53) = .101, p = .920), Self Acceptance (t(53) = .297, p = .767), Positive Affect (t(53) = 1.527 p = .133) and Negative Affect (t(53) = .798, p = .429) did not. Overall, the model showed a significant relationship to Reduced Motivation, the only unique predictor of which was Positive Relations with Others.

3.2.6.7 Depression

A standard multiple regression was performed with Depression as the dependent variable and Environmental Mastery, Positive Relations, Personal Growth, Purpose in Life, Self-Acceptance, Positive Affect and Negative Affect as independent variables. These seven variables accounted for a significant amount of variance in Depression (R^2 = .558, Adjusted R^2 = .498, (F(7, 51) = 9.207, p < .001). The partial regression coefficients showed that Positive Affect (B = -.299, β = -.351, t(53) = 2.756, p = .008) made an independent contribution to Depression. However, the other predictors were not independently associated with Depression: Environmental Mastery (t(53) = .471, p = .640), Positive Relationships with Others (t(53) = .410, p = .684), Personal Growth

(t(53) = .534, p = .596), Purpose in Life (t(53) = 1.154 p = .254), Self Acceptance (t(53) = 1.098, p = .277) and Negative Affect (t(53) = .185, p = .854). Therefore, the model showed a significant relationship to Depression, the only unique predictor of which was Positive Affect.

3.2.6.8 Anxiety

A standard multiple regression was performed with Anxiety as the dependent variable and Autonomy, Environmental Mastery, Self Acceptance, Positive Affect and Negative Affect as independent variables. These five variables accounted for a significant amount of variance in Anxiety (R^2 = .632, Adjusted R^2 = .597; F(5, 53) = 18.172, p <.001;). The partial regression coefficients showed that Autonomy (B = -.108, β = -.217, t(55) = 2.205, p = .032) and Negative Affect (B = .623, β = .564, t(55) = 4.693, p < .001) made significant, unique contributions to Anxiety. However, Environmental Mastery (t(55) = .010, p = .992), Self Acceptance (t(55) = 1.779, p = .081) and Positive Affect (t(55) = 1.069, p = .290) were not independently associated with Anxiety. Therefore, the model showed a significant relationship to Anxiety, the only unique predictors of which were Negative Affect and to a lesser extent Autonomy.

A summary of the regression analyses is presented in Table 12. The 0.05 column is shown for completeness; however, 0.01 was used as the significance level. All regression models were significant. In terms of physical aspects of fatigue (physical fatigue and reduced activity) and pain intensity, Environmental Mastery was found to be a unique predictor: A high level of Environmental Mastery predicted a low level of

pain intensity, physical fatigue and Reduced Activity. Reduced Motivation, a psychological aspect of fatigue was strongly related to all aspects of well-being and uniquely predicted by Positive Relations with Others: A high level of Positive Relations with Others predicted a low level of Reduced Motivation. In terms of predicting psychological distress, a high level of Positive Affect uniquely predicted a low level of Depression and a low level of Negative Affect and to a lesser extent a high level of Autonomy, predicted a low level of Anxiety.

Table 12.

Summary of regression analyses

Symptom	Significant Correlation		Variance Explained by Model (%)	Unique Predictor in Model
	.05	.01		
General Fatigue	EM, PR, SA PA	EM PA	21.9	-
Physical Fatigue	EM PA	EM	19.4	EM
Mental Fatigue	AU, EM, PR, PG, PL, SA PA, NA	EM, PG, SA	27.0	-
Pain	EM	EM	12.2	EM
Reduced Activity	EM, PG, SA PA	EM	30.3	EM Treatment stage
Reduced Motivation	AU, EM, PR, PG, PL, SA PA, NA	EM, PR, PG, PL, SA PA, NA	37.1	PR
Depression	AU, EM, PR, PG, PL, SA PA, NA	EM, PR, PG, PL, SA PA, NA	55.8	PA
Anxiety	AU, EM, PG, SA PA, NA	AU, EM, SA PA, NA	63.2	NA AU

Notes: AU = Autonomy, EM = Environmental Mastery, PR = Positive Relations with Others, PL = Purpose in Life, PG = Personal Growth, SA = Self-Acceptance, PA = Positive Affect, NA = Negative Affect.

3.3 Section B

The data for non-clinical, control participants was obtained from two previous doctoral thesis studies into psychological well-being (Blackburn, 2014; Edmondson, 2012). A total of 50 Control participants were available to match with the CFS participants. Forty-two Control participants were successfully selected to match forty-two CFS participants on the basis of age, gender (female vs. male), ethnicity (white vs. non-white), employment status (unemployed vs. not unemployed) and marital status (in a relationship vs. not in a relationship). This left 8 control participants and 18 CFS participants who were unmatched and therefore, excluded.

3.3.1 Data Screening

In the CFS group (N = 42) the six PWB were all within normal distribution limits and there were no outliers. In the Control group, five of the PWB categories (Environmental Mastery, Personal Growth, Self-Acceptance, Purpose in Life and Autonomy) were within normal distribution limits and there were no outliers. The Positive Relations with Others category was significantly negatively skewed ($z = -3.54$) in the Control Group. Therefore, transformations were carried out for both groups, which resulted in them being normally distributed.

3.3.2 Participant Demographics

Demographics for the two groups are displayed in Table 13. The mean age for the Control group (N = 42) was 34.93 years (SD = 11.26). The mean age for the CFS group (N= 42) was 36.13 years (SD = 13.11). Independent sample t-test indicated that the two groups did not differ significantly in mean age ($t(82) = 0.449$, $p = .654$).

Current employment status was collapsed to unemployed/ not unemployed; both groups had 16 participants who were unemployed and 26 participants who were not unemployed.

Chi-square tests were carried out on the other demographic categories (Gender, Ethnicity and Relationship Status). Results showed that Gender ($X^2(1) = 0.233$, $p = .629$) did not differ significantly between the Control group and the CFS group. Ethnicity was collapsed to white/ non-white and there was no significant difference between the two groups ($X^2(1) = 3.111$, $p = .078$). Relationship status was collapsed to in a relationship/ not in a relationship and there was no significant difference between groups ($X^2(1) = 1.730$, $p = .188$).

Table 13.

Participant Characteristics for the CFS and Control group

Demographic Variables	CFS Group (N= 42)	Control Group (N= 42)
Gender		
N Female (%)	31 (73.8%)	29 (69.0%)
N Male (%)	11 (26.2 %)	13 (31.0%)
Age (years)		
Mean (SD)	36.13 (13.11).	34.93 (11.26)
Ethnicity		
N White (%)	40 (95.2%)	35 (83.3%)
N Non-White (%)	2 (4.8%)	7 (16.7%)
Relationship Status		
N In a relationship (%)	22 (52.4%)	16 (38.1%)
N Not in a relationship (%)	20 (47.6%)	26 (61.9%)
Employment Status		
N Unemployed (%)	16 (38.1%)	16 (38.1%)
N Not Unemployed	26 (61.9%)	26 (61.9%)

3.3.3 Hypothesis 2: Ratings of Current PWB will be Significantly Lower in the CFS Group than the Control group

In order to examine group differences in PWB variables a Group (CFS group vs. Control group) X PWB (Positive Relations with Others, Environmental Mastery, Personal Growth, Self-Acceptance, Purpose in Life, and Autonomy) mixed model ANOVA was conducted. Huynh-Feldt was used because Mauchly's test of sphericity was significant. A significant main effect of PWB was found ($F(2.96, 242.86) = 183.89$, $p<.001$), suggesting that the six PWB category scores differed significantly from each other. There was also a significant main effect for Group ($F(1,82) = 130.39$,

p<.001), where the Control Group had a higher PWB score than the CFS Subgroup. The interaction of Group and PWB category was significant (F(2.96, 242.86) = 22.76, p<.001), indicating that the difference between the CFS group and the Control group varied across PWB variables.

Post hoc Fisher's protected t-tests compared the CFS group and Control group on the PWB variables (see Table 14 for means). The CFS group scored significantly lower (more negative) than the Control group on Environmental Mastery, Positive Relationships with Others, Personal Growth, Purpose in Life and Self-Acceptance. There was no significant difference between the two groups on Autonomy.

Table 14

Means and standard deviations of the self-report scales of PWB for the CFS and Control groups and significance of difference between the groups.

PWB Category	CFS Mean (SD)	Control Mean (SD)	t(82)	p
Autonomy	36.52 (8.86)	39.52 (8.92)	1.55	.130
Environmental Mastery	30.10 (7.83)	42.57 (6.59)	7.90	<.001*
Positive Relations	38.24 (6.98)	45.05 (8.02)	3.29	.002*
Personal Growth	34.52 (7.96)	46.31 (5.79)	7.76	<.001*
Purpose in Life	35.95 (9.64)	42.83 (6.60)	3.82	<.001*
Self Acceptance	30.16 (8.90)	41.69 (6.92)	6.63	<.001*

*Difference significant at the 0.01 significance level (2 tailed)

Therefore, there was partial support for hypothesis 2. As predicted the CFS group scored significantly lower than the Control group on five of the six PWB subscales. There was no significant difference between the CFS and Control group in their scores on the Autonomy subscale of PWB.

To profile the PWB of the CFS group, a comparison was made using the Control group scores as baseline scores for each dimension of PWB. Each CFS participant's score for a dimension was calculated as the distance from the Control group (baseline) mean and divided by the Control group standard deviation, to produce a set of standardised scores. The CFS group scores shown in Figure 1 therefore, represent standard deviations from the Control group mean.

The CFS group scored below the Control group mean on all six dimensions. Personal Growth was more than two standard deviations from the Control group mean; Environmental Mastery and Self Acceptance were more than 1.5 standard deviations from the Control group mean; Purpose in Life was over one standard deviation from the Control group mean; Positive Relationships with Others was over 0.5 standard deviations from the Control group mean; Autonomy was the nearest dimensions to the Control group mean, at less than 0.5 standard deviations below it.

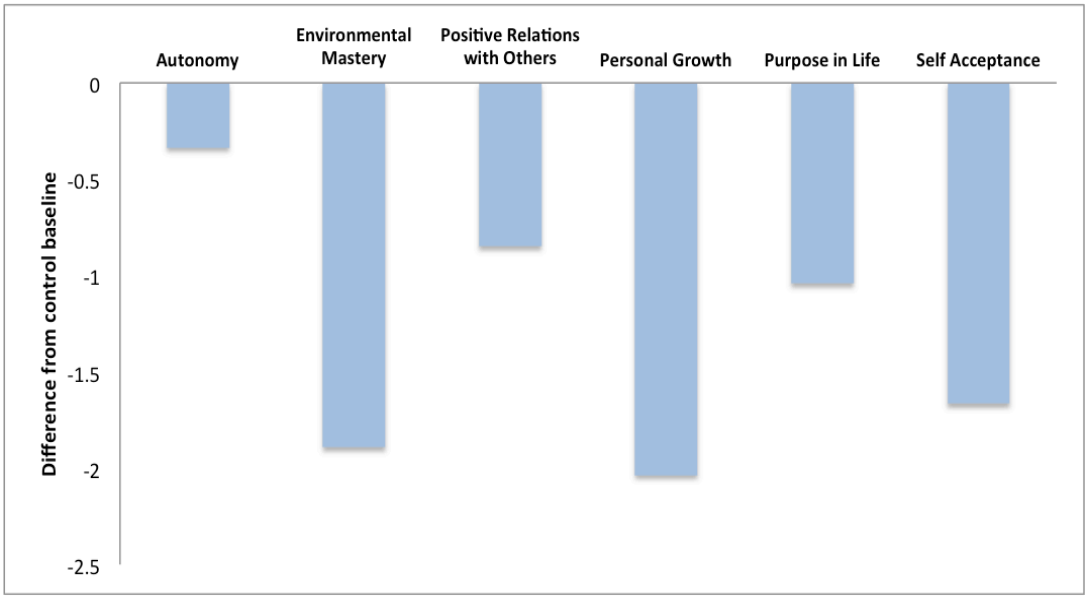

Figure 2: Psychological well-being profile of the CFS group relative to the Control group baseline (where units represent standard deviations of CFS group scores from control group mean).

A repeated measures ANOVA showed a main effect of CFS group profile scores ($F(3.98,163) = 22.93$, $p < .001$). Post hoc Fisher's protected paired-samples t-tests compared the CFS group's category profile scores to each other. Nine significant differences were found (see Table 15). Personal Growth, Environmental Mastery and Self-Acceptance were significantly lower than the other three variables, and did not differ significantly from each other. To summarise, the CFS group had the largest deficits in Personal Growth, Environmental Mastery and Self-Acceptance and to a lesser extent Purpose in Life and Positive Relations with Others. Their level of Autonomy was comparable to that of the Control group and therefore fell within normal limits.

Table 15

Mean differences between the Ryff Psychological Well-being Profile scores for the CFS group.

	Autonomy	Environ-mental Mastery	Positive Relations	Personal Growth	Purpose in Life	Self-Acceptance
Autonomy	-	< .001*	.014	< .001*	.012	.001*
Environ-mental Mastery		-	< .001*	.351	< .001*	.107
Positive Relations			-	< .001*	.332	< .001*
Personal Growth				-	< .001*	.047
Purpose in Life					-	.001*
Self-Acceptance						-

* Mean difference significant at the 0.01 significance level (2 tailed)

Chapter 4: Discussion

Chapter Overview

Previous psychological research into CFS has focused almost exclusively on the identification of negative mental processes, whilst positive mental processes have been relatively ignored. In patients with CFS, therapies that focus on reducing negative criteria, such as CBT, produce unsatisfactory recovery rates in symptoms relating to fatigue and psychological distress. Finding ways to enhance the efficacy of existing treatments is a clinical priority (Price et al, 2008). Research into related conditions like chronic pain, rheumatoid arthritis and depression suggests that individuals who maintain positive affect and psychological well-being, experience less distress and disability. Therefore, the present study attempted to focus on positive psychological functioning and the relationship it may have to symptoms of fatigue, pain and psychological distress in CFS. This is the first reported study to conduct a theoretically informed, multi-dimensional investigation of well-being in adults with CFS, incorporating both aspects of Psychological Well-Being (as operationally defined by Ryff, 1989), and Subjective Well-Being (as operationally defined by Diener et al., 2010). It was suggested that building a profile of well-being would help us better understand the experiences of people with CFS, identify new treatment targets and distinguish CFS from its co-morbid partners.

The first objective was to examine the relationships between symptomatology and dimensions of psychological and subjective well-being in CFS. It was predicted that

participants' self-reported scores on two measures of wellbeing (SPANE and PWB) would be significantly related to their self-reported scores on measures of symptoms (Fatigue, Pain) and psychological distress (Anxiety, Depression). Where relationships were found to be significant at the 0.01 level, the second objective was to examine whether participants' scores on well-being variables could predict their scores on measures of symptoms and psychological distress. The third objective was to examine the profile of psychological well-being in CFS participants. It was predicted that the CFS group would report significantly lower scores on Ryff's six dimensions of psychological well-being, than a matched, non-clinical Control group.

This chapter will begin by providing a summary of the study's findings. Although an examination of group differences in well-being between the CFS and Control groups was not the main part of the study and was presented second in the results, it will be presented here first for coherence. The relationships between measures of symptomatology and well-being will then be examined second. Findings will be interpreted in light of existing research, before discussing the limitations of the study, its clinical implications and suggestions for future research.

4.1 Summary of Findings

As was expected from the CFS population, the sample in the present study was predominantly female and contained participants with a wide range of ages and durations of CFS. Fatigue was measured using the Multi-dimensional Fatigue Inventory, which comprehensively assesses physical and psychological components of

fatigue. All CFS participants included in the study met criteria for severe fatigue. Only 21.7% of participants had a co-morbid diagnosis of fibromyalgia, which was lower than reported in previous research (35%- 75%; Buchwald & Garrity, 1994; Goldenberg et al., 1990). Pain was measured using the Pain Visual Analogue Scale and on average, the CFS group scored below the cut-off for fibromyalgia, indicating mild pain. Psychological distress was measured using the Hospital Anxiety and Depression Scale. Approximately two thirds of the sample scored above the cut off for clinically significant anxiety and depression, which is consistent with rates of psychological distress reported in existing CFS research (Bell, 1991; Taerk Toner, Salit, Garfinkel & Ozersky, 1987). Participants' scores across the five fatigue subscales were highly correlated, in particular Physical Fatigue and Reduced Activity. No relationship was found between General Fatigue and Mental Fatigue. Strong bivariate relationships were found between Depression and the Fatigue dimensions, in particular Reduced Motivation and Mental Fatigue. No significant bivariate relationships were found between Fatigue, Pain and Anxiety. Compared to Diener et al.'s (2010) normative sample, the CFS sample reported high levels of Negative Affect and low levels of Positive Affect, indicating that they were low in SWB. This contests Marshall et al.'s (1996) previous finding that CFS patients' had relatively normal levels of negative affect. PWB dimensions were strongly inter-correlated, in particular Environmental Mastery and Self-Acceptance; Environmental Mastery and Personal Growth; and Purpose in Life and Personal Growth. SWB dimensions showed the strongest relationships to Environmental Mastery and Self Acceptance. Well-being variables were not related to demographic variables.

A subgroup of the CFS sample was matched on demographics (age, gender, ethnicity, relationship status and employment status) to a non-clinical Control group and there were no significant differences between groups. Successful matching of these factors was deemed to be a significant strength of the present study, as previous research suggests they can affect well-being (Diener et al., 1999; Ryff, 1995; Ryff & Singer, 2008). Compared to the Control group, the CFS group reported significantly lower psychological well-being scores on five of Ryff 's six dimensions (Environmental Mastery, Positive Relations with Others, Personal Growth, Purpose in Life, and Self-Acceptance). There was no significant difference found between the CFS and Control groups' scores on the Autonomy subscale. This provided partial support for the present study's second hypothesis, which predicted that the CFS group would show deficits across all domains of psychological well-being. The greatest deficits observed in the CFS group from the Control group mean were Personal Growth (being open to new experiences and considering the self as growing and expanding over time), Environmental Mastery (being able to choose and create environments that meet ones specific needs), and Self-Acceptance (being able to positively evaluate oneself and one's past life, acknowledging the presence of good and bad qualities in the self), and to a lesser extent Purpose in Life (having goals, intentions and a sense of direction which contributes to the feeling that life is meaningful) and Positive Relations with Others (having warm and trusting interactions). Their level of Autonomy (being able to evaluate oneself according to personal standards and not look to others for approval) was comparable to that of the Control group and thus, within normal limits.

Correlational analyses revealed that in CFS, well-being dimensions were largely independent of physical symptoms, namely levels of Pain intensity, Physical Fatigue (referring to physical sensations related to fatigue), Reduced Activity (referring to the influence of fatigue on activity levels) and General Fatigue (referring to general aspects of fatigue and impaired functioning). The exceptions were Environmental Mastery, which showed a moderate, negative association with all physical symptoms and Positive Affect, which showed a moderate, negative association with General Fatigue.

In comparison to physical symptoms, well-being in CFS showed a much greater association with the presence of psychological components of fatigue and psychological distress, namely Mental Fatigue, Reduced Motivation, Anxiety and Depression. The presence of Depression and Reduced Motivation (for initiating activity) were related to low levels of all well being dimensions, with the exception of Autonomy. The presence of Mental Fatigue was independent of SWB but moderately associated with low levels of three PWB dimensions: Self-Acceptance, Environmental Mastery and Personal Growth. The presence of Anxiety was related to low levels of SWB and three PWB dimensions: Autonomy, Self-Acceptance, and Environmental Mastery.

A series of multiple regression analyses were conducted to establish whether well-being variables predicted symptoms in CFS participants. Environmental Mastery uniquely predicted lower levels of Physical Fatigue (explaining 19% of the variance),

Reduced Activity (explaining 30% of the variance when entered into a model with treatment stage), and Pain (explaining 12% of the variance). Environmental Mastery and Positive Affect together predicted lower levels of General Fatigue (explaining 22% of the variance). Environmental Mastery, Self Acceptance and Personal Growth predicted lower levels of Mental Fatigue (explaining 27% of the variance). A model containing all the well-being variables (except Autonomy) was found to predict lower levels of Reduced Motivation (explaining 37% of variance), which was uniquely carried by Positive Relations with Others and; lower levels of Depression (explaining 56% of variance), which was uniquely carried by Positive Affect. Finally, a model containing Autonomy, Environmental Mastery, Self Acceptance, Positive Affect and Negative Affect predicted lower levels of Anxiety (explaining 63% of the variance); an effect that was uniquely carried by Negative Affect and to a lesser extent Autonomy.

In summary, partial support was found for hypothesis 1. In CFS, psychological components of fatigue and psychological distress were significantly related to several aspects of well-being. Reduced Activity levels and physical symptoms of fatigue and pain however, were largely independent of well-being dimensions.

4.2 Interpretations of Findings

4.2.1 CFS and Psychological Well-being

As previously stated, the CFS group had significantly lower psychological well-being scores than the Control group across all dimensions, with the exception of Autonomy, where their level was within normal limits. This highlights the burden of CFS beyond symptoms and is consistent with research associating CFS with reduced emotional health, life satisfaction, social functioning and occupational functioning (Collin, et al., 2011; Rakib, et al., 2005; Schoofs et al., 2004). It also supports previous findings on Ryff psychological well-being scores in other physical and mental health disorders, where clinical participants have consistently reported lower levels of psychological well-being than the general population (Mangelli et al., 2002; Nierenberg et al., 2010; Schleicher, et al., 2005). The pattern of deficits however, varies between conditions. Compared to other physical health (fibromyalgia) and mental health (depression and borderline personality disorder) conditions the CFS group in the present study demonstrated a distinct *pattern* of deficits, with the greatest differences observed between the CFS and Control group means in Environmental Mastery, Personal Growth and Self-Acceptance. In comparison, fibromyalgia (Schleicher, et al., 2005), depressed (Edmondson, 2012) and borderline personality disorder (Blackburn, 2014) participants showed the greatest difference from their control group means in Environmental Mastery, Self Acceptance and Positive relations with Others. This suggests that there maybe fundamental differences in the experience and impact of living with CFS. However, further research directly comparing matched samples of CFS participants to participants with fibromyalgia, depression or borderline personality disorder is required to verify such conclusions.

To provide a context for the *magnitude* of deficits in the CFS group, the psychological well-being profiles of Edmonson and MacLeod's (2014) depressed sample and Blackburn's (2014) Borderline Personality Disorder (BPD) sample are shown in Figure 3. Unfortunately, no other studies have examined the profile of PWB in CFS, fibromyalgia or rheumatoid arthritis, where the six psychological well-being dimension scores in the Control Group act as a baseline for comparison and the clinical groups' standard deviation differences to these mean baseline scores are explored. As a result, Mangelli et al.'s (2002) rheumatoid arthritis sample and Schleicher et al.'s (2005) fibromyalgia sample could not be included in Figure 3. Edmonson and MacLeod (2014) profiled PWB in depression, controlling for confounding factors by comparing patients to a matched non-clinical control group. Given the high co-morbidity between CFS and depression, and that 65% of CFS participants in the current study scored above the clinical cut-off for depression, depressed patients were considered the next reasonable alternative for comparison. Individuals with BPD typically experience difficulties with impulsivity, managing their emotions, unstable images of self and unstable interpersonal relationships (DSM-5; American Psychiatric Association, 2013). There is some limited evidence to suggest that compared to the general population, personality disorders are more prevalent in CFS patients (Henderson & Tannock, 2004; Johnson, DeLuca, Natelson, 1996; Nater et al., 2010). Reported rates of BPD in CFS range from 1.8% to 17% (Johnson et al., 1996). It was therefore considered that the profile of PWB in BPD patients would also make an interesting comparison.

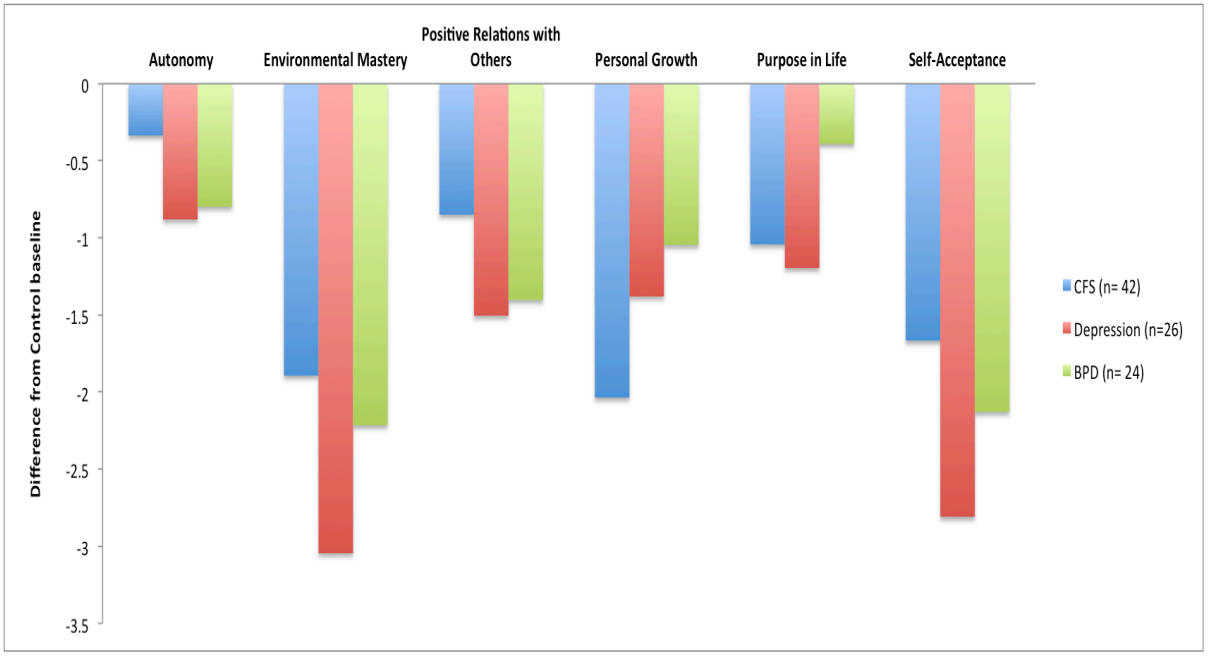

Figure 3: Psychological well-being profile of the present study's CFS group compared to Edmondson & MacLeod's (2014) depressed group and Blackburn's (2014) BPD group (where units represent standard deviations of patient group scores from their control group mean).

Edmondson and MacLeod (2014) compared 26 patients with depression to 26 non-clinical controls. Depressed patients ranged in age from 18 – 60 years (Mean= 38.85, SD = 10.91) and were mostly female (65%), White British (65%), and not in a relationship (58%). Blackburn (2014) compared 24 patients with Borderline Personality Disorder (BPD) who were currently receiving treatment to 24 non-clinical controls. BPD participants ranged in age from 18 – 60 years (M = 34.46, SD = 8.31) and were mostly female (63%), White British (54%), and not in a relationship (75%). In comparison to both samples, the CFS group were similar in age (Mean = 36.13, SD = 13.11) and had more participants that were female (73.8%), White British (95.2%) and in a relationship (47.6% were not in a relationship). In the present study the

greatest differences in the CFS group's psychological well-being dimensions from their control group mean were in Personal Growth, Environmental Mastery and Self-Acceptance, which were all close to two standard deviations from the Control group mean. Out of the other three dimensions, Purpose in Life and Positive Relationships with Others were close to one standard deviation from the Control group mean, whereas Autonomy was less than 0.5 standard deviations below it and within normal limits. Compared to the Depressed group, the CFS group had smaller deficits from their Control group mean across all dimensions of well-being, except Personal Growth, where they showed a deficit approximately 0.7 standard deviations larger. The largest differences between the Depressed and CFS groups were in the dimensions of Environmental Mastery and Self Acceptance (with the Depression group showing a deficit from their control baseline close to one standard deviation larger). Compared to the BPD group, the CFS group showed smaller deficits from their Control Group mean in four PWB dimensions (Environmental Mastery, Autonomy, Self-Acceptance and Positive relations with Others) but larger deficits in Personal Growth and Purpose in Life. The greatest differences between the CFS and BPD group's deficits were in Personal Growth and Purpose in Life (with the CFS group showing a deficit from their control baseline approximately one standard deviation larger).

Caution must be taken when drawing conclusions, as the statistical significance of the reported differences are unknown and the groups were not matched on demographic variables. Any differences could be attributable to confounding factors and further research is needed to verify the findings.

Difficulties in Environmental Mastery (managing everyday affairs) and Personal Growth (a sense that one is growing and expanding) maybe explained by the CFS's groups varied and fluctuating symptoms. Sufferers experience unpredictable good days and bad days, a lack of understanding about the nature of their medically unexplained illness and disbelief from professionals. This may make it hard for them to create an environment that can accommodate their needs and many report feelings of helplessness and a loss of control (Anderson & Ferrans, 1997; Clarke & James, 2003). Complaints of cognitive impairment are significant. Previous research suggests that 85-95% of people with CFS self-report cognitive difficulties (Grafman, 1994; Komaroff & Buchwald, 1991). Symptoms include impaired memory, attention, concentration, word-finding difficulties, processing speed and mental exhaustion (Shanks, Jason, Evans, & Brown, 2013). Compared to the Control group, the presence of cognitive impairment in the CFS group may make it harder for them to complete day-to-day tasks, problem solve challenges and learn new skills (difficulties associated with reduced Environmental Mastery and Personal Growth).

Without a clear explanation for their symptoms, individuals with CFS have been found to develop maladaptive illness beliefs and avoidant coping strategies, which may also be associated with reduced Environmental Mastery and Personal Growth. Catastrophic interpretations of illness and fear avoidance are common in CFS, and result in patients avoiding new activities and ways of doing things, for the fear that they will exacerbate symptoms (Moss-Morris, Petrie & Weinman, 1996). Several researchers have associated maladaptive illness beliefs with increased helplessness, distress, disability, reduced activity levels (Moss-Morris & Chalder, 2003; Moss-

Morris, 2005) and failures to embrace new directions and interests (Gray &Fosey, 2003). Over time, a restricted range and number of activities and a cognitive perception of oneself as unable to master even the most basic tasks, may gives rise to feelings of personal stagnation and boredom (associated with reduced Personal Growth). Furthermore, excessive rest and sedentary behaviour can lead to physical deconditioning and body sensitivity (Hotopf, Noah & Wessely, 1996); potentially adding to the loss of mastery, self-confidence and growth reported by the CFS group.

A diagnosis of a chronic illness can drastically impact how a person views their life, self and future. Bury (1982) named this impact biographical disruption and it may be particularly relevant to explaining low levels of Self-Acceptance in the CFS group. Adjustment to living with a chronic illness presents an intense psychological challenge, as a person is confronted with the task of incorporating this new limitation into their sense of self and corresponding goals and beliefs. With regard to CFS, biographical disruption could ensue following an abrupt, unwanted transition from an active, lifestyle to one that necessitates rest and a more sedentary existence (Asbring, 2001). Neuroticism and perfectionism may also contribute to the low levels of self-acceptance reported by the CFS group. Cross-sectional evidence suggests that high levels of these personality dimensions exacerbate adjustment problems, because modifying rigid, pre-morbid high standards presents a further challenge (Baricza, et al., 2011; Shanmugasegaram et al., 2014). A negative discrepancy between who one currently is and who one used to be (past self), would like to be (ideal self) or ought to be (ought self) is likely to result in feelings of disappointment and personal dissatisfaction (associated with low levels of Self-Acceptance; Goossens et al., 2010).

The present study is the first study to quantitatively measure Self-Acceptance in CFS. A paucity of qualitative studies using small sample sizes have examined self-perception in CFS. Consistent with the present study, they document a disrupted sense of identity and competence (Gray & Fossey, 2003), a lost sense of self (Edwards, Thompson & Blair, 2007), low levels of self-esteem and a powerful longing for a life lived earlier (Asbring, 2000). The contested, illegitimate status of CFS may also impact on patients' degree of Self-Acceptance, especially if they are left feeling responsible for their illness. Travers and Lawler (2008) found that doubt from others about the reality of CFS and the legitimacy of their impairments shattered patients' perceptions of themselves as experts of their own lives. Individual dialogues of self dissatisfaction and discrepancy captured in interview studies provide powerful support for the reduced levels of Self-Acceptance reported in the present study's CFS group: "I feel like I'm the ugly twin that has nothing to offer….. I think probably the foremost thing would be that I just feel like I'm so different" (Travers & Lawler, 2008; p. 319).

The substantial reduction in previous levels of occupational, educational, social, and personal functioning associated with a diagnosis of CFS, may be responsible for reported impairments in several domains of psychological well-being. In support of this Gray and Fossey (2003) found that CFS participants regarded activity as the key to maintaining well-being, fostering a sense of enjoyment, purpose and control, and utilising their capacities. Engagement in employment and education has been associated with higher levels of well-being in all of Ryff's dimensions, particularly Purpose in Life and Personal Growth (Ryff & Singer, 2008). An unwanted loss of role at home or work can lead to a loss of routine, social status, identity, sense of purpose,

and financial security (Shields & Wheatley, 2005). It can also put a strain on relationships. In support of this, Andersen & Ferrans (1997) found that 100% of participants described CFS as having devastated their social activities and relationships. The physical limitations imposed by CFS may make it harder for individuals to participate in the types of activities necessary to build satisfactory relationships and maintain relational obligations. In sum, reduced functioning may explain the CFS groups' lower scores in the PWB domains of Environmental Mastery, Purpose in Life, Positive Relations with Others, Self-Acceptance and Personal Growth, compared to the general population.

Interpersonal difficulties have been documented in individuals with CFS. Research suggests that CFS patients are highly sensitive to criticism and rejection and tend to experience other people as unavailable, disrespectful and negatively interfering (Taerk & Gnam, 1994; Vandenbergen, Vanheule, Rosseel , Desmet & Verhaeghe, 2009). A small number of studies have retrospectively linked CFS to childhood trauma, victimisation starting in childhood and exposure to adverse parenting (Clark et al., 2011; Fisher & Chalder, 2003; Van Houdenhove, et al 2001). Compared to the general population, higher rates of insecure attachment styles, particularly a fearful attachment style have been found in those with medically unexplained conditions (Noyes et al., 2003; Taylor, Mann, White, & Goldberg, 2000; Wearden, Lamberton, Crook & Walsh, 2005). A fearful attachment style is characterised by a fear of intimacy, low trust of others and low self esteem (Bartholomew & Horowitz, 1991); qualities consistent with Ryff's (1989) definition of low levels of Positive Relations with Others. Importantly, it has been linked to higher levels of self-reported interpersonal problems and lower levels of satisfaction with medical care (Noyes et

al., 2003). Attachment theory presents an interesting framework for understanding interpersonal behaviour in patients with medically unexplained conditions however; most studies so far have been cross-sectional investigations of adults. Longitudinal studies of young children are required to validate results. As previously discussed, individuals with CFS frequently describe experiencing a lack of empathy and understanding from health professionals. Consistent with this, medical practioners report scepticism of the diagnosis and feelings of impatience during consultations with patients (Deale &Wessely, 2001). Negative interactions with health professionals, along with conflicting advice, inappropriate tests and accusations of malingering likely exacerbate feeling of rejection and criticism in CFS patients, contributing to the reduced levels Positive Relations with Others reported in the CFS group.

As previously stated, the CFS group showed significantly smaller (but still substantial) deficits in Purpose in Life and Positive Relations with Others, compared to their levels of Environmental Mastery, Self-Acceptance and Personal Growth. This is a pattern similar to that found in Nierenberg et al.'s (2010) study of PWB in patients with minor depression, except patients with minor depression showed no deficit in Personal Growth. Nierenberg et al.'s (2010) interprets the relative preservation of a sense of purpose coupled with feeling unable to achieve that purpose because of the lack of Environmental Mastery, as a risk factor for developing a ruminative, learned-helplessness style of thinking and persistent sense of failure, associated with depression. Similarly, the far greater deficit in levels of Self-Acceptance in contrast to Positive Relations with Others in CFS, may reflect the finding that individuals with CFS feel shame and guilt over their dependency on friends and family (Anderson &

Ferrans, 1997) and perhaps a corresponding sense of gratitude to those who understand their condition and offer them support (Nierenberg et al., 2010).

According to Ryff's taxonomy, Autonomy refers to one's ability to be independent and self-determining and not look to others for approval. The present study found that that Autonomy was preserved in CFS. This contradicts existing research suggesting that individuals with the condition are unassertive and overly accommodating (Vandenbergen, Vanheule, Rosseel, Desmet &Verhaeghe, 2009). It also disputes the stereotypical portrayal of individuals with CFS as seekers of approval and reassurance. Nevertheless, in the presence of perfectionism, autonomy, independence and social disconnection can represent a defence against underlying attachment needs (e.g. a wish to be accepted, cared for, loved and recognised; Chen, Hewitt, Flett, Cassels, Birch & Blasberg, 2012).

4.2.2 The Relationship Between Well-Being and Symptomatology in CFS

As previously stated, the present study found that levels of pain intensity and physical components of fatigue (namely physical sensations of fatigue and the impact of fatigue on activity levels) were largely independent of well-being dimensions in participants with CFS. Of the eight well-being dimensions examined only one, Environmental Mastery, showed a consistent negative association with physical symptoms. In contrast, psychological components of fatigue (Mental Fatigue and Reduced Motivation) and distress (Anxiety and Depression) were strongly related to several dimensions of wellbeing. An important limitation of the present study is its

cross-sectional design; it does not permit inferences about causality to be made and it is likely that the relationships between well-being and symptomatology are reciprocal. Consistent with other studies of psychological well-being in individuals with chronic conditions, what may be causing low levels of well-being in CFS then is largely psychological factors and the impact of chronic illness more generally, as opposed to fatigue itself.

No studies have examined the relationship between symptoms and psychological well-being in CFS. To help interpret the lack of association found between physical symptoms and well-being in CFS, findings are compared to psychological well-being research conducted in other chronic health conditions, specifically chronic pain and rheumatoid arthritis. On the whole, findings from the present study replicate those reported in chronic pain patients, where several studies have reliably demonstrated that pain intensity is independent of psychological well-being. In women with fibromyalgia, Schleicher et al. (2005) and Hubera, Sumana, Biasib and Carlia, (2008) found that PWB was associated with less disability but not pain per se. Similarly, in patients with rheumatoid arthritis Mangelli, et al. (2002) found that three disease variables (pain, disease activity and limitations in daily activities) were unrelated to PWB dimensions. The only exception was a small negative association between levels of Environmental Mastery and limitations in daily activities. On the basis of such findings, researchers have concluded that pain and arthritic disease only lead to debilitating distress in the presence of other physical and psychological features. Reducing pain or arthritic behaviour rather than physical sensations per se is the recommended treatment target (Schleicher et al., 2005; Hubera et al., 2008).

In contrast to the research on patients with rheumatoid arthritis and fibromyalgia, the present study found a consistent, moderate relationship between Environmental Mastery and disease variables in CFS, with higher levels of Environmental Mastery predicting a small amount of variance in lower levels of physical symptoms (pain, physical fatigue and general fatigue) and a moderate amount of variance in Reduced Activity levels. The emergence of this scale as a predictor is particularly poignant given CFS patients' tendency to report little control over their condition. It is also consistent with Findley et al.'s (1998) findings that greater self- efficacy predicted lower levels of symptoms, disability and distress in CFS, even after controlling for demographic variables. Together with the present study this suggests that treatments that focus on promoting individuals' sense of control and choice, as well as their ability to make may effective use of surrounding opportunities, may be particularly beneficial for this client group.

In the present study Positive Affect was significantly related to all five fatigue subscales at the <0.05 significance level; however only its relationship with General Fatigue and Reduced Motivation reached significance at the <0.01 level. The General Fatigue subscale on the Multi-dimensional Fatigue Inventory, consists of four generalised statements about one's physical state and functioning: "I feel fit", "I feel tired", "I am rested" and "I tire easily". The moderate, negative association found between General Fatigue and Positive Affect supports Wood et al.'s (1992, 1996) previous findings. His interpretation is that both constructs may contribute to a more general affective state, which he describes as "feeling good" (Wood et al., 1992; p. 198). However, it could also indicate that similarly to pain, fatigue is best defined as a

physiological and emotional state. The Broaden-and-Build Theory (Fredrickson, 1998, 2001; Fredrickson & Joiner, 2002) has been successfully tested in a range of observational, experimental and clinical studies. It proposes that in contrast to Negative Affect, which leads to cognitive narrowing, Positive Affect functions to expand the scope of attention, cognition and behavioural choices. Positive Affect may enhance CFS participants' general appraisal of their fitness, by facilitating their ability to access a wider range of ideas and sensory information. Finally, the significant bivariate correlations found between Positive Affect and General Fatigue, Reduced Motivation and psychological distress supports research into chronic pain, where Positive Affect has been extensively researched and there is robust evidence to suggest that it acts as a source of resilience against symptoms (Finan & Garland, 2015).

Mental Fatigue in the present study refers to participants' self-reported cognitive functioning and statements such as "I have difficulties concentrating" and "My thoughts easily wander" represent a high score on this scale. Although CFS patients commonly report symptoms of cognitive dysfunction, objective studies confirming their presence are mixed. This discrepancy could be due to the heterogeneity of presenting symptoms found in different samples. Capuron (2006) investigated the relationship between subjective complaints of mental fatigue in CFS participants and performance on objective neuropsychological tests and findings revealed a strong concordance. A large body of research evidences the negative effects of psychological distress, primarily depression on cognitive functioning (Veiel, 1997). However, the present study is the first to examine the relationship between cognitive functioning and psychological and subjective wellbeing, using Ryff's (1989) scale of

psychological well-being and Diener et al.'s (2010) scale of positive and negative affect. Findings revealed that lower levels of Self Acceptance (meaning one feels dissatisfied with self, is disappointed with what has occurred with past life, is troubled about certain personal qualities, wishes to be different than what he or she is), Environmental Mastery (meaning one has difficulty managing everyday affairs, feels unable to change or improve surrounding context, is unaware of surrounding opportunities, lacks sense of control over external world) and Personal Growth (meaning one has a sense of personal stagnation lacks sense of improvement or expansion over time, feels bored and uninterested with life, feels unable to develop new attitudes or behaviors) predicted higher levels of Mental Fatigue.

The relationship between Mental Fatigue and Self-Acceptance, Personal Growth and Environmental Mastery is most likely bi-directional. As previously discussed, cognitive difficulties such as poor attention and memory may make it hard for individuals with CFS to problem solve challenges and learn new skills, leading to a loss of mastery over everyday affairs and opportunities for personal growth. Mental aptitude is predictive of educational and occupational achievement (Schmidt & Hunter, 2004; Spinath, Spinath, Harlaar, & Plomin, 2006) and is therefore, likely to be imperative to an individuals' sense of self. Prior to getting ill, scientific researchers characterises CFS patients as conscientious, hardworking perfectionists (van Geelen, Sinnema, Hermans, & Kuis, 2007). Consequently, unexplained symptoms of cognitive dysfunction may be especially threatening to their values, sense self and identity. Frequent mistakes and reduced performance at work or socially is likely to result in increased self-criticism and feelings of dissatisfaction and inadequacy (associated with

low Self-Acceptance). Nevertheless, it is also conceivable that constantly doubting, criticising and scrutinising one's self and one's performance is mentally exhausting. In support of this Austin, Mitchell and Goodwin (2001) hypothesises that cognitive impairment in depression is the result of patients selective attention to and catastrophic interpretation of, perceived failures. Given the extra effort required to complete cognitive tasks, CFS patients may withdraw from challenging or novel activities that are necessary for a sense of mastery and growth. Over time this lack of stimulation will likely exacerbate feelings of reduced motivation and apathy. Austin et al.'s (2001) second hypothesis is that reduced motivation is the cause of cognitive impairment in depressed patients. A review of neuropsychological functioning in CFS concludes that symptoms of cognitive impairment can only partly be explained by the presence of depression and anxiety (Michiels & Cluydts, 2001). The present study advances our understanding of cognitive impairment in CFS, as it suggests that it may result from a loss of positive elements, not simply the presence of negative, and infers a specific route for intervention.

In the present study, Reduced Motivation for engaging in activity was negatively related to all aspects of SWB and PWB, with the exception of Autonomy. Well-being variables predicted a large amount of variance in levels of Reduced Motivation, which was uniquely carried by Positive Relations with Others. This confirms previous findings indicating that perceived social support is an important predictor of symptoms, illness burden and health outcomes in CFS (Saltzstein et al., 1998). Furthermore, it emphasises the importance of the quality of patients' interactions, as opposed to simply the quantity of interactions or the breadth of their social network

(Prins et al., 2004). The relationship between Reduced Motivation and Positive Relations with Others is again probably bi-directional. Debilitating symptoms and reduced energy levels make people with CFS less able to engage in activity, which in turn may make them less motivated too. Most activities are socially orientated, as result those with CFS are likely to become isolated from the types of activities necessary to build and maintain satisfactory relationships with other people. On the other hand, difficulties with getting others to recognise and respect that CFS is a legitimate illness may de-motivate patients, making them more ambivalent about engaging in social or therapeutic activities. A systemic approach that focuses on enhancing levels of empathy, understanding and encouragement in the wider network of people surrounding CFS patients, might help motivate them to re-engage with life. In support of this, two recent papers propose that the first step towards change should be addressing negative attitudes in medical students and GPs, so that CFS patients feel validated, listened to and thus, more receptive to recommended management strategies such as pacing and graded exercise therapy (Bayliss et al., 2014; Stenhoff, Sadreddini, Peters, & Wearden, 2013).

As previously stated, psychological distress in CFS showed a large association with well-being factors. This supports findings from previous research, indicating that SWB and PWB have a stronger relationship to psychological health than to physical health (Mangelli et al., 2002). This is not surprising given their closer correspondence. However in terms of correlations, the partial overlap of these constructs confirms that the presence of well-being is not synonymous with the absence of distress (Fava & Sonino, 2000; Heszen-Niejodek, Gottschalk, & Januszek, 1999; Rafanelli et al., 2000;

Ryff & Singer, 2000). The present study found that Depression was strongly associated with Self-Acceptance (r= -0.64), Positive Affect (r= -0.62) and Purpose in Life (r= -0.61); moderately associated with Environmental Mastery (r= -0.59), Personal Growth (r= -0.58) and Negative Affect (r= 0.46) and; weakly associated with Positive Relations with Others (r= -0.36). Positive Affect however, was the only unique predictor of depression. This is the first study to demonstrate that depression and anxiety in CFS are associated not only with the presence of negative constructs such as negative beliefs about emotion (Rimes & Chalder, 2010) and self-critical perfectionism (Luyten et al., 2011) but also the absence of the positive constructs. Importantly, the well-being dimensions identified in the present study offer several new targets for the treatment of distress in CFS. The findings replicate investigations of subjective wellbeing in depressed patients and support researchers' characterisation of depression as the loss of positive affect. Cummin (2010) suggests that when homeostasis fails due to the overwhelming nature of an aversive challenge, people lose contact with positive affect and negative affect prevails. If this condition becomes chronic, then people are thought to have clinical depression. Compared to PWB research in other conditions, depression in CFS showed a much stronger relationship to low levels of PWB. In patients with affective disorders, Rafanelli et al. (2000) found Environmental Mastery (r= - 0.58, $p < .01$) to be the only dimension significantly related to depression; whereas in a sample of participants with moderate to severe depression, Edmondson (2012) found Personal Growth (r= -0.43, $p = .028$) was the only dimension that showed a significant correlation with depression scores. In Nierenberg et al.'s study (2010) of participants with minor depression, correlations between depression symptom severity and the six PWB dimensions were all very low ($r = -0.06$ to -0.29). Lastly, in patients with rheumatoid arthritis, depression showed

a strong relationship to Environmental Mastery (r_s = -0.64, $p < .0001$), but a weak to moderate relationship with the other five dimensions (r_s = -0.26 to -0.48; Mangelli et al., 2002).

In comparison to depression, the present study found that anxiety in CFS was strongly associated with Negative Affect (r= 0.72) and moderately associated with Autonomy (r= -0.54). Like depression, it was also associated with Environmental Mastery (r= -0.51) and Positive Affect (r= -0.40). All other dimensions were unrelated to anxiety, suggesting each disorder has a somewhat distinct relationship to well-being in CFS. Findings go against previous research in mental health disorders, suggesting Anxiety is only significantly related to Environmental Mastery ($r = -0.57$, $p < .01$) in patients with affective disorders (Rafanelli et al., 2000) and unrelated to all psychological well-being dimensions in patients with moderate to severe clinical depression (Edmondson, 2012). In patients with rheumatoid arthritis Mangeli et al. (2002) found anxiety showed a small to moderate association (r_s = -0.23 to -0.57) with all dimensions of psychological well-being. In the present study Anxiety was uniquely predicted by an increase in Negative Affect and a decrease in Autonomy (being able to evaluate oneself according to personal standards and not look to others for approval). Existing research suggests that being in a state of anxiety can make a person more threat focused, indecisive, intolerant of uncertainty, and more likely to seek reassurance and approval from others (Dugas, Buhr, & Ladouceu, 2005; Salkovskis, 1991). One explanation for the present study's findings is that high levels of Negative Affect lead to cognitive narrowing, which in turn makes a person more likely to interpreting stimuli as threatening and dangerous (Fredrickson, 1998, 2001).

In support of this, greater levels of distress have been associated with catastrophic interpretations of illness in CFS (Moss-Morris et al., 1996). A study by Parfitt & Pates (1999) suggests that in the general population, higher levels of self-confidence are associated with lower levels of anxiety. Although this finding is correlational, it seems reasonable to speculate that having conviction in the validity of one's illness and opinions (qualities associated with Ryff & Keyes (1995) definition of Autonomy) could make CFS patients less anxious in response to social threats such as stigma and disbelief from others.

In sum, low levels of PWB and SWB broadly (opposed to specific facets) appear to be a pertinent risk factor for psychological distress and reduced motivation in CFS patients.

4.3 Clinical Implications

A number of the findings from the present study have relevant theoretical and clinical implications. Firstly, findings from the present study highlight that compared to the general population individuals with CFS have lower levels of Hedonic and Eudiamonic well-being. This challenges i) the over emphasis on maladaptive cognitive and personality traits in past research and ii) the premise of current treatments like CBT that focus largely on the removal of negative mental processes. Importantly, it gives a more balanced perspective and offers several new treatment targets that are less pathologising.

The present study found that well-being was largely independent of physical symptoms but a significant predictor of psychological symptoms and distress in CFS. This supports the notion that impairments in well-being domains represent vulnerability factors for mood disorders and adjustment problems (Mangelli et al., 2002; Wood & Joseph, 2010). On this basis, researchers may wish to consider shifting the paradigm of psychological treatments for CFS away from an exclusive focus on symptom reduction, towards the enhancement of strength, happiness and virtue (Seligman & Csikszentmihalyi, 2000). Well-being therapy (WBT) is a short-term psychotherapeutic strategy that offers one possible alternative or adjunct to CBT (Fava & Ruini, 2003). It uses techniques such as self-monitoring of moments and feelings of well-being (opposed to distress) and optimal engagement in pleasant activities, to improving the patients' levels of happiness and psychological well-being across Ryff's (1989) six dimensions. When compared to standard CBT or used as an adjunct, WBT has been found to be more effective at reducing residual symptoms of depression and anxiety and enhancing psychological well-being at post-treatment and follow-up (Fava, 1998a, 1998b; Fava, Rafanelli, Ottolini, Ruini, Cazzaro, & Grandi, 2001). Furthermore, Ruini et al. (2009) found that in addition to enhancing Personal Growth, WBT can reduce somatisation.

Solution focused therapy, in a similar manner to WBT, helps individuals to identify positive exceptions to psychological distress, disability and life problems, by focusing on solution building rather than problem solving. It is a short-term, goal orientated therapy that is based on the philosophy that clients are the experts in their own lives (MacDonald, 2011). Specific techniques include helping the client to create a problem-free vision for their future and identify strengths, resources and existing

skills that will assist them in reaching their goal (MacDonald, 2011). Although solution focused therapy is an under-researched area, there is preliminary evidence to suggest that solution focused therapy is an effective and acceptable intervention for patients with long-term physical health conditions (Carr, Smith & Simm, 2014; Viner, Christie, Taylor, & Hey, 2003). One recent randomised controlled trial (N= 98) of solution focused therapy for patients with fatigued inflammatory bowel disease, indicates that compared to treatment as usual, it has a significant beneficial effect on quality of life and fatigue severity (Vogelaar et al., 2013).

The dominant outcome measures employed by CFS services and clinical trials are questionnaires assessing symptomatology and psychopathology. Moos (1977) argues that despite the many physical, cognitive, and emotional challenges associated with chronic illness, individuals can continue to lead happy, fulfilling and virtuous lives. As a result, recovery from such conditions should not simply be conceived as the resolution of physical and psychiatric symptoms but rather the restoration of well-being. Including the Ryff (1989) Psychological Well-being Scale and Diener et al.'s (2010) Scale of Positive and Negative Emotions as outcome measures could broaden our understanding of the effectiveness of CFS treatments.

Given the profile of psychological well-being found in CFS, clinical services may wish to priorities ways of promoting Environmental Mastery, Personal Growth and Self-Acceptance specifically. The emergence of Environmental Mastery as a unique predictor of physical symptoms and activity levels supports the use of treatments such

as pacing and graded exercise therapy in CFS. The aim of pacing is to help patients adapt to their illness and break boom bust cycles of activity that exacerbate physical symptoms. Organising their day into balanced, sustainable periods of activity and rest, makes symptoms more predictable and optimises activity levels; giving patients improved self-confidence and a greater sense of stability and control over their illness. The PACE trial (White et al., 2011) demonstrated that interventions that encourage an initial stabilisation of activity levels, followed by gradual increases or changes in activity in line with planned treatment goals, are more effective at reducing CFS symptoms than specialist medical care alone. That said, gaining control over uncontrollable symptoms is not always possible and treatments that help CFS patients accept their limitations may be equally important. Research with chronic pain patients suggests that attempts to control uncontrollable pain can intensify feelings of frustration, distress and hypervigilance for symptoms (McCracken, Eccleston & Bell, 2005). Whereas, giving up control strategies and accepting pain has been linked to better adjustment and reduced distress and disability (McCracken, Carson, Eccleston & Keefe, 2004). In qualitative studies, CFS participants frequently cite acceptance of their illness and limitations as a fundamental first step in recovery (Dickson, Knussen & Flowers, 2008). Furthermore, as discussed in Chapter 1, cross-sectional evidence suggests that higher levels of acceptance may protective against the occurrence of psychological distress in CFS (Van-Dammea et al., 2006).

Ryff and Keyes (1995) define Personal Growth as being open to new experiences and having a sense of oneself as fulfilling one's potential and developing over time. The significant deficit in this dimension in the CFS group suggests that because of their

symptoms and low energy levels they may not be in a position to be able to have new experiences that are essential for growth. It could be that individuals with CFS become so focused on their illness that it is hard for them to see past it or compartmentalise it, so that they can connect with other areas of their life. As a treatment strategy for enhancing feelings of Personal Growth and psychological well-being more generally, several researchers recommend goal setting and attainment (Fava & Ruin, 2003; MacLeod, 2010; MacLeod, Coates & Hetherton, 2008; Sheldon, Kasser, Smith & Share, 2002). Top down theorists hypothesise that goal attainment creates positive changes in one's self-concept (as one re-evaluates their capabilities) and life circumstances (as new opportunities or relationships are gained), inducing large shifts in one's growth related judgments (Sheldon et al., 2002). In antithesis, bottom up theorists suggest that progressing towards a goal results in small fulfilling experiences, which over time accrue to influence growth related appraisals (Sheldon et al., 2002). CBT incorporates elements of goal attainment, however, goals tend to be short-term and treatment focused. Research suggests that the greatest gains in well-being and personality integration are attained when individuals pursue goals related to their underlying values and interests (Sheldon & Kasser, 1998; Deci & Ryan, 1991).

Acceptance and Commitment Therapy (ACT) is a third-wave CBT intervention that can be broadly classified as having a well-being focus owing to its concern above and beyond the removal of symptoms. ACT aims to help people accept their difficulties and reconnect with what they truly value, as a way of providing direction and meaning in life (Hayes, 2004). Once armed with the awareness of their most deeply cherished values, people are asked to identify a life domain that is high priority for change and

set realistic short-term and long-term goals. Compared to treatment-based goals, value-based goals are longstanding, meaningful and personal, and if achieved, should bring patients a greater sense of happiness, fulfillment and growth. ACT is an effective intervention for long-term conditions. A systematic review of 14 studies (9 RCTs and 5 controlled studies) suggests that when compared against any comparator (active or wait-list control) ACT for chronic pain demonstrates small positive effects for pain, depression, anxiety, physical well-being and quality of life (Veehof, Oskama, Schreurs, & Bohlmeije, 2011). Together with the present study's findings, this suggests that ACT may also benefit those with CFS.

Having a healthy attitude towards oneself can be conceptualised in several different ways including self-acceptance (Ryff, 1989), self-esteem (Rosenberg, Schooler, Schoenbach & Rosenberg, 1995) and self-compassion (Gilbert, 2000, 2009; Gilbert & Proctet, 2006). The past decade has seen a rapid increase in therapies designed to enhance a positive self-attitude. The practice of mindfulness involves focusing one's attention on the present moment, in an attempt to gain a balanced, non-judgmental, observer-like perspective of one's internal state (Kabat-Zinn, 1994). There is evidence to suggest that regular practice of mindfulness enhances numerous positive psychological processes including happiness, self-acceptance, personal growth, and positive affectivity (Brown & Ryan, 2003). As a result, it could be used to target low levels of these variables found in CFS in the present study. Mindfulness based interventions have shown efficacy in various psychological disorders and medical conditions such as depression, anxiety, chronic pain and cancer (Chiesa, Anselmi & Serretti, 2014). A paucity of studies have investigated mindfulness-based

interventions in CFS: Three exploratory studies (Surawy, Roberts & Silver, 2005), one uncontrolled study (Stubhaug & Kvale, 2010), one controlled study (Sampalli, Berlasso, Fox & Petter, 2009) and one pilot RCT (Rimes & Wingrove, 2013). Despite clear weakness in their design, these studies provide preliminary evidence for the effectiveness of mindfulness at improving fatigue, pain, distress, functioning, quality of life, maladaptive illness beliefs and most importantly self-compassion in individuals with CFS.

Compassion focused therapy may offer a second means of enhancing levels of Self-Acceptance in CFS patients. Compassion Focused Therapy was specifically designed for people with high shame and self-criticism (Gilbert, 2000, 2009). Through the use of strategies such as compassionate imagery and behaviour, it helps individuals to develop an internal compassionate relationship with themselves and appreciate their efforts, as opposed to simply focusing on whether or not they achieve their goals. Compassion Focused Therapy has yet to be tested in CFS. However, as an adjunct to CBT it has proven to be clinically effective at reducing levels of self-criticism in psychosis (Braehler, Gumley, Harper, Wallace, & Gilbert, 2013), eating disorders (Gale, Gilbert, Read, Goss, 2014), personality disorders (Lucre & Corten, 2013), trauma (Beaumont, Galpin & Jenkins, 2012) and brain injury (Ashworth, Gracey & Gilbert, 2011).

4.4 Limitations

There are several limitations to the present study that should be considered when evaluating the findings. Firstly, CFS is a highly heterogeneous condition that is notoriously difficult and controversial to diagnoses. Before diagnosing CFS, a physician is required to exclude other possible causes of fatigue by completing a comprehensive assessment including a physical examination and blood tests. There is dispute over whether a diagnostic waiting period is necessary, with the International Consensus Criteria (Carruthers et al., 2011) recommending no diagnostic waiting period and the Centres for Disease Control (CDC; Fukuda et al., 1994) recommending six months. In the present study 38 participants had a CFS diagnosis confirmed by a clinical service, however 22 participants were recruited from outside of services, through CFS support groups and online advertisements. As a result, it is not possible to conclude whether their symptoms were attributable to an explanatory condition or CFS. All participants were asked to confirm that a physician or General Practioner had given their diagnosis and the Multi-dimensional Fatigue Inventory was used to screen out those who did not meet criteria for severe fatigue. In the present study, participants' self-reported time taken to receive a diagnosis from the onset of symptoms ranged from 1 month to 18 years, which is representative of the diverse array of diagnostic experiences in the CFS population. Correlational analyses indicated that symptom severity was independent of number of years with CFS and time taken to receive a diagnosis. The scope of the present study and the training requirements necessary to diagnose CFS meant that it was not viable to conduct diagnostic interviews. If replicated in the future, the inclusion of a full diagnostic interview, may make findings more generalisable to people suffering from CFS. It is

also worth noting that the majority of participants in the present study were White British and female. Although this is representative of the UK CFS population, findings may not be as generalisable to men or patients from other cultures or ethnicities.

Participants were asked to complete the questionnaires in their own time and return them by post to the researcher. This ensured very fatigued participants were able to complete the questionnaires in a paced manner and respond whenever they could. It also reduced the risk of interviewer bias, meaning participants may have been more likely to respond honestly. However, with self-completion questionnaires and postal returns there are often several limitations too. Typically there is low response rate, as there is no real pressure for participants to complete or return the questionnaire. It can also bias the sample, for example in favour of those who were more functional or more interested in psychological concepts. As a result, findings may not be generalisable to CFS patients who are more severely fatigued, bedbound or who find psychological research into CFS stigmatising. Furthermore, there is no way of verifying whether the right person actually completed the questionnaire or whether they fully understood the questions being asked.

A third consideration is the involvement of CFS participants in different services and treatments. Participants in the present study were recruited from two CFS services based in different counties and offering slightly different treatment packages. Specifically, the London based service offered homeopathic treatments alongside

routine care. Eight participants recruited from support groups or online advertisements also identified themselves as currently receiving treatment from a CFS service. In terms of recruitment, there was no limitation as to participants' stage of treatment and all clients with a diagnosis of CFS were eligible to take part. Twenty-three participants had been assessed by a service and were on the waiting list to start treatment. Another 15 were currently receiving treatment and the number of treatment sessions received ranged from one to twenty (mean = 7.52). Treatment programmes aim to help participants understand their condition and learn strategies to manage physical symptoms (e.g. pacing) and stress. Consequently, they could impact on a person's well-being. Being engaged in a service may enhance a participants' well-being, for the virtue that it offers the prospect of support and improvement in one's condition. Those in treatment could also be biased in their reporting of symptoms and well-being. If they are concerned about being perceived as a 'good patient', meaning someone who has followed his or her treatment plan and done well, then they may report lower symptoms and higher well-being. To protect against this type of reporting bias, participants in the present study returned the completed questionnaires directly to the researcher (not their clinician) and were informed that all data would be anonomyised. MANOVAs were computed to examine the effect of treatment stage (Assessment vs. in treatment vs. not in a service) on symptoms and well-being and results found no significant differences between group on well-being variables and seven out of eight symptom variables (see results section). This supports findings from research in routine clinical practice indicating that 70% of CFS patients still met criteria for excessive fatigue after receiving CBT (Quarmby et al., 2007). The only exception was a positive effect of treatment on activity levels, with participants

currently receiving treatment reporting greater levels of activity than those at the assessment stage or not in a service.

A fourth consideration is that the present study examined the relationship between self-rated measures of well-being and symptoms and did not include objective measures of disease. Self-rated measures of health are known to reflect one's actual physical condition but also one's degree of emotional adjustment (Hooker & Siegler, 1992). A review of activity levels in patients with chronic fatigue and pain found different results depending on whether studies employed subjective or objective measures of activity, indicating a discrepancy between the methods (van Weering, Vollenbroek-Hutten, Kotte & Hermens, 2007). A further study directly compared objective and subjective methods and findings revealed that in patients with lower back pain, self-reported activity levels were relatively inaccurate when compared to objective measurements (Van Weering, Vollenbroek-Hutten & Hermens, 2011). Thirty percent of participants were found to underestimate their activity levels, whilst fourteen percent over-estimated them. One means of controlling for this discrepancy in the present study would be to replicate it with the inclusion of objective and subjective measures. For instance, including a cognitive assessment as an objective measure of symptoms of Mental Fatigue; exercise duration (measuring muscle endurance), as an objective measure of Physical Fatigue; a pedometer, as an objective measure of Activity Levels and lastly, dolorimetry evaluation or palpitation of tender points as an objective measure of Pain symptoms.

A further limitation is that control participants in the present study were obtained from two existing doctoral projects, with different inclusion criteria and information. Controls, were successfully matched to CFS participants on important demographics such as age, gender, ethnicity, employment status and relationship status. Furthermore, Edmondson (2012) and Blackburn (2014) screened control participants for mental health disorders and scores on self-report measures of anxiety and depression confirmed their non-clinical status. Symptoms of fatigue and pain however, were not measured in control participants. Similarly, explainable chronic conditions were not assessed, for example asthma or diabetes. As a result, it is not possible to confirm that control participants in the present study did not have a chronic health condition or levels of fatigue and pain in the clinical range. Further research and replication of the present study's novel results controlling for explainable chronic health conditions and symptoms of CFS in the control sample is required. Another limitation pertaining to the control data is that it was historical (2 – 4 years old) and thus, between group difference could be confounded by socio-economic changes or other extraneous variables. Twelve CFS and eight control participants were also excluded because they could not be matched, potentially introducing selection bias.

Co-morbidity between depression and CFS has previously been discussed. Comparing the profile of well-being in the CFS group to that of depressed participants in Edmondson and MacLeod's (2014) study proved interesting. It potentially highlights important differences between the conditions that could further add to the debate about whether or not they are a single syndrome. The groups however, were not matched on demographic variables or symptoms of anxiety and depression and so

further research is needed to validate the findings. Controlling for symptoms of anxiety and depression could help answer the question of whether well-being deficits in the present study are related to the diagnosis of CFS or merely due to clients having some level of anxiety or depression. Similarly, a chronic illness control group would help identify whether the group differences are a result of CFS or the experience of chronic illness more generally.

Within the context of the present study's correlational design, it is not possible to establish causal conclusions. Relationships between well-being and symptom variables are most likely bi-directional and Schleicher et al., (2005) remind us that it would be presumptuous to think that all disabled individuals should or could maintain a positive attitude in the face of severe disability. Findings need replication in a longitudinal study. Nevertheless, they do suggest that maintaining well-being could potentially influence the disease course of CFS and protect against the risk of mood disorders (Fischler et al., 1997; Komaroff & Buchwald, 1991).

A final limitation of the present study is that it conducted multiple comparisons, increasing the risk of Type 1 error (findings of false "significance"). To protect against this, a more stringent statistical significance criterion was adopted throughout the analyses ($p < .01$). A classic criticism of p-value adjustments is that they are too conservative, meaning that they raise the risk of type II errors (false negatives; Feise, 2002). If you lower the alpha level and maintain the beta level then a study loses power. With alpha set to 0.01 and power set to 0.8, the present study remained

adequately powered to detect large effect sizes. However, if replicated with a larger sample size, allowing small and medium effect sizes to be detected, some of the non-significant correlational findings may be significant. Alternative strategies to p-value adjustments when conducting multiple comparisons, include selecting a primary outcome measure or creating a composite score consisting of a combination of variables. As previously stated CFS is a highly heterogeneous condition with multiple manifestations. No presentation dominates and different people are impacted in different ways. Consequently, there is no obvious way to select a primary symptom. Furthermore, authors of the Multi-dimensional Fatigue Inventory (Smets, et al., 1995) and the Ryff Psychological Well-being Scale (Ryff, 1989) advise against summarising the subscales to create a composite score.

4.5 Future Research

A number of research suggestions were made when discussing the limitations such as replicating the study using a full diagnostic assessment, objective symptom measures, a larger sample size and a depression comparison group. Research comparing the profile of well-being in CFS to matched groups of participants with fibromyalgia and IBS would add to the debate about whether or not there are important differences in the experience and psychological impact of living with these conditions. However, longitudinal research is required to establish whether lower levels of subjective and psychological well-being are the cause or consequence of CFS.

This is the first study to examine well-being in CFS and consider its relationship to disease variables and psychological distress. The results identify several new

treatment targets. Services would initially benefit from research investigating how effective current treatments (CBT, pacing, graded exercise therapy) are at enhancing well-being in CFS, by assessing participants' well-being before and after treatment. Then studies examining the efficacy of suggested alternative treatments that have more positive content (Well-being Therapy, Solution Focused Therapy, Acceptance and Commitment Therapy, Mindfulness and Compassion Focused Therapy) should be a major research priority. Used alone or in conjunction with CBT it may be that they are not only more effective at enhancing well-being but also at reducing symptoms.

4.6 Conclusion

The present study aimed to explore subjective and psychological well-being in adults with Chronic Fatigue Syndrome. It was hypothesised that well-being would be significantly related to symptomatology in CFS and that individuals with CFS would report significantly lower psychological well-being across Ryff's six dimensions than a group of matched, non-clinical controls. As this was the first study to conduct a theoretically driven, multi-dimensional investigating of well-being in CFS and its relationship to symptoms, there were no grounds for making strong predictions. Correlational analyses revealed that in CFS, well-being dimensions were largely independent of physical symptoms (Pain intensity, Physical Fatigue, Reduced Activity and General Fatigue) but strongly related to psychological components of fatigue (Mental Fatigue and Reduced Motivation) and psychological distress (Depression and Anxiety). The exceptions were Environmental Mastery, which showed a consistent, moderate association with low levels of all physical symptoms and Positive Affect,

which was related to low levels of General Fatigue. Participants' scores on well-being dimensions were also found to predict their scores on symptom measures. Five well-being dimensions were identified as unique predictors of symptomatology. Regression models containing SWB and PWB dimensions explained a particularly large amount of variance in psychological distress. Hypothesis 1 in the present study was therefore partially supported. In line with previous investigations of well-being in chronic health conditions, findings suggest that what may be causing low levels of well-being in CFS is largely psychological factors and the general impact of living with a chronic illness. Future research comparing levels of well-being in CFS participants to that of participants with explainable medical conditions is required to investigate the possible effects of CFS's contested status.

Results also showed that the CFS group had lower psychological well-being than the Control group on five of Ryff 's six dimensions (Environmental Mastery, Positive Relations with Others, Personal Growth, Purpose in Life, and Self-Acceptance). No significant difference was found between the CFS and Control groups on the Autonomy subscale. Therefore, hypothesis 2 was partially supported. The greatest differences observed between the CFS and Control group means were in Personal Growth, Environmental Mastery and Self-Acceptance. This is a unique pattern of deficits to that documented in individuals with depression and fibromyalgia, suggesting that there maybe fundamental differences in the experience and impact of living with these conditions.

Despite the present study's limitations and the need for further research, findings give further support for the theory that psychological wellness is more than the absence of distress and physical illness. What is more, findings advance our understanding of CFS, challenge the over emphasis on maladaptive cognitive and personality traits in past research and offer several new treatment targets. Future research must continue to investigate whether interventions targeting well-being enhancement, can boost the efficacy of symptom-focused treatments, which currently produce unsatisfactory recovery rates in CFS.

5.0 References

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6.0 Appendices

Appendix I: NHS Ethics Approval Letter

Appendix II: NHS Ethics Amendment Approval Letter

Appendix III: LPFT Letter of Access for Research

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Appendix V: Participant Information Sheet

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Appendix VII: Participant Questionnaire containing the Demographic Information Sheet, the Scale of Positive and Negative Emotion (SPANE; Diener et al., 2010), the Pain Visual Analog Scale (VAS; McCormack et al., 1988), The Multi-dimensional Fatigue Inventory (MFI-20; Smets et al., 1995), The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) and the Ryff Psychological Well-being Scale 54 item version (Ryff, 1989).

Appendix VIII: Pearson correlations between symptoms and demographic variables for the CFS Sample (N= 60)

Appendix IX: Means and standard deviations on the self-report scales of symptoms for CFS participants who were in a relationship versus those who were not in a relationship, and the significance of difference between the groups.

Appendix X: Means and standard deviations on the self-report scales of symptoms for CFS participants who were unemployed versus those who were not unemployed, and the significance of difference between the groups.

Appendix XI: Non-significant ANOVAs examining the effect of treatment stage (assessment vs. in treatment vs. not in a service) on symptoms

Appendix I: NHS Ethics Approval Letter

EoSRES

NHS SCOTLAND
Research Ethics Service

East of Scotland Research Ethics Service (EoSRES) REC 1
Tayside Medical Sciences Centre (TASC)
Residency Block C, Level 3
Ninewells Hospital & Medical School
George Pirie Way
Dundee DD1 9SY

Miss Hannah Jackson
Trainee Clinical Psychologist
Camden & Islington NHS Foundation Trust
Royal Holloway University, Department of Clinical Psychology
Egham Hill
Egham
TW20 0EX

Date: 18 April 2014
Your Ref:
Our Ref: LR/**14/ES/0053**
Enquiries to: Mrs Lorraine Reilly
Direct Line: 01382 383878
Email: eosres.tayside@nhs.net

Dear Miss Jackson

Study title:	**Psychological Well-Being in Individuals With Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis**
REC reference:	**14/ES/0053**
Protocol number:	**NCT02094820**
IRAS project ID:	**146565**

Thank you for your email of 16 April 2014, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Lorraine Reilly, lorraine.reilly@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

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Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Evidence of insurance or indemnity		02 September 201

Investigator CV – Hannah Jackson		
Investigator CV – Any MacLeod		
Other: Hannah Jackson - Approval		14 March 2014
Other: email covering letter		16 April 2014
Participant Consent Form	1	31 March 2014
Participant Information Sheet	2	16 April 2014
Protocol	1	31 March 2014
Questionnaire: Demographics Questionnaire	1	31 March 2014
Questionnaire: Meaning of Life Questionnaire		
Questionnaire: Multimensional fatigue Inventory		
Questionnaire: Psychological Well-Being Scale		
Questionnaire: Scale of Positive and negative Experience		
REC application	146565/590635/1/460	03 April 2014
Response to Request for Further Information		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

14/ES/0053: ***Please quote this number on all correspondence***

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

Yours sincerely

pp
Mrs Sandra Forbes
Vice-chair

eosres.tayside@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Gary Brown, Royal Holloway, University of London
Gerry Leonard, Barts Health NHS Trust

Appendix II: NHS Ethics Amendment Approval Letter

EoSRES

NHS SCOTLAND
Research Ethics Service

East of Scotland Research Ethics Service (EoSRES) REC 1
Tayside Medical Sciences Centre (TASC)
Residency Block C, Level 3
Ninewells Hospital & Medical School
George Pirie Way
Dundee DD1 9SY

Miss Hannah Jackson
Trainee Clinical Psychologist
Camden & Islington NHS Foundation Trust
Royal Holloway University, Department of Clinical Psychology
Egham Hill
Egham
TW20 0EX

Date: 15 August 2014
Your Ref:
Our Ref: LR/**14/ES/0053**
Enquiries to: Mrs Lorraine Reilly
Direct Line: 01382 383878
Email: eosres.tayside@nhs.net

Dear Miss Jackson

Study title:	**Psychological Well-Being in Individuals With Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis**
REC reference:	**14/ES/0053**
Protocol number:	**NCT02094820**
Amendment number:	**AM01 (for REC reference only)**
Amendment date:	**24 July 2014**
IRAS project ID:	**146565**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The Committee commented on method for recruiting NHS patients currently receiving treatment by the clinician. They asked that the researcher ensure that the participants did not feel they had to take part in the study as the clinician had given them the questionnaire pack.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP)	AM01	24 July 2014
Other [Cover email]		27 July 2014
Participant consent form	2	18 July 2014
Participant information sheet (PIS) [People for treatment]	3	04 July 2014

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Participant information sheet (PIS) [Support Groups]	4	18 July 2014
Research protocol or project proposal	2	16 April 2014

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

14/ES/0053: Please quote this number on all correspondence

Yours sincerely

pp
Dr Carol Macmillan
Chair

E-mail: eosres.tayside@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Gerry Leonard, Barts Health NHS Trust
Gary Brown, Royal Holloway, University of London

East of Scotland Research Ethics Service REC 1

Attendance at Sub-Committee of the REC meeting on 11 August 2014

Committee Members:

Name	Profession	Present	Notes
Dr Carol Macmillan	Consultant Anaesthetist	Yes	Chair
Dr Gary Lyon	Retired	Yes	

Also in attendance:

Name	Position (or reason for attending)
Mrs Lorraine Reilly	Senior Co-ordinator

Written comments received from:

Name	Position
Dr Carol Macmillan	Consultant Anaesthetist, Chair
Dr Gary Lyon	Retired

Appendix III: LPFT Letter of Access for Research

Lincolnshire Partnership NHS
NHS Foundation Trust

Ref
Date: 25 April 2014

Research Innovation and Effectiveness Team
Trust Headquarters Unit 9
The Point, Lions Way
SLEAFORD
Lincolnshire
, NG34 8GG

Miss Hannah Jackson
Royal Holloway University of London
Department of Clinical Psychology
Egham Hill
EGHAM
Surrey
TW20 0EX

Tel: 01529 222206
Fax: 01529 222226
Email: Research@lpt.nhs.uk

Dear Miss Jackson

Letter of access for research – Psychological well-being in individuals with chronic fatigue syndrome

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this NHS organisation that the necessary pre-engagement check are in place in accordance with the role you plan to carry out in this organisation. This letter confirms your right of access to conduct research through **Lincolnshire Partnership NHS Foundation Trust (LPFT)** for the purpose and on the terms and conditions set out below. This right of access commences on **25 April 2014** and ends on **2 March 2015** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to **Lincolnshire Partnership NHS Foundation Trust** premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through **Lincolnshire Partnership NHS Foundation Trust**, you will remain accountable to your employer **University College London Hospitals NHS Foundation Trust** but you are required to follow the reasonable instructions of your nominated manager **Dianne Tetley Assistant Director of Research and Effectiveness** in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with **Lincolnshire Partnership NHS Foundation Trust** policies and procedures, which are available to you upon request, and the Research Governance Framework.

[redacted] POSITIVE ABOUT DISABLED PEOPLE INVESTOR IN PEOPLE

Chairman: Eileen Ziemer
Chief Executive: Chris Slavin

You are required to co-operate with **Lincolnshire Partnership NHS Foundation Trust** in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on **Lincolnshire Partnership NHS Foundation Trust** premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Lincolnshire Partnership NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. **Please contact R&D office before visiting Trust premises to agree arrangements for the issue of ID Badge**. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Where applicable, your substantive employer will initiate your Independent Safeguarding Authority (ISA) registration in-line with the phasing strategy adopted within the NHS (as from 26th July 2010 at the earliest). Once you are ISA-registered, your employer will continue to monitor your ISA registration status via the on-line ISA service. Should you cease to be ISA-registered, this letter of access is immediately terminated. Your substantive employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or ISA registration, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

Dianne Tetley

Dianne Tetley
Assistant Director Research Innovation & Effectiveness
On behalf of HR Department
Lincolnshire Partnership NHS Foundation Trust

cc: HR department of the substantive employer - Ian Sawyer, HR Office Manager Ian.Sawyer@candi.nhs.uk

[redacted]

POSITIVE ABOUT DISABLED PEOPLE

INVESTOR IN PEOPLE

Chairman: Eileen Ziemer
Chief Executive: Chris Slavin

Appendix IV: UCLH Honorary Contract for Research

University College London Hospitals NHS
NHS Foundation Trust

TERMS OF PLACEMENT AS HONORARY APPOINTEE

Hannah Jackson
65 Richbone Terrace
London
SW8 1AT

Placement Title: Honorary Researcher - RLHIM

Place of Work or Main Base: UCLH (University College London Hospitals NHS Foundation Trust)

Starting Date of Honorary Appointment: 04-Jul-2014

Honorary Appointment expires: 03-Jul-2014

Responsible to: John Hughes

FURTHER CONDITIONS

1. This honorary appointment will enable you to undertake your role Honorary visiting, UCL Hospitals NHS Foundation Trust.

2. Your honorary attachment to the Trust does not constitute employment and you will not be entitled to any form of payment on its cessation. For the avoidance of doubt, this appointment does not constitute an employment relationship.

3. RESEARCH GOVERNANCE
University College London Hospitals NHS Trust manages all research in accordance with the requirements of the Research Governance Framework. All research active appointees must familiarise themselves with the UCL Hospitals NHS Trust policies for research governance and be aware of the obligations this places on them. You must comply with all reporting requirements, systems and duties of action put in place by the Trust to deliver research governance. You are reminded that any breach in research governance policy will result in appropriate action. This may include discontinuation of your honorary appointment and cessation of your involvement with all research at UCL Hospitals NHS Trust.

4. PROFESSIONAL REGISTRATION

Dependent upon the nature of your role, you may be required to be registered with a relevant professional body eg GMC, NMC, CPSM.

A copy of confirmation of your professional registration should be attached and returned with this document.

A copy of your registration renewal document must also be provided to the Trust.

1 of 6

Failure to be registered with the appropriate professional body, and to maintain professional registration, may result in your honorary appointment being terminated.

5. PRE-APPOINTMENT HEALTH SCREENING

This honorary appointment is conditional upon confirmation of your medical fitness to undertake the full duties of the honorary appointment.

6. CRIMINAL RECORDS/CONVICTIONS

This honorary appointment is exempt from the Rehabilitation of Offenders Act 1974. It is therefore essential that you disclose conviction(s), that would otherwise be "spent" under the provisions of the Act, and that you have notified the Trust if you are "bound over", have received a police caution, warning or reprimand or if you have been charged with a criminal offence that is not yet disposed of.

In cases where the role of the honorary appointment is defined as a "regulated position" under the terms of the Protection of Children Act 1999 (as amended by the Criminal Justice and Court Services Act 2000), checks will be carried out by the Criminal Records Bureau in accordance with the Protection of Children Act 1999. It is an offence for someone who is legally barred from working with children to knowingly apply for, offer to do, accept or do such work. Appointees will be notified if their appointment is designated as a "regulated position" and therefore subject to the above checks.

If you are convicted of a criminal offence whilst an appointee of the Trust, you must inform your manager of the nature of the conviction even if it does not relate to your work. Dependent upon the nature of the conviction and details of the sentence, the continuation of your honorary appointment may not be put at risk. However, the Trust reserves the right to terminate your appointment in relation to any such conviction or sentence.

7. CONFIDENTIALITY

During the course of your honorary appointment, you will have access to information of a confidential nature including (but not exclusively) patient and staff information. This information must be treated as strictly confidential at all times.

All appointees must familiarise themselves with the UCL Hospitals NHS Trust Information Governance Policy and be aware of the obligations it places on them. A breach of confidentiality will result in appropriate action, which may include discontinuation of your honorary appointment, being taken.

8. VALUING DIVERSITY

UCL Hospitals NHS Trust undertakes to provide equality of opportunity in its twin role as employer and provider of health services.

All appointees have a personal responsibility towards the public and their colleagues for the implementation of the Equal Opportunities Policy within their duties.

Appointees should familiarise themselves with the Equal Opportunities Policy and be aware of the obligation it places on them and the individual rights extended to them.

9. HEALTH, SAFETY, FIRE & SECURITY

9.1 Occupational Health

Occupational Health aims to make sure that appointees are fit for their work and are not becoming ill because of work. This means promoting the physical and mental health, safety and welfare of all working in the Trust, both by seeing individuals with problems and by advising management on measures to safeguard staff.

9.2 No Smoking Policy

The Trust has a policy of restricting smoking to designated areas as part of it's responsibility for the promotion of health. Smoking is not permitted in public areas and there may be a local agreement prohibiting or restricting it in the place where you work.

9.3 Safety at Work

It is the policy of the Trust to give the greatest importance to the health and safety of appointees, considering this is a management responsibility equal to that of any other managerial task.

Appointees are responsible for following all health, safety and hygiene regulations, as laid down locally from time to time and are required to play their full part in ensuring the safety of others.

In the event of an accident occurring to an appointee in the course of their work, the facts should be immediately reported to your supervisor who will decide on the arrangements for any necessary medical treatment. In the event of an accident, an accident report form must be completed by the injured party and any witnesses and be signed by the supervisor.

It should be noted that Trusts and individuals are not exempt from statutory enforcement procedures and will be subject to prosecution for failure to discharge their duties under the Health & Safety Act 1974. Should appointees not comply with health, safety and hygiene regulations, appropriate action will be taken.

9.4 Ionising Radiation (Medical Exposure) Regulations 2000

Under the above Regulations, the Trust is obliged to maintain a register of all persons entitled to act as Practitioners or Operators (ie to justify or to carry out a medical exposure) and to keep records of their training.

If your post includes the responsibilities of either Practitioner or Operator as defined by these regulations, you must provide the Trust with evidence of training. This should include evidence of completion of an approved training course plus details of practical experience.

Please note that if, during the course of your duties, you refer a person for a medical exposure you are obliged to provide sufficient relevant clinical information to the Practitioner who justifies the use of ionising radiation. You are expected to follow any guidelines for such referrals that the Trust provides.

9.5 Investigation of Untoward Incidents

All appointees are expected to assist management fully in the investigation of incidents by supplying written statements and, where appropriate, acting as a witness.

9.6 Fire Precautions

It is your responsibility to make sure that you are aware of the procedure to be followed on discovering a fire or hearing a fire alarm. Appointees should attend at least one period of fire training each year.

9.7 Personal Indemnity

The Trust has Public Liability Insurance which will cover you while you are on Trust premises, on Trust business or working for the benefit of the Trust against accidental injury.

Additionally, the Trust will provide coverage for negligent acts or omissions by you which occur whilst on Trust premises and whilst you are acting in your professional capacity in the course of your honorary appointment with NHS patients of the Trust. This coverage will not apply where your acts are recklessly negligent or criminal, occur outside the course and scope of your honorary position with the Trust or result from contact with non-Trust patients or employees. For this coverage to apply, you must notify the Trust of an incident or occurrence which has resulted in an injury or possible injury to a patient within 48 hours of the incident or occurrence or the date of knowledge or discovery of the incident or occurrence. This coverage does not extend to work which does not fall within the scope of the NHS indemnity for clinical negligence. It does not cover non-NHS and private practice work, for which the Trust would encourage you to ensure that you have adequate and appropriate defence cover to cover you for such work.

9.8 Security

The security of property belonging to the Trust, appointees and the public at large is a matter which must be the concern of every member of staff. In this respect, appointees are required to assist management in maintaining and improving security.

9.9 Identification Badges

If you are issued with an identity badge, it should be worn visibly all the time you are on duty or on site. If you are issued with an identity badge, it must be returned should you leave the Trust. If you lose the badge at any time, this must be reported to your manager.

9.10 Property and Claims for Compensation

You must comply with local regulations with regard to patients' cash/property. You are also asked to ensure that all property of the Trust in your charge is correctly used. Furthermore, it is your duty to report any loss or accidents which may give rise to a claim for compensation to your manager. In addition, you should also report any suspect fraud or theft.

9.11 Property Disclaimer

The Trust cannot accept responsibility for money/property lost or damaged on Health Service premises and strongly recommends appointees to consider taking out insurance policies to cover themselves against such a loss. Whilst lockers may be provided, these are intended for the convenience of appointees and no responsibility can be accepted for money, jewellery or similar valuables stolen from these lockers. Appointees providing their own tools or equipment belonging to them should take out their own insurance policies against theft or fire.

10. INTELLECTUAL PROPERTY (IP)

10.1 Intellectual Property (IP) may be generated during the course of your honorary appointment that may have value in the delivery of better patient care.

10.2 IP can be in the form of inventions, discoveries, surgical techniques or methods, developments, processes, schemes, formulae, specifications, or any other improvements which may give rise to

certain rights such as patents, trade marks, service marks, design rights, copyright, know-how, trade or business names and other similar rights (all of the foregoing rights being referred to as "Intellectual Property Rights" or "IPR")

10.3 Potential IPR means any works, information or other elements from which IPR may derive.

10.4 You and the Trust confirm it is foreseeable that IPR may arise in the course of or in connection with your honorary appointment to the Trust.

10.5 Cases involving IPR and/or Potential IPR will be managed in accordance with the Trust's management procedures for intellectual property (IP). These procedures have been approved by the Trust Board and are available on request from the Research & Development Directorate and are consistent with the Management Framework for IP of the Department of Health.

10.6 IPR and/or Potential IPR created during the course of your honorary appointment will generally belong to the substantive employer or the Trust, unless agreed otherwise in writing.

10.7 Where you consider that IPR and/or Potential IPR has been created, you shall promptly notify the Research & Development Directorate providing full details.

11. TERMINATION OF HONORARY PLACEMENT

If your honorary appointment with the Trust arises as a result of your employment by another body (being either an NHS Trust or an academic establishment) should your employment terminate with that NHS Trust or academic establishment, your honorary appointment will terminate immediately. You are required to inform the Trust should such employment be terminated.

If you have any queries regarding the terms of your honorary placement, please contact your manager or Recruitment Services Manager.

Please sign both copies of the Terms of Placement as Honorary Appointee and return one signed copy to the relevant Recruitment Services Department (see below), keeping the remaining copy for yourself.

Signed: ..... **Date:** 3/7/14

Print Name: Sylvia Noor

Job Title: Honorary Contract Issuer
Honorary Contracts Department

I ACKNOWLEDGE RECEIPT OF MY TERMS OF HONORARY PLACEMENT AND ACCEPT THE TERMS AND CONDITIONS SET OUT THEREIN.

Signed: ..... **Date:** .....

Print Name: .....

PLEASE RETURN ONE SIGNED COPY TO:-

HONORARY CONTRACTS DEPARTMENT
UCL HOSPITALS NHS FOUNDATION TRUST
2nd FLOOR WEST
250 EUSTON ROAD

Appendix V: Participant Information Sheet

Participant Information Sheet

Study title: Well-Being in Individuals Diagnosed with Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ ME).

You are being invited to take part in a research study. Before you decide to take part, it is important for you to understand why the research is being done and what it would involve. Talk to others about the study if you wish and please ask me, the researcher, if there is anything that is not clear or if you would like more information. You can contact me by emailing hannah.jackson.2012@live.rhul.ac.uk or by leaving a message on the following answer phone number 01784 414012 (Please quote "Hannah 2012" and clearly leave your name and contact details). Take time to decide whether or not you wish to take part.

What is the purpose of the study?
This study is interested in finding out about a variety of aspects of quality of life, specifically psychological well-being, in people experiencing Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ ME). At present we do not have a detailed profile of which aspects of well-being and quality of life are affected and which are unaffected by the experience of CFS/ ME. Building such a profile could help us better understand the experiences of people with CFS/ ME and develop more effective interventions.

Why have I been chosen?
You have been invited to take part in this study because you are currently being seen by a Chronic Fatigue Syndrome Service and are believed to be experiencing the condition. The study is hoping to recruit at least 60 participants to take part.

Do I have to take part?
No, it is up to you to decide whether or not you would like to take part in this study. If you do take part you are still free to withdraw at any time, without giving a reason. A decision to withdraw or a decision not to take part, will not affect the standard of care you receive.

What will I have to do if I take part?
If you decide to take part, please sign the consent form, complete the questionnaires and return them both to the researcher, using the prepaid self-addressed envelope provided. In total, the questionnaire pack should take approximately 30 minutes to complete. The questionnaires are made up of multiple choice questions and you will be required to tick boxes to choose your response. The questionnaires will ask about your well-being, physical symptoms related to CFS/ ME (e.g. fatigue, pain) and your experience of a range of emotions (positive and negative). You will be asked to return the questionnaires at the earliest convenience to the researcher via post, using the

prepaid, self-addressed envelope provided. If you wish, you can also return the questionnaires to the CFS team at your next therapy session.

What are the possible disadvantages and risks in taking part?
There are no foreseen risks or disadvantages of taking part in this study. However, if you feel distressed at any time, then you are free to withdraw without giving a reason. If you feel you need to talk to someone, please contact your GP or, if more urgent, go to the nearest Accident and Emergency Department. The Samaritans are available 24 hours a day, 7 days a week. Telephone: 08457 909090 email: jo@samaritans.org

What are the possible benefits of taking part?
This study was not designed to offer any direct benefits to those taking part. However, participating in this study will hopefully enable us to gain a better understanding of the psychological well-being of individuals with CFS. This information will hopefully inform interventions for CFS/ ME that enhance individuals' quality of life.

What if there is a problem?
It is unlikely that there will be any problems, but if you are unhappy with any aspect of the study, then you should speak to the researcher, Hannah Jackson, who will do her best to answer any questions. Hannah can be contacted by emailing hannah.jackson.2012@live.rhul.ac.uk or leaving a message on the following answer phone number 01784 414012 (Please quote "Hannah 2012" and clearly leave your name and contact details). You are free to withdraw from the study at any time and you also have the right to make a formal complaint about the way you have been dealt with, throughout the course of the study.

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, then you can also contact your local Patient Advice and Liaison Service (PALS).
Lincolnshire Partnership Foundation Trust on 01529 222265 or by email: PALS@lpft.nhs.uk
Royal London Hospital for Integrated Medicine on 020 3447 3042 or by email: PALS@uclh.nhs.uk.

Will my taking part in the study be kept confidential?
Yes. All information collected will be strictly confidential. The only exception to this is if you tell the researcher something that could put yourself or someone else at risk, then they will be obliged to pass this information on to a clinician at your CFS service. A unique identifier code will be allocated to you and you name will not be put on any of the questionnaires or data collected about you. Furthermore, all completed questionnaires will be stored securely in a locked cupboard, and will only be accessible to people who are involved in the study. The data will be kept for five years and then destroyed.

What will happen if I don't want to carry on with the study?
You are free to withdraw at any time and without giving a reason. This will not affect your treatment in any way. If you choose to withdraw, then you may consent to the

data that has already been collected from you to be used within the study. Alternatively, you can request for all the data to be destroyed.

What will happen to the results of the research study?
The results of the study will form part of a dissertation for a Doctorate in Clinical Psychology from Royal Holloway, University of London. The results may also be published in a scientific journal. You will not be identifiable in any of these reports. Findings will be presented as group averages and there will be no information to identify participants. If you would like to be notified of the results please indicate this on the consent form and then the researcher is happy to send a summary of them to you.

Who has reviewed this study?
This research has been looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, well-being and dignity. This study has been reviewed and given favourable opinion by Royal Holloway, University of London Research Ethics Committee. The East of Scotland Research Ethics Committee REC 1, which has responsibility for scrutinising all proposals for medical research on humans in Tayside, has also examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant records, be made available for scrutiny by monitors from Royal Holloway, University of London and participating NHS Trusts, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

The researcher will be supervised by Professor Andrew MacLeod, Director of Clinical Psychology training at Royal Holloway University of London.

Thank you for taking the time to read this information sheet.

Appendix VI: Participant Consent Form

Project ID: 146565

Centre Number:

Patient Identification Number:

CONSENT FORM

Title of Project: **Well-Being in Individuals Diagnosed with Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ ME).**

Name of Researcher: **Hannah Jackson**

Please initial or tick all boxes

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had them answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I agree to take part in the above study ☐

4. I would like to receive a summary of the results (Please provide contact details below) ☐

If you would like to receive a summary of the results please write your email address or postal address below:

Email: _____

Postal Address: _____

Please Sign Below:

_____ _____ _____

Name of Participant Date Signature

Appendix VII: Participant Questionnaires

Centre Number:
Participant Number:

Psychological Well-being in Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ ME)

THE QUESTIONNAIRE

This study is interested in finding out about a variety of aspects of quality of life, specifically psychological well-being, in people experiencing Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ ME). At present we do not have a detailed profile of which aspects of well-being and quality of life are affected and which are unaffected by the experience of CFS/ ME. Building such a profile could help us better understand the experiences of people with CFS/ ME and develop more effective interventions.

Please complete all of the questionnaires enclosed. Pages are double sided. Try to answer every item, even if you are unsure and be careful not to skip any. Please remember that there are no right or wrong answers.

Thank you for taking part in this study.

Please return using the freepost envelope provided (no stamp needed)

PLEASE WRITE YOUR NAME BELOW:

First name _____ Surname _____

DATE OF COMPLETION | | | | | | |

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Demographics Questionnaire

1. Age (to the nearest month): _____ years _____ months

2. Gender *(Please tick)*: Male or Female

3. Ethnicity *(Please tick)*:

White British	Indian
White Other	Pakistani
Black African	Bangladeshi
Black British	Other Asian
Black Caribbean	Chinese
Black Other	Other (please state)_____.

4. Marital Status *(Please tick)*:

Single
Married/ Living with partner
In a Relationship
Divorced/ separated
Widowed

3. Employment *(Please tick)*:

Unemployed
Student
Employed full-time
Employed part-time
Retired

4. How many hours a week do you work? _____ hours

5. Highest Level of Educational Attainment: *(Please tick)*

No qualifications
GCSE/ O'levels
A' levels
Vocational training/ college
University/ professional qualification

6. Do you have a diagnosis of Chronic Fatigue Syndrome or Myalgic Encephalomyelitis (CFS/ ME)? Yes/ No

7. How long have you had CFS/ ME? _____ years _____ months

8. From the onset of symptoms, how long did it take for you to be diagnosed with CFS/ ME? _____ years _____ months

9. Have you received treatment for CFS/ ME before? Yes/ No

10. Since being referred to your current CFS service, how many sessions of treatment (individual or group) have you received?

11. Do you have a diagnosis of Fibromyalgia? Yes/ No

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Scale of Positive and Negative Experience (SPANE)

Please think about what you have been doing and experiencing during the past **four weeks**. Then report how much you experienced each of the following feelings, using the scale below. For each item, **select a number** from **1 to 5**, and indicate that number on your response sheet.

	1. Very rarely or Never	**2**. Rarely	**3.** Sometimes	**4.** Often	**5.** Very often or Always
Positive					
Negative					
Good					
Bad					
Pleasant					
Unpleasant					
Happy					
Sad					
Afraid					
Joyful					
Angry					
Contented					

Pain Visual Analog Scale (VAS)

Directions: Indicate on the line how severe your physical pain is in relation to the two extremes**.**

No Pain — Pain as bad as it could possibly be

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Multidimensional fatigue inventory (MFI-20)

We would like to get an idea of how you have been feeling recently. For example, the statement:

"I FEEL RELAXED"

If you think that this is entirely true, that you have been feeling relaxed lately, please place an X in the extreme left box like this:

X				

yes, that is true no that is not true

The more you disagree with the statement, the more you can place an X in the direction of "no, that is not true". Please, do not miss out a statement and place one X next to each statement.

1. I feel fit

yes, that is true no that is not true

2. Physically I feel only able to do a little

yes, that is true no that is not true

3. I feel very active

yes, that is true no that is not true

4. I feel like doing all sorts of nice things

yes, that is true no that is not tru

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5. I feel tired

yes, that is true no that is not true

6. I think I do a lot in a day

yes, that is true no that is not true

7. When I am doing something, I can keep my thoughts on it

yes, that is true no that is not true

8. Physically I can take on a lot

yes, that is true no that is not true

9. I dread having to do things

yes, that is true no that is not true

10. I think I do very little in a day

yes, that is true no that is not true

11. I can concentrate well

yes, that is true no that is not true

12. I am rested

yes, that is true no that is not true

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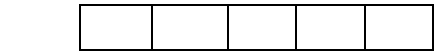
13. It takes a lot of effort to concentrate on things



yes, that is true no that is not true

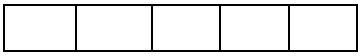
14. Physically I feel I am in a bad condition

yes, that is true no that is not true

15. I have a lot of plans

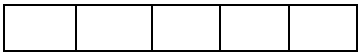
yes, that is true no that is not true

16. I tire easily



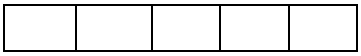
yes, that is true no that is not true

17. I get little done



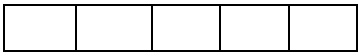
yes, that is true no that is not true

18. I don't feel like doing anything



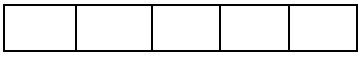
yes, that is true no that is not true

19. My thoughts easily wander



yes, that is true no that is not true

20. Physically I feel I am in an excellent condition



yes, that is true no that is not true

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Hospital Anxiety and Depression Scale (HADS)

Please choose one response from the four possible answers given that best describes the way you are currently feeling. Please tick only one in each section

A	**I feel tense or 'wound up':**	
	Most of the time	
	A lot of the time	
	From time to time, occasionally	
	Not at all	

D	**I feel cheerful:**	
	Not at all	
	Not often	
	Sometimes	
	Most of the time	

D	**I still enjoy the things I used to enjoy:**	
	Definitely as much	
	Not quite so much	
	Only a little	
	Hardly at all	

A	**I can sit at ease and feel relaxed:**	
	Definitely	
	Usually	
	Not often	
	Not at all	

A	**I get a sort of frightened feeling as if something awful is about to happen:**	
	Yes definitely and quite badly	
	Yes, but not to badly	
	A little, but it doesn't worry me	
	Not at all	

D	**I feel as if I am slowed down:**	
	Nearly all the time	
	Very often	
	Sometimes	
	Not at all	

D	**I can laugh and see the funny side of things:**	
	As much as I always could	
	Not quite so much now	
	Definitely not so much now	
	Not at all	

A	**I get a sort of frightened feeling like butterflies in the stomach:**	
	Not at all	
	Occasionally	
	Quite often	
	Very often	

A	**Worrying thoughts go through my mind:**	
	A great deal of the time	
	A lot of the time	
	From time to time, but not too often	
	Only occasionally	

D	**I have lost interest in my appearance:**	
	Definitely	
	I don't take as much care as I should	
	I may not take quite as much care	
	I take as much care as ever	

A	**I feel restless as I have to be on the move:**	
	Very much indeed	
	Quite a lot	
	Not very much	
	Not at all	

A	**I get sudden feelings of panic:**	
	Very often indeed	
	Quite often	
	Not very often	
	Not at all	

D	**I look forward with enjoyment to things:**	
	As much as I ever did	
	Rather less than I used to	
	Definitely less than I used to	
	Hardly at all	

D	**I can enjoy a good book or radio or TV program:**	
	Often	
	Sometimes	
	Not often	
	Very seldom	

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Psychological Well-Being Scale

The following set of questions deals with how you feel about yourself and your life. Please remember that there are no right or wrong answers.

Circle the number that best describes your **present** agreement or disagreement with each statement

Circle the number that best describes your present agreement or disagreement with each statement	**Strongly Disagree**	**Disagree Somewhat**	**Disagree Slightly**	**Agree Slightly**	**Agree Some-what**	**Strongly Agree**
1. Most people see me as loving and affectionate.	**1**	**2**	**3**	**4**	**5**	**6**
2. In general, I feel I am in charge of the situation in which I live.	**1**	**2**	**3**	**4**	**5**	**6**
3. I am not interested in activities that will expand my horizons.	**1**	**2**	**3**	**4**	**5**	**6**
4. When I look at the story of my life, I am pleased with how things have turned out.	**1**	**2**	**3**	**4**	**5**	**6**
5. Maintaining close relationships has been difficult and frustrating for me.	**1**	**2**	**3**	**4**	**5**	**6**
6. I am not afraid to voice my opinions, even when they are in opposition to the opinions of most people.	**1**	**2**	**3**	**4**	**5**	**6**
7. The demands of everyday life often get me down.	**1**	**2**	**3**	**4**	**5**	**6**
8. I live life one day at a time and don't really think about the future.	**1**	**2**	**3**	**4**	**5**	**6**
9. In general, I feel confident and positive about myself.	**1**	**2**	**3**	**4**	**5**	**6**
10. I often feel lonely because I have few close friends with whom to share my concerns.	**1**	**2**	**3**	**4**	**5**	**6**
11. My decisions are not usually influenced by what everyone else is doing.	**1**	**2**	**3**	**4**	**5**	**6**
12. I do not fit very well with the people and the community around me.	**1**	**2**	**3**	**4**	**5**	**6**

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13. I tend to focus on the present, because the future nearly always brings me problems.	**1**	**2**	**3**	**4**	**5**	**6**
14. I feel like many of the people I know have gotten more out of life than I have.	**1**	**2**	**3**	**4**	**5**	**6**
15. I enjoy personal and mutual conversations with family members or friends.	**1**	**2**	**3**	**4**	**5**	**6**
16. I tend to worry about what other people think of me.	**1**	**2**	**3**	**4**	**5**	**6**
17. I am quite good at managing the many responsibilities of my daily life.	**1**	**2**	**3**	**4**	**5**	**6**
18. I don't want to try new ways of doing things - my life is fine the way it was.	**1**	**2**	**3**	**4**	**5**	**6**
19. Being happy with myself is more important to me than having others approve of me.	**1**	**2**	**3**	**4**	**5**	**6**
20. I often feel overwhelmed by my responsibilities.	**1**	**2**	**3**	**4**	**5**	**6**
21. I think it was important to have new experiences that challenge how you think about yourself and the world.	**1**	**2**	**3**	**4**	**5**	**6**
22. My daily activities often seem trivial and unimportant to me.	**1**	**2**	**3**	**4**	**5**	**6**
23. I like most aspects of my personality.	**1**	**2**	**3**	**4**	**5**	**6**
24. I don't have many people who want to listen when I need to talk.	**1**	**2**	**3**	**4**	**5**	**6**
25. I tend to be influenced by people with strong opinions.	**1**	**2**	**3**	**4**	**5**	**6**
26. When I think about it, I haven't really improved much as a person over the years.	**1**	**2**	**3**	**4**	**5**	**6**

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27. I don't have a good sense of what it is I'm trying to accomplish in life.	**1**	**2**	**3**	**4**	**5**	**6**
28. I made some mistakes in the past, but I feel that all in all everything has worked out for the best.	**1**	**2**	**3**	**4**	**5**	**6**
29. I would generally do a good job of taking care of my personal finances and affairs.	**1**	**2**	**3**	**4**	**5**	**6**
30. I used to set goals for myself, but that now seems like a waste of time.	**1**	**2**	**3**	**4**	**5**	**6**
31. In many ways, I feel disappointed about my achievements in life.	**1**	**2**	**3**	**4**	**5**	**6**
32. It seems to me that most other people have more friends than I do.	**1**	**2**	**3**	**4**	**5**	**6**
33. I enjoy making plans for the future and working to make them a reality.	**1**	**2**	**3**	**4**	**5**	**6**
34. People describe me as a giving person, willing to share my time with others.	**1**	**2**	**3**	**4**	**5**	**6**
35. I have confidence in my opinions, even if they are contrary to the general consensus.	**1**	**2**	**3**	**4**	**5**	**6**
36. I am good at juggling my time so that I can fit everything in that needs to be done.	**1**	**2**	**3**	**4**	**5**	**6**
37. I have a sense that I have developed a lot as a person over time.	**1**	**2**	**3**	**4**	**5**	**6**
38. I am an active person in carrying out the plans I set for myself.	**1**	**2**	**3**	**4**	**5**	**6**
39. I don't experience many warm and trusting relationships with others.	**1**	**2**	**3**	**4**	**5**	**6**
40. It is difficult for me to voice my own opinions on controversial matters.	**1**	**2**	**3**	**4**	**5**	**6**

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41. I don't enjoy being in new situations that require me to change my old familiar ways of doing things.	**1**	**2**	**3**	**4**	**5**	**6**
42. Some people wander aimlessly through life, but I am not one of them.	**1**	**2**	**3**	**4**	**5**	**6**
43. My attitude about myself is probably not as positive as most people feel about themselves.	**1**	**2**	**3**	**4**	**5**	**6**
44. I often change my mind about decisions if my friends or family disagree.	**1**	**2**	**3**	**4**	**5**	**6**
45. For me, life has been a continuous process of learning, changing, and growth.	**1**	**2**	**3**	**4**	**5**	**6**
46. I sometimes feel as if I've done all there is to do in life.	**1**	**2**	**3**	**4**	**5**	**6**
47. I know that I can trust my friends, and they know they can trust me.	**1**	**2**	**3**	**4**	**5**	**6**
48. The past had its ups and downs, but in general, I wouldn't want to change it.	**1**	**2**	**3**	**4**	**5**	**6**
49. I have difficulty arranging my life in a way that is satisfying to me.	**1**	**2**	**3**	**4**	**5**	**6**
50. I gave up trying to make big improvements or changes in my life a long time ago.	**1**	**2**	**3**	**4**	**5**	**6**
51. If I compare myself to friends and acquaintances, it makes me feel good about who I was.	**1**	**2**	**3**	**4**	**5**	**6**
52. I judge myself by what I think is important, not by the values of what others think is important.	**1**	**2**	**3**	**4**	**5**	**6**
53. I am able to build a home and a lifestyle for myself that is much to my liking.	**1**	**2**	**3**	**4**	**5**	**6**
54. There is truth to the saying that you can't teach an old dog new tricks.	**1**	**2**	**3**	**4**	**5**	**6**

Appendix VIII: Pearson correlations between symptoms and demographic variables for the CFS Sample (N= 60)

Symptoms	Age (years)	Years with CFS	Years taken to receive a diagnosis of CFS
General Fatigue	.000 (p = .999)	.053 (p = .688)	-.104 (p = .430)
Physical Fatigue	.008 (p = .954)	-.209 (p = .109)	-.185 (p = .158)
Mental Fatigue	-.087 (p = .511)	-.032 (p = .808)	-.051 (p = .699)
Reduced Activity	.070 (p = .596)	-.181 (p = .166)	-.156 (p = .234)
Reduced Motivation	.027 (p = .836)	-.053 (p = .688)	-.035 (p = .788)
Pain[1]	-.040 (p = .764)	-.072 (p = .591)	-.129 (p = .333)
Anxiety	-.170 (p = .194)	.013 (p = .924)	-.010 (p = .942)
Depression	.112 (p = .392)	-.057 (p = .667)	.004 (p = .977)

[1] N= 58

Appendix IX: Means and standard deviations on the self-report scales of symptoms for CFS participants who were in a relationship versus those who were not in a relationship, and the significance of difference between the groups.

Symptom	In a relationship (N= 34) Mean (SD)	Not in a relationship (N= 26) Mean (SD)	t(58)	p
General Fatigue	17.82 (2.50)	18.19 (1.50)	.075	.940
Physical Fatigue	17.12 (3.25)	16.73 (3.57)	.555	.581
Mental Fatigue	15.68 (4.22)	15.15 (3.36)	.766	.447
Reduced Activity	14.35 (4.03)	14.42 (4.66)	.062	.950
Reduced Motivation	13.12 (3.99)	12.65 (3.45)	.472	.638
Pain	4.53 (2.98)[a]	4.74 (2.10)[b]	.295[c]	.769
Anxiety	10.50 (5.11)	8.54 (4.08)	1.605	.114
Depression	8.94 (4.19)	9.12 (4.07)	.162	.872

[a]N= 32, [b] N= 24, [c]df= 56

Appendix X: Means and standard deviations on the self-report scales of symptoms for CFS participants who were unemployed versus those who were not unemployed, and the significance of difference between the groups.

Symptom	Unemployed (N= 25) Mean (SD)	Not unemployed (N= 35) Mean (SD)	t(58)	p
General Fatigue	18.64 (2.08)	17.51 (2.05)	2.493	.016
Physical Fatigue	17.72 (3.25)	16.40 (3.39)	2.254	.028
Mental Fatigue	15.84 (4.37)	15.17 (3.47)	1.324	.193
Reduced Activity	15.40 (4.30)	13.66 (4.17)	1.576	.120
Reduced Motivation	13.40 (4.08)	12.57 (3.50)	.843	.403
Pain	5.10 (2.75)	4.27 (2.46)	1.213	.230
Anxiety	9.76 (5.46)	9.57 (4.27)	.150	.881
Depression	9.56 (5.03)	8.63 (3.32)	.865	.391

Appendix XI: Non-significant ANOVAs examining the effect of treatment stage (assessment vs. in treatment vs. not in a service) on symptoms

Symptom	F (2, 55)	P value
General Fatigue	2.650	.080
Physical Fatigue	1.670	.198
Mental Fatigue	.711	.496
Reduced Motivation	2.705	.076
Pain	.845	.435
Anxiety	.137	.872
Depression	.848	.434