

Developing an Expressive Writing
Intervention for People with Chronic
Fatigue Syndrome

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Abstract

Expressive writing has been shown to improve health outcomes in a variety of populations, from healthy college students to people with rheumatoid arthritis. A number of hypotheses have been suggested to account for these beneficial effects, but the precise mechanism of action underlying expressive writing has yet to be established. Positive outcomes obtained in studies with clinical populations, have led to the question of whether expressive writing could be helpful for people with Chronic Fatigue Syndrome (CFS). This study aimed to pilot an expressive writing intervention for people with CFS and to explore their experience of the intervention. It aimed to investigate the feasibility, acceptability and perceived helpfulness of the intervention, and attempted to shed light on its possible mechanism of action.

Nine patients were recruited from a specialist CFS clinic. They were asked to write about an emotionally upsetting or traumatic experience, for twenty minutes, once a week, for four consecutive weeks. Following the expressive writing intervention, they participated in a semi-structured interview to explore their experience. Interpretative Phenomenological Analysis (IPA) was used to analyse the transcribed interviews.

Expressive writing was found to be both feasible and acceptable to the people with CFS in this study. Participants reported that overall the home-based writing intervention had been helpful and had provided them with a possible coping strategy for the future. They articulated how they thought the writing had made a difference and from this three possible mechanisms of action were proposed, including emotional expression,

behavioural activation and cognitive organisation. These findings lend support to the notion that there may be more than one mechanism of action underlying the beneficial effects of writing.

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1. Introduction

Writing about emotional experiences has received increasing interest in recent years due to its association with a wide variety of health benefits. Improvements have been demonstrated in both physical and mental health, across a number of different populations, including both healthy participants and clinical health populations. Current research is concerned with identifying the underlying mechanism of action in expressive writing and with determining for whom this intervention might be helpful.

This chapter will begin by providing an outline of the expressive writing paradigm, a review of current research and a discussion of the hypothesised mechanisms by which this intervention may be working. It will then consider Chronic Fatigue Syndrome (CFS) and how the expressive writing paradigm might be useful for people with this condition. Finally, it will outline the rationale for the current study.

1.1 The Expressive Writing Paradigm

Pennebaker and Beall (1986) originally developed the expressive writing paradigm to explore the links between written emotional expression and long term health in healthy college students. They discovered that students who wrote about their thoughts and feelings associated with their most traumatic life events, had a significantly reduced number of visits to the campus health centre and reported fewer physical health complaints in the following months compared with those who wrote about a neutral topic (e.g. how they spent their time). To determine why this outcome occurred, a follow up study was conducted to evaluate how the immune system of the students

responded to the expressive writing intervention. Pennebaker, Kiecolt-Glaser and Glaser (1988) found that students who wrote about a traumatic experience had an increased number of T helper lymphocytes following the writing, suggesting they had an improved immune system response. Pennebaker and colleagues (1988) hypothesised that inhibiting thoughts, emotions and behaviours in relation to traumatic events was associated with physical work that over time could manifest itself in long term stress and disease. They proposed, therefore, that actively confronting upsetting experiences through writing reduced the negative effects of inhibition thus resulting in improvements in physical health.

As a result of this pioneering research, interest in the expressive writing paradigm exploded and a plethora of similar studies have since looked to replicate and understand the effects of expressive writing on health. A variety of different formats have been employed since the initial writing study, however, the typical design for expressive writing studies is to have participants randomly assigned to one of two writing groups. The participants in the experimental condition are asked to write about a traumatic or emotionally upsetting event. The standard instructions for these participants are a variation on the following:

'You should use these sessions to write about your inner most thoughts and feelings about emotionally upsetting or traumatic experiences that have occurred in your life. In your writing you should try to 'really let go' and explore your deepest thoughts and feelings. You can write about major conflicts or problems that you have experienced or are currently experiencing, particularly those you have not discussed in great detail with others. For each writing episode you can write about the same experience or different experiences. The only rule is to write continuously until your time is up. If you run out of things to say, repeat what you have already written. Whilst writing, do not worry about grammar, spelling or sentence structure. All of your writing will be completely confidential'.

Participants in the control condition are asked to write about an emotionally neutral topic, such as a time management exercise that involves writing about the previous week's activities. Both groups of participants are asked to write continuously under laboratory conditions for the same length of time and for the same number of sessions. Pennebaker and Beall's (1986) original study included four fifteen minute writing sessions. Investigators examining the written disclosure procedure have since varied the number of writing sessions from 1 to 7, the length of the sessions from 10 minutes to 45 minutes, as well as the writing instructions used (Sloan & Marx, 2004). However, the majority of studies have adhered to the original protocol.

Studies examining the expressive writing paradigm have reported positive outcomes across a variety of outcome measures and populations. These include: frequency of health care utilisation in elderly primary care attendees (Klapow et al., 2001), infirmity visits in psychiatric prison inmates (Richards, Beal, Seagal & Pennebaker, 2000), employee absentee rates in university staff (Francis & Pennebaker, 1992), re-employment status in senior professionals (Spera, Buhrfeind & Pennebaker, 1994), and both immune functioning (Booth, Petrie & Pennebaker, 1997; Petrie, Booth, Pennebaker, Davidson and Thomas, 1995) and psychological health (Lepore, 1997) in college students. Given the many reported positive outcomes, interest emerged in the relationship between written emotional expression and health and the role of possible moderating factors.

Smyth (1998) conducted a meta-analysis of expressive writing studies in which 13 randomised studies were reviewed. He evaluated a number of potential moderating

variables including participant characteristics, dose (how much writing was done) and outcome type, as well as the overall effect size and significance of the writing intervention. Smyth reported that expressive writing lead to significantly improved health on four outcomes: reported physical health, psychological well-being, physiological functioning and general functioning. He found that studies where the writing was spaced out over a longer period of time had a higher mean overall effect size, however, the number and length of writing sessions were unrelated to improvement. He reported the overall effect size across the 13 studies to be $d = 0.47$ ($r = 0.23$, $p < 0.0001$) and concluded that the findings suggest that the medium effect size of the writing intervention is similar to that found in other quantitative analyses of psychological interventions.

One of the limitations of Smyth's (1998) review, however, was that most of the studies were conducted using healthy student samples. Furthermore, students were found to have significantly higher effects for psychological well-being outcomes than non-students. The generalisability of these findings to non-student samples and their clinical relevance for less healthy individuals, therefore needed to be addressed. As a result, the initial positive outcomes obtained by the use of expressive writing with healthy populations led to a growing interest in the possible effectiveness of this brief intervention among individuals with health problems.

1.2 The use of Expressive Writing in clinical health populations

The first study to investigate expressive writing in people with health problems was conducted by Smyth, Stone, Hurewitz and Kaell (1999). They studied the effects of

writing about stressful experiences on symptom reduction in patients with asthma and rheumatoid arthritis. They recruited 112 patients (61 with asthma, 51 with rheumatoid arthritis) who were randomised to either the expressive writing intervention or a control intervention. Clinically relevant changes in health status at four months were found for those assigned to the experimental group compared to those in the control group. This was demonstrated by a reduction in disease activity in the patients with arthritis and improved lung function in the patients with asthma.

This was one of the first studies to suggest that expressive writing can have positive effects for clinical populations and it demonstrated that addressing the psychological needs of patients with chronic illness can help to improve their physical health status. Despite these results, Smyth and colleagues (1999) highlighted that caution should be taken in translating these results across other chronic conditions as results may not be generalisable. They also noted that approximately half of the patients in both conditions did not show improvements in response to the exercise indicating the need for additional research to explore the characteristics of responders versus non-responders.

In a more recent study, Stanton and colleagues (2002) investigated the written emotional disclosure procedure in 60 women with breast cancer. They conducted a randomised trial with three different conditions: written emotional disclosure focussing on thoughts and feelings about breast cancer, writing about positive thoughts regarding the breast cancer experience, and a control condition of writing about the facts of breast cancer. The addition of a positive writing condition was a variation of the usual design employed in traditional expressive writing research. The authors looked at the effects of

these three conditions on psychological and physical outcomes at one and three months and looked at whether outcomes varied as a function of participants' cancer-related avoidance. Compared with the control group, the emotional writing group reported decreased physical symptoms, and both the emotional and positive writing groups had fewer medical appointments during the follow up period. A significant cancer-related avoidance interaction emerged on psychological outcomes where emotional writing was effective for women low in avoidance and positive writing was more effective for women high in avoidance. They concluded that emotional expression and positive writing may be effective ingredients of physical health maintenance after breast cancer diagnosis and suggested that the suitability of each of the interventions may be best determined by the level of avoidance exhibited. One limitation of this study is the generalisability of the findings because participants were identified as having more positive psychological adjustment than other samples. The authors suggest that for very distressed or less motivated women further study is needed to determine the effectiveness of this intervention. Nonetheless, this research provided support for the use of expressive writing in people with health conditions and identified a possible moderator of its effects.

Individual difference moderators of the effects of written disclosure were also investigated by Norman, Lumley, Dooley and Diamond (2004) in a sample of 48 women with Chronic Pelvic Pain. In a randomised trial, participants either wrote specifically about the stressful consequences of their pain or about positive events. They found that writing about the stressful consequences of their pain resulted in significantly lower evaluative pain intensity ratings than control writing at two month follow up. However,

there were no effects for reported sensory or affective pain, disability or affect. Three individual difference measures appeared to significantly moderate group effects.

Women in the expressive writing condition with higher baseline ambivalence towards emotional expression or higher catastrophising were found to report less disability at follow up compared with controls. In addition, women with higher baseline negative affect who wrote expressively were found to have increased positive affect compared with controls. They conclude that despite the limited main effects of expressive writing, women with higher ambivalence or negative affect respond more positively to the intervention. They also suggest the intervention should be used as an adjunct to other approaches to management of chronic pelvic pain, rather than as a solitary intervention due to its moderate effects. One possibility for the more moderate positive effects in this study could be that the majority of the sample had current or lifetime depression. This may have made it difficult for some of the participants to manage the negative affect aroused by the writing intervention. In addition, the authors point out that some of the women may have been disappointed that the study did not provide a more active intervention or much interaction with the researcher.

The above research examining the effects of expressive writing with people with physical and mental health problems provides less consistent support for the positive effects of expressive writing than do studies of healthy people. Additional studies using clinical populations have failed to replicate the positive results achieved in research with healthy participants; however, it may be that methodological issues account for these null effects. For example, a study by Walker, Nail and Croyle (1999) did not find improved psychosocial adjustment in women with breast cancer, but the sample in their

study was small. Similarly, Batten, Follette, Hall and Palm (2002) did not find any positive effects of writing for sexual abuse survivors. However, they instructed participants to write about their child sexual abuse rather than allowing them to choose their own writing topic, which may have affected the outcome.

In summary, initial research into the expressive writing paradigm suggests that for healthy participants, writing has positive effects across a number of physical and mental health outcomes. However, research using this intervention with people suffering from physical and mental health problems has produced more variability in its findings. Initial studies suggest that expressive writing can be helpful for some patient groups, although conclusions about its applicability to all chronic conditions cannot be made. Further research is required to determine the effectiveness of expressive writing in helping with other health conditions and to identify the factors associated with its positive effects.

1.3 Hypothesised mechanisms of action in Expressive Writing

A number of hypotheses have been explored to account for the beneficial effects of expressive writing, but the precise mechanism of action underlying these effects has yet to be determined. Pennebaker's (1989) theory of inhibition was initially proposed to explain how written emotional disclosure may affect health but some contradictory evidence for this theory prompted other areas of investigation. A number of additional mechanisms have since been hypothesised. Pennebaker and Segal (1999) suggest that changing emotions and experiences into words changes the way the person thinks and organises events. Kloss and Lisman (2002) support the view that writing is a form of

exposure-based therapy. Other possible mechanisms have also been researched but are not reported here due to insufficient evidence. The following section will consider the three most researched hypotheses and will briefly review the evidence for each proposed mechanism underlying expressive writing.

The earliest explanatory mechanism underlying the health benefits of writing was Pennebaker's (1989) theory of inhibition. He proposed that the reduction of active inhibition led to a reduction in stress and consequently improved immune functioning and health. Active inhibition refers to the effortful holding back of one's impulse to disclose about a traumatic life event and is thought to involve physiological work. This exertion is suggested to result in chronic autonomic arousal and eventual weakening of the immune system. The speculation of writing therefore, is that it allows the individual to reduce inhibition, release pent up emotion and come to terms with the undisclosed trauma.

The idea that emotional inhibition may lead to psychological distress is influential in contemporary psychology and related literature suggests that people who engage in emotional inhibition may be more prone to physical disease (Sloan & Marx, 2004). Research has shown that suppression of emotion increases sympathetic activation (Gross, 1998; cited in Sloan & Marx, 2004), so it may be that chronic sympathetic activation due to emotional inhibition results in adverse physical and psychological outcomes. Stress, which is associated with physiological arousal, has also been shown to result in health problems, particularly infectious illnesses, thus lending support to this idea (Cohen & Williamson, 1991).

Studies examining the expressive writing paradigm have shown that writing leads to improvements in immune functioning, including growth in T helper cells (Pennebaker et al., 1988), antibody response to Epstein-Barr virus (Esterling, Antoni, Fletcher, Marguiles, & Schneiderman, 1994) and hepatitis B vaccinations (Petrie et al., 1995). Furthermore, the importance of emotional release was demonstrated in research showing that participants who avoided emotional content showed no positive effects of writing (Pennebaker & Beall, 1986). Taken together these findings initially lent support to the theory that emotional disinhibition mediates the effects of writing.

However, later research has been more equivocal regarding the emotional inhibition theory and the evidence that disclosure reduces inhibition has not materialised.

Inhibitory personality styles are not reliably related to the benefits of disclosure (Smyth & Helm, 2003) suggesting that reduction of inhibition may not be the underlying mechanism in expressive writing. Research by Greenberg and Stone (1992) found that individuals benefited as much from writing about traumas about which they had told others, as from writing about traumas they had kept secret. A possible explanation for these findings is that there is a difference between superficially discussing traumatic experiences with others and disclosing deep emotions and thoughts related to traumas (Sloan & Marx, 2004). Overall the precise role of disinhibition in promoting health within the writing paradigm is unclear and attention has shifted towards other theories.

In recent years, the critical role of cognitive and linguistic change has been investigated in relation to expressive writing. The act of writing has been proposed to alter the way an event is represented and organised in memory (Esterling, L'Abate, Murray &

Pennebaker, 1999) and researchers have suggested that coherence is a key factor.

Coherence implies structure, use of causal explanation, repetition of themes and an appreciation of the audience's perspective (Esterling et al., 1999). Writing, like talking, is thought to force structure on an otherwise chaotic experience and converting emotions and images into words is thought to change the way the person thinks about the trauma. Developing a coherent schema has been suggested to result in less effortful processing as it is more easily stored and forgotten, and has been associated with lower chronic stress levels (Esterling et al., 1999).

Pennebaker and Seagal (1999) report research that supports this notion of coherence.

This research analysed the language used by participants in their writing and examined the use of positive emotion words, negative emotion words, causal words and insight words over the course of the writing. Three factors were found to reliably predict improved physical health: 1) greater use of positive emotion words, 2) moderate use of negative emotion words and 3) an increase in the use of causal and insight words over the course of writing. The increase in causal and insight words correlated with independent researchers' evaluations of the construction of a narrative and it was concluded that people who benefit from writing begin with a poorly organised description and progress to a coherent story over time. Pennebaker and Seagal (1999) suggest that creating a story to explain and understand past and current traumas, allows us to develop an ordered sequence for a complex event that simplifies the experience. Smyth, True and Souto (2001) examined this narrative hypothesis by asking participants to write about a traumatic event in either a narrative fashion or in a fragmented manner. Results indicated that participants who wrote in a narrative fashion reported less illness-

related restriction of activity at follow up compared to the fragmented group. They concluded that merely writing about an event may not be sufficient to produce benefit, rather, writing may need to be narrative in format to result in improved health.

Although the cognitive change model associated with expressive writing is supported by research, some have suggested that the beneficial effects observed may be the result of exposure to aversive conditioned stimuli (Kloss & Lisman, 2002; Sloan & Marx, 2004). Foa and Kozak (1986) have argued that in exposure based treatments individuals should initially experience intense negative affect when confronted with a highly aversive stimulus, followed by gradual decreases in affect within and across stimulus presentations. Kloss and Lisman (2002) suggest that inhibition can be considered as avoidance behaviour and written disclosure as the exposure procedure. They propose writing may allow individuals to feel more in control of overwhelming reactions by engaging in the process of repeated exposure to aversive stimuli. This leads to eventual extinction of negative emotional associations allowing individuals to confront, re-evaluate and accept their fears.

To test this hypothesis, Kloss and Lisman (2002) assigned participants to a traumatic writing condition, a positive writing condition or a trivial control group. Measures of physical and psychological health were employed both prior to and 9 weeks following the writing sessions. An anxiety measure was also used immediately before and after writing to help the researchers investigate whether emotional reactivity associated with written traumatic disclosure initially increased and then gradually decreased both within and across the writing sessions. Surprisingly, no significant group differences were

found on any of the outcome measures and anxiety did not decrease across writing sessions. The findings, therefore, did not lend support to the exposure hypothesis. Kloss and Lisman (2002) suggest the instructions that participants could write about the same or different experiences across all three days could have contributed to the null results.

Sloan & Marx (2004), however, suggested that caution should be used when interpreting these findings as they felt the investigators also used an inappropriate measure of emotional activation. To further assess the exposure hypothesis, they examined activation of negative emotion during expressive writing using both subjective and physiological measures of emotional reactivity. They found that physiological activity was increased for disclosure participants compared with controls to their first writing session only. This initial physiological activation was associated with greater reduction of psychological symptoms but not with changes in physical symptoms. The authors suggest that repeated exposure may not be necessary, rather, it may be the case that any stimulus that elicits the desired negative affective state may be the critical component for extinction and the ultimate success of any exposure treatment. They also note, however, that a reason disclosure participants did not show physiological activity to the second and third writing sessions may be because the procedure was no longer novel. They state that the physiological measure they used has been shown to be sensitive to novelty, so decreased reactivity may not have been due to extinction. Therefore, despite some evidence to support the exposure hypothesis, there are a number of limitations that reduce the strength of these findings.

In summary, it is clear that there is no conclusive evidence to support any one hypothesised mechanism underlying the health benefits associated with expressive writing. Although the narrative model seems to be best supported by the literature at present, there is an obvious need for further research to investigate these predominant hypotheses, as well as to identify other possible explanations. It may be that there are a number of pathways to improved health through expressive writing. Pennebaker (2004) suggests that as expressive writing affects people on multiple levels (cognitive, emotional, and biological), it is in fact unlikely that there is any one theory that may explain this variety of findings. He also states that although it is important for researchers to try to understand the mechanisms underlying the expressive writing paradigm, it is also important to find out when it does and does not work and with whom. He comments that in the real world, a large number of people need inexpensive, fast and effective treatments in their dealing with traumas and emotional upheavals, so for whom and how well expressive writing works is equally as important as uncovering why expressive writing works.

The preceding sections have provided an outline of the expressive writing paradigm and a review of research investigating its associated health benefits in both healthy and clinical populations. It has also provided a brief overview of the hypothesised mechanisms by which this intervention may be working. The next section will now discuss Chronic Fatigue Syndrome (CFS) and its aetiology and treatment. It will then discuss how the expressive writing paradigm might be useful for people with CFS and will outline the rationale for the current study.

1.4 Chronic Fatigue Syndrome

CFS is characterised by a constellation of symptoms with a principal complaint of severe disabling fatigue. The host of other symptoms experienced include sleep disturbance, musculoskeletal pain, joint pain, impaired memory and concentration, painful lymph nodes and headaches. People with CFS have a substantially impaired functional status, including a decrease in social relationships (Sharpe et al., 1991) and a reduced capacity for work (Bombardier & Buchwald, 1996). This results in significant personal and economic morbidity. Various names have been used to describe this syndrome including Myalgic Encephalomyelitis (ME), Fibromyalgia and Post Viral Fatigue Syndrome (PVFS), all associated with a presumed cause of the illness. However, there is little consensus on the aetiology, symptomatology, management or prognosis of this syndrome, and as such an agreed medical term has yet to be established. The current study will use the term Chronic Fatigue Syndrome as it is a purely descriptive term which makes no assumptions about the cause of the illness and is most appropriate at present given that the condition is still poorly understood.

Diagnosis of CFS is based purely on clinical presentation, as there are no specific medical tests that can be carried out. A number of case definitions are currently in use, including one proposed by the Centres for Disease Control (CDC) in the United States which was modified in 1994 (Fukuda et al., 1994), one specified by the Oxford group in the United Kingdom (Sharpe et al., 1991) and another put forward by the Australian group (Lloyd, Hickie, Boughton, Spencer & Wakefield, 1990). All definitions require a common principal complaint of fatigue for at least six months which is accompanied by substantial functional impairment not attributable to any known medical cause. Where

the definitions differ is in the types and number of symptoms experienced, the onset of the illness and the exclusion criteria. Fukuda and colleagues (1994) revised the original CDC definition to reduce the number of physical symptoms required and to modify the criteria so that only people with severe psychiatric disorders were excluded. This was to ensure that the definition was not too restrictive and people with anxiety disorders and less severe depression were included, given that these commonly occur in CFS sufferers. The Oxford and Australian CFS definitions, however, are much broader than the CDC definitions and include fewer symptoms with less focus on somatic complaints. Neither excludes individuals with major depression. These definitions are not definitive as there is no evidence to suggest that CFS is a discrete illness. A report by the joint committee of the Royal Colleges of Physicians, Psychiatrists and General Practitioners (1996) suggested that it is unlikely that any single explanation found will unite the different illness phenomena. In addition, Wessely, Hoptopf and Sharpe (1998a) argue that 'any specific diagnostic criterion for CFS risks imposing an arbitrary barrier where none exists in nature, and creating spurious associations'. The above case definitions therefore arose out of the need to define standardised research criteria and vary accordingly. The most widely used criteria for research internationally is the revised CDC definition (Fukuda et al., 1994) so it is this definition that is used in the current study.

1.5 The aetiology of Chronic Fatigue Syndrome

Despite more than a decade of research, the aetiology of CFS remains elusive. Researchers have hypothesised that CFS is actually a complex condition of multifactorial aetiology and that symptoms may be manifestations of different

pathophysiological processes. The variety of symptoms reported by patients has resulted in the investigation of several theories that may underlie the condition, including earlier theories focusing on the prominence of symptoms suggestive of viral infection and psychiatric disorder, and later theories emphasising neuroendocrine responses and immune function.

Initial theories postulating a viral infection suggested that infectious agents including Epstein-Barr virus (EBV), human herpesvirus, retroviruses, enteroviruses, human T cell lymphotropic virus and others could be causes of CFS. However, none of these has been established or accepted (Royal Colleges Report, 1996), with the exception of EBV which has been shown to present as a risk factor for CFS (White et al., 1998). Many patients give a history of preceding infection and the symptoms accompanying fatigue are often characteristic of viral infections but there is no evidence to suggest that CFS is maintained by the infectious agent itself. Although impaired cellular immunity was hypothesised to result in persistent viral activity in those patients with high EBV antibodies, similar antibody profiles have been found in healthy adults and seem to be non-specific (Straus, 1993). The role of infectious agents in CFS is therefore unclear at present.

The lack of a consistent physical marker for CFS, has led some researchers to suggest that the symptoms of the illness are actually manifestations of psychiatric disorder (Shorter, 1992; Stewart, 1990). Due to the high prevalence of depression and anxiety disorders in CFS compared with the general population (Wessely, Chalder, Hirsch, Wallace & Wright, 1996), it has been proposed that unexplained symptoms such as

fatigue could be attributable to psychiatric causes. However the data so far suggest that chronic fatigue and psychiatric disorders are distinct and the relationship between them remains an area of controversy (Afari & Buchwald, 2003).

A review of neuroendocrine studies has reported that abnormalities in the hypothalamic-pituitary-adrenal (HPA) axis and serotonin pathways have been identified in CFS, suggesting an altered physiological response to stress (Scott, Svec & Dinan, 2000; cited in Afari & Buchwald, 2003). Specifically, low levels of cortisol and increased serotonin neurotransmitter function have been reported (Parker, Wessely & Cleare, 2001; cited in Afari & Buchwald, 2003), although it has not yet been made clear how these findings relate to symptomatology in CFS. Interestingly, these findings are opposite to those found in depressed patients who have shown higher levels of cortisol and decreased serotonin neurotransmitter function. It is unclear, however, how these findings account for patients with both CFS and depression. Afari and Buchwald (2003) maintain that the studies of subtle abnormalities in HPA function, hormonal stress responses and serotonin transmission in CFS patients are the most robust findings to date, but it is still uncertain how this relates to the onset of CFS.

Abnormalities of the immune system have also been linked to CFS as some of the symptoms are associated with immune dysfunction (e.g. swollen glands). Some studies have reported that CFS patients demonstrate increased expression of markers on T lymphocytes (Strauss, Fritz, Dale, Gould & Strober, 1993; cited in Afari & Buchwald, 2003), in particular cytotoxic T cells (Landay, Jessop, Lennette & Levy, 1991; cited in Afari & Buchwald, 2003), as well as deficiencies in natural killer cell function (Caligiuri

et al., 1987) and higher frequencies of various autoantibodies (von Mikeck, et al., 1997; cited in Afari & Buchwald, 2003). Collectively these may point to chronic low level immune system activation but inconsistencies in research make it difficult to link this to symptoms of CFS. Some of the inconsistencies could be explained by the heterogeneity of CFS and patient control populations, combined with the varying methodologies employed in these studies. At present the significance of these findings in relation to clinical symptoms and observed changes in immunological status in CFS remains debatable.

In addition to investigations into physical causes of CFS, there has been research to look at the impact of psychological factors, such as stress, in relation to the development and course of CFS. Stressful life events have been linked to various illnesses and health conditions and it has been suggested that a number of adverse life events over a short period of time may be a factor in stress-related illness (Paykel, 1983). A number of studies have researched the relationship between stressful life events and the development of CFS, but as with previous research the findings have been inconclusive. Although many CFS sufferers report stressful life events preceding the onset of illness (Suraway, Hackman, Hawton & Sharpe, 1995; Ware, 1993; Wood, Bentall, Gopfert, & Edwards, 1991), research by Lewis, Cooper and Bennett (1994) found no differences in overall severity of life events between CFS patients, irritable bowel syndrome patients and healthy controls prior to the onset of illness. Other research has suggested that although stress may not be associated with the onset of CFS, it may be a factor in maintaining illness after initial onset (Bruce-Jones, White, Thomas & Clare, 1994).

Clearly further research is needed to explore the relationship between stressful life events and CFS.

In summary, a number of theories have been investigated with regards to the aetiology of CFS. EBV has been identified as a risk factor for CFS and subtle abnormalities in the HPA axis, hormonal stress responses, serotonin pathways and immune function have been highlighted. Psychological factors such as stress may also play a role.

Unfortunately much of the research has produced contradictory findings and no evidence has been found to conclusively support any one hypothesis to account for the symptomatology of CFS.

1.6 Treatment Approaches in Chronic Fatigue Syndrome

Given the heterogeneity of CFS and the lack of consensus regarding aetiology, an instant cure for CFS seems unlikely at present. Interventions to date reflect the multiple pathophysiological mechanisms proposed in CFS as well as the diversity of clinical disciplines involved in the management of CFS patients. Antidepressants, corticosteroids, antiviral agents, immunotherapy, dietary supplements, rest, graded exercise and cognitive behaviour therapy (CBT) have all been advocated as possible treatments for CFS, but none have been firmly recommended. Treatment has tended to focus on relieving symptoms and improving function regardless of whether pharmacological or non-pharmacological.

In an evidence based review of management of CFS by Reid, Chalder, Cleare, Hotopf and Wessely (2000), limited support was found for the use of antidepressants in CFS,

although it was reported that they may still be useful in treating associated depression. Similarly, insufficient evidence was found for the use of corticosteroids. Any benefit from these was found to be short lived and in some cases adverse effects were experienced. Antiviral agents have not been shown to alter clinical symptoms of fatigue in patients with high EBV specific titres and CFS (Strauss, 1993), possibly because an antiviral agent acts only on a specific pathogen involved in infection and a specific infection has not been identified in CFS. Immunotherapy to correct immune dysfunction has also been used in treatment, but again only limited benefit has been identified and considerable adverse effects have been reported (Reid et al., 2000). In addition, dietary supplements such as evening primrose oil and magnesium have been evaluated, but limited evidence has been found to support their use and no such deficiencies have been identified in CFS patients (Reid et al., 2000).

As stated above, pharmacological treatments do not appear to have been found beneficial for people with CFS. This has resulted in the introduction of non-pharmacological treatments in an attempt to manage the symptoms of CFS patients. Prolonged rest was initially advocated but this is no longer recommended as an effective treatment as it may actually be detrimental to health. Research suggests that whilst rest may be effective in the short term, if used as a long term strategy it can result in harmful effects on muscle function and overall cardiovascular performance, as well as increased fatigue (Edwards, Clague, Gibosn & Helliwell, 1994; Sandler & Vernikos, 1986). Two non-pharmacological interventions that are currently recommended for CFS, are graded exercise programs and cognitive behaviour therapy.

Powell, Bentall, Nye and Edwards (2001) conducted a randomised controlled trial of patient education to encourage graded exercise in 148 patients with CFS. They found that treatment incorporating evidence based physiological explanations for symptoms was effective in encouraging self managed graded exercise, which resulted in substantial improvement compared with standardised medical care. Similarly, in their review of treatment, Reid and colleagues (2000) reported two graded exercise programs both leading to significantly improved outcomes measured by physical fatigue and functioning. One note of caution they mention is that exacerbation of symptoms can result from over ambitious attempts at exercise, so setting of targets and providing information is a necessity in this approach.

Cognitive behavioural therapy (CBT) has also demonstrated positive outcomes with CFS patients. Sharpe and colleagues (1996) investigated the acceptability and efficacy of adding 16 sessions of CBT to the medical care of 60 patients with CFS in a randomised controlled trial. They found that coping behaviour previously associated with poor outcome changed more with CBT than with medical care alone, and that CBT led to a sustained reduction in functional impairment. They noted that the treatment was acceptable to patients and also that improvement in disability among CBT patients continued after completion of therapy. In another randomised trial comparing CBT with relaxation, Deale, Chalder, Marks and Wessely (1997) found CBT to be more effective in improving functional status and fatigue in CFS patients. Similarly, Reid and colleagues (2000) reported a systematic review of CBT that concluded it was an effective intervention for people with CFS.

1.7 Difficulties with treatment

Despite the relative success of CBT and graded exercise compared with other treatments in efficacy trials, there are still difficulties associated with their clinical utility and effectiveness. There are high refusal rates for CBT (Butler, Chalder, Ron & Wessely, 1991), possibly due to the fact that some patients are not keen to accept psychological treatment for a condition they believe to be physical. This limits the extent to which the treatment can be said to be applicable to all CFS sufferers. Poor treatment adherence to CBT was shown in Butler and colleagues (1991) study, highlighting difficulties associated with the acceptability of this approach to patients. Additional research has suggested that some patients do not respond well to CBT (Prins et al., 2001) and others demonstrate high relapse rates when they are followed up in the long term (Sharpe, 1998). In addition, questions about the generalisability of CBT to less specialist settings have been raised (Reid et al., 2000) given the level of expertise required to deliver treatment. Difficulties with graded exercise treatments have also been identified, including the risk of patients increasing exercise too quickly thus exacerbating symptoms which can result in relapse and subsequent drop out. Taken together these findings suggest that there are some limitations and difficulties with both treatments.

A review of all published studies of follow up of CFS patients found that less than 10% returned to their premorbid levels of functioning and the majority remain significantly impaired (Joyce, Hotopf & Wessely, 1997). Another 10-20% of CFS patients have been shown to worsen during follow-up (Afari & Buchwald, 2003). In tertiary services, in particular, recovery from CFS is rare (Bombardier & Buchwald, 1995). This may not be surprising given the inevitable selection bias in those that have been referred for

specialist treatment who are likely to have been ill for many years prior to being seen. In primary care research, outcome tends to be slightly better with 32% of patients improved at one year follow up (Joyce et al., 1997), however, prognosis is still somewhat pessimistic. Older age, longer illness duration, fatigue severity, comorbid psychiatric illness and a physical attribution for CFS tend to be risk factors for poorer prognosis (Joyce et al., 1997)

Therefore, despite the promise shown by CBT and graded exercise in improving the outcome of CFS, it is clear that research is necessary to delineate the patient population that would obtain the most benefit from these treatments. The development of additional treatments for those who are unable to participate in or benefit from CBT and graded exercise, or find them unacceptable, is also required.

1.8 Rationale for the current study

Rationale for the use of Expressive Writing in CFS

The above research findings indicate that although there are some benefits from CBT and graded exercise for CFS patients, these treatments are not effective for all patients and are only partially effective for many. Additional interventions are therefore required to provide alternative avenues for patients who cannot be helped with these treatments. Given the effectiveness of the expressive writing paradigm in improving well-being and immune function in some clinical health populations, it would be useful to establish whether this intervention could be used as a tool to enhance health, improve functioning and reduce distress for people with CFS. In addition, expressive writing has been shown to facilitate coping with difficult life situations. This suggests it may be helpful for

people with CFS who have to deal with the stigma associated with an ambiguous illness, as well as the inevitable stress caused by the resulting disability. The range of psychological and physical benefits that have been demonstrated through the use of written emotional disclosure make its use particularly appropriate with a group who display a variety of health difficulties. Expressive writing has also been shown to improve immune functioning in some studies. This may be important in CFS, given research suggesting immune dysfunction may play a role in the aetiology and maintenance of the illness. Furthermore, expressive writing is a simple intervention that does not require as much clinical expertise or time investment from patients as other more complex treatments such as CBT.

Rationale for an exploratory approach

Campbell and colleagues (2000) advocate the use of a phased approach in the development and evaluation of interventions. They state that it is good practice and a necessary preliminary step to do a pilot study and qualitative analysis. They suggest that research should harness both qualitative and quantitative methods at different stages of the research process to answer the different questions being asked. The first step they describe in developing an intervention is to identify evidence that the intervention may have the desired effect. They propose that exploratory trials should be conducted to test the feasibility of delivering the intervention and to determine whether it is acceptable to potential recipients (e.g. the proposed intensity and duration of the intervention). They also recommend that outcome measures be piloted during the exploratory phase. Once an exploratory trial has been conducted, they state you can then move onto the next

stage of development and conduct a randomised controlled trial, before examining the implementation of the intervention into practice.

An exploratory pilot study was therefore carried out to evaluate whether expressive writing could be helpful for this client group and to determine its feasibility and acceptability. One long term aim is that this study will set the foundations for the development and funding of a randomized controlled trial in the future to determine the effectiveness of expressive writing as compared with other treatments.

Rationale for using a Qualitative approach

In view of the variability of current research into written emotional disclosure in clinical health populations and the continued debate about the mechanisms of action of expressive writing, a qualitative analysis of participants' experiences was conducted. Campbell and colleagues (2000) suggest that qualitative research can be used to show how an intervention works and to find potential barriers to change. The earlier discussion of the theoretical underpinnings of expressive writing and its mechanism of action shows there is no one unified theory that accounts for its effects. As such, it was thought that a qualitative approach may shed light on these underlying processes. In addition, there is a relative shortage in the written emotional disclosure literature, of studies employing qualitative methodologies that focus on the process of expressive writing and therefore this research is valuable in increasing this body of knowledge.

Interpretative Phenomenological Analysis (IPA) was felt to be the most appropriate choice of qualitative analysis for this study, given the desire to gain an understanding of

the writing intervention from the perspective of people with CFS. As it attempts to access individual's lived experience and the meaning those experiences hold for people, it is particularly useful for trying to understand how people with CFS experience the writing intervention and how they view the underlying mechanisms of change.

1.9 Research Questions

The following investigative research questions were formulated to address the gaps in current research and to guide the research process:

1. Is an expressive writing intervention for people with CFS feasible and acceptable to potential participants?
2. How do people with CFS experience the expressive writing intervention? Do they perceive it to be helpful?
3. What are the possible mechanisms by which this intervention works, as perceived by participants?

In summary, the aim of this exploratory study is to develop an expressive writing intervention for people with CFS and to contribute to the understanding of its mechanisms of change.

2. Method

2.1 Participants

Participants were recruited from the waiting list of a specialist Chronic Fatigue Clinic at a general London Hospital awaiting cognitive behavioural therapy (CBT). Participants were diagnosed with CFS using the Centres for Disease Control criteria (Fukuda, Strauss, Hickie, Sharpe, Dobbins, & Komaroff, 1994). Exclusion criteria were: (1) a clearly defined physical illness, (2) severe current psychiatric disorder, (3) on-going psychotherapy, (4) being deemed unable to comply with the protocol (e.g. being unable to write for a period of twenty minutes) and (5) insufficient English language. Patients taking anti-depressants were not excluded provided they had been on a stable dose for three months before participating in the study.

A total of 15 people agreed to take part, 5 of whom dropped out prior to commencing the writing study and 1 who dropped out following the assessment. The reasons given by the people who dropped out prior to commencing the study were: recently having had a baby, not being able to do the study until after the end of the data collecting period, experience of anxiety problems, family difficulties and no longer being interested. The participant who dropped out following the assessment said their health had deteriorated and they were too unwell to participate. It is unclear exactly how many people were approached about participation in the study, as the recruiting therapists did not keep records of this. In some cases potential participants were not informed about the study because the recruiting therapists forgot to ask and in other cases therapists decided they were not appropriate. However, no more than approximately 100 people would have

been asked to participate based on the number of assessments during the data collecting period, and it is most likely to have been much less than this number for the reasons mentioned above. Reasons given by patients for not wanting to participate in the research were that it was too far to travel to the clinic, they were too fatigued to participate or too busy, they did not want to think about negative things or they had been offered an early appointment for CBT and did not want to delay this for the purposes of the research.

Of the nine participants who completed the study, eight were female and one was male. Their ages ranged from 25-62 years, with a mean of 41.9 years. The duration of their illness ranged from two to seventeen years, with a mean of 7.4 years. Two participants were working full time, two part-time and five were not working or were retired. Three participants were on a stable dose of anti-depressants, the remainder were not taking any medication. Four participants had received some form of counselling in the past. The majority of participants described their ethnicity as ‘White British’, one said ‘Black British’, one used the term ‘Mixed racial background’ and one ‘White European’. (See Table 1 below for a summary of participant details).

Table 1: Participant Details

Pp no.	Sex	Age	Duration of illness (yrs)	Ethnicity	Employment Status	Taking Anti-depressants	Previous Therapy
1	F	50	2	White British	Working PT	No	Yes
2	F	25	4	White British	Working FT	Yes	No
3	F	29	11	White British	Not working	Yes	No
4	F	34	12	Black British	Not working	No	No
5	M	35	3	White British	Working PT	No	Yes
6	F	47	9	Mixed	Not working	No	Yes
7	F	37	3	White European	Not working	No	No
8	F	40	4	White British	Working FT	No	Yes
9	F	60	9	White British	Retired	Yes	No

2.2 Procedure

Ethical approval for the study was gained from the South London and Maudsley NHS Trust ethics committee ref: 142/03 (see appendix 1 for letter of approval).

Patients referred to the out-patient chronic fatigue clinic were informed about the research project at the end of their initial assessment. They were provided with the rationale for the research and given an information sheet (see appendix 2), and those who conveyed an interest to their therapist in participating in the study were contacted by the researcher. It was stressed to all participants that their involvement in the study was voluntary and their decision whether or not to take part would in no way affect their treatment. Patients were reminded that they were free to withdraw from the study at any time and this would not affect the treatment they received. Patients who agreed to participate in the research were given an appointment or were telephoned to further discuss the intervention, to complete an assessment for eligibility, consent form (see appendix 3) and baseline questionnaires, and to agree a time with the researcher for completing the writing.

Participants were then asked to participate in a follow up interview about their experience of the writing one to two weeks after the end of the intervention. Interviews were carried out at the chronic fatigue clinic, except in some circumstances where the participants were unable to attend the clinic. In these cases the researcher either went to the home of the participant to conduct the interview or conducted the interview over the telephone. A verbal explanation was provided about confidentiality, anonymity, the right to withdraw and of the interview process itself, in addition to the explanation

already provided on the information sheet. Interviews were tape recorded and transcribed verbatim with all identifying details excluded in order to ensure confidentiality (see appendix 4 for an interview excerpt). Participants were assured that tapes would only be listened to by the main researcher. Consent was obtained for interviews to be recorded and it was made clear that the tapes would be destroyed at the end of the research process. The recruitment and interview process was carried out from October 2003 to May 2004 until nine people had completed the intervention and been interviewed.

2.3 Intervention

The writing intervention took place once a week for four consecutive weeks. The writing sessions were conducted in the participants' own homes at a time negotiated by the researcher and participant, with the researcher phoning the participant before and after the writing session. One participant completed their first writing session at the clinic. This was because the original design of the study was to have participants attend the clinic to complete their writing sessions, however, due to poor recruitment the procedure was changed to allow participants to conduct all the writing sessions in their own homes. Since some participants had difficulty arranging specific times to do the writing that co-ordinated with the researcher, they were given the flexibility to carry out the writing when it was convenient for them and the researcher rang once a week to remind them to do the writing session.

Participants were provided with writing packs and were told that this type of study was usually done by asking people to come into the clinic for all the writing sessions. They

were informed that in order to provide flexibility, the researcher was allowing the writing to be carried out in participants' own homes, but did not want to lose any of the environmental conditions. Participants were therefore asked to make the conditions as similar to the writing environment set up at the clinic as possible, by following the instructions in the writing pack as follows. Participants were asked to isolate themselves in a quiet room, to ensure there were no distractions (e.g. by taking the telephone off the hook, no television/radio), to clear a space in which to write at a desk or table, not to eat or drink and to make sure they had a comfortable chair.

Participants were asked to write continuously for twenty minutes about their deepest thoughts and feelings in relation to a traumatic or emotionally upsetting experience that had occurred in their life, preferably one they had not discussed in detail with others (see appendix 5 for full instructions given). At the end of the session, participants were asked to post the manuscript to the researcher in the stamped addressed envelope provided. Participants' were informed that their writing would remain strictly confidential and would be marked only with assigned ID numbers for anonymity; the one exception to this being that, if the writing indicated that the participant intended to harm themselves or others, the researcher would be legally bound to match the ID number with the name of the participant. Participants were also reminded that sometimes people felt a little upset after writing but that these feelings dissipated after a short time. However, they were advised to contact their G.P or the therapist who conducted their initial assessment should they experience any persistent distress following the intervention.

2.4 Measures

Participants completed questionnaires at three stages of the research, once at baseline assessment, at the end of the intervention and at two weeks follow up. This was to pilot the outcome measures and to provide further information regarding the characteristics of this particular group of people with CFS. Measures included a demographic information sheet, the CDC criteria checklist for CFS, the Fatigue Scale (Chalder et al., 1993) as a measure of symptoms of fatigue, the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) as a measure of distress and the Work and Social Adjustment Scale (WSAS; Marks, 1986) as a measure of functional impairment.

The Fatigue Scale

The Fatigue Scale (Chalder et al., 1993) was developed for use in both hospital and community populations. It is an eleven item scale; the first seven items relate to physical fatigue and the remaining four items relate to mental fatigue. A bi-modal scoring system can be used to derive caseness or a Likert scoring system can be used to examine the distribution of scores. The Likert method of scoring was used in this study. A minimum possible score of 0 and a maximum score of 33 can be obtained. A score of 4 or more for 6 months or more is considered to indicate caseness for Chronic Fatigue. The Fatigue Scale has been demonstrated to be both reliable and valid (Chalder et al., 1993).

The Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) is a self-report instrument designed as a brief assessment tool for use in medical populations to

facilitate detection of emotional disorder. It was specifically developed to detect anxiety and depression among medical patients and therefore excludes items that might relate to the somatisation of mood or to physical illness (e.g. headaches, dizziness). It is a 14 item questionnaire consisting of two sub-scales of seven items designed to measure levels of both anxiety and depression. Items are rated on a four point scale, scored from 0-3. The minimum total score for each sub-scale is 0 and the maximum total score for each sub-scale is 21. A score of 0-7 is considered to be within the normal range, a score of 8-10 is considered to indicate possible emotional disorder and a score of 11-21 is considered to indicate definite emotional disorder. The HADS has been demonstrated to be both a reliable and valid measure for detecting emotional disorder in non-psychiatric populations (Zigmond & Snaith, 1983) and has been recommended as a screening tool of choice for CFS (Deale & Wessely, 2000).

The Work and Social Adjustment Scale

The Work and Social Adjustment Scale (WSAS; Marks, 1986) is a five item self-report instrument designed to measure functional impairment that is attributable to an identified problem or disorder. It assesses the extent to which the areas of work, home management, social leisure activities, private leisure activities and relationships are impacted upon as a result of a disorder. It has a simple Likert scoring system, from 0-8 for each item, and is easy to use. It has a minimum total score of 0 and a maximum total score of 40. It has been demonstrated to be both reliable and valid (Mundt, Marks, Shear & Griest, 2002).

2.5 The Semi-structured Interview

An interview schedule was developed (see appendix 6), informed by previous expressive writing research (Crockett, Michie & Weinman, 2003). Initially, broad areas of interest were identified: initial reactions to the writing intervention, how participants found the intervention, whether the intervention was helpful to them, if it was helpful, how they thought it was helpful and whether they would use it in the future. Questions were generated that would allow detailed discussion of these areas. The questions were then placed in an order beginning with those judged to be less threatening in order to build rapport with participants. Prompts following the main questions were included to assist the researcher in asking for more detail or for paraphrasing questions. Every effort was made to ensure the questions were neutral, jargon-free and open-ended in accordance with Smith's (1995) interview guidelines. Once in draft form, the interview schedule was given to an experienced researcher for comment, after which it was revised. Piloting the interview schedule was not possible due to the paucity of patients able to participate in the study.

Interviews began with the researcher giving a brief introduction to participants, to provide them with information about the structure of the interview (e.g. the likely duration) and the procedure after interview (e.g. regarding follow-up questionnaires). Following the introduction, the interview schedule was used to guide the interview. It provided some structure to the interviews, but was not rigidly adhered to, so that participants could describe aspects of the experience they felt were important. Questions were not always asked in the same order to allow a more natural flow of the conversation from one topic area to another. This approach to data collection is more

flexible than the structured interview and allows the researcher to vary the avenues of questioning, focus on particular areas of interest and gain a rich and detailed picture of participants' accounts of a topic.

2.6 Data Analysis

Interpretative Phenomenological Analysis (IPA) was used to analyse the semi-structured interviews. The aim of this idiographic approach is to attempt to 'get inside' someone else's experience on the basis of their description of it. The participants' account becomes the phenomenon with which the researcher engages and the analysis produced is the researchers' interpretation of the participants' experience. The idea is to explore the individual's personal perception of the event.

The analysis of the interviews was carried out following the guidelines described by Smith & Osborn (2003). Each interview was read through a number of times to provide the author with familiarity of the text, before initial thoughts and summaries of the text were recorded in the left margin. Themes that characterised each section of the text were noted in the right hand margin. Four interviews were analysed in the first batch and preliminary themes were discussed with another researcher (with extensive experience of qualitative analysis) who had gone through the same process as the author. Emerging themes were evaluated in the analysis of the second batch of three interviews and any new themes that emerged were checked against the previous four interviews. The last two interviews were analysed with respect to the themes identified from the preceding seven interviews; no new themes emerged. At this stage, themes that were identified in only one or two participants' transcripts and which did not appear to be

related to any other identified themes were dropped from the analysis. Findings were discussed and a list of themes was produced which integrated the themes from each transcript into an inclusive master list that reflected the experiences of the transcripts as a whole. The naming of the master themes was undertaken to best reflect the content of the subordinate themes. A final summary table was produced which depicted a clear and systematic overview of the themes presented in a coherent order (Table 2, Results chapter). A complete set of quotations for each master theme and sub-theme was then gathered (see appendix 7), which provided the basis of the narrative account given in the Results chapter.

2.7 Reliability and Validity

Issues of reliability and validity in qualitative research must be evaluated within context and therefore different methods are utilised to those employed in quantitative research.

Elliott, Fischer & Rennie (1999) propose a number of methods by which the validity and reliability of qualitative research can be assessed some of which are discussed below:

- 1) 'Owning one's perspective' is good practice which involves explaining theoretical, methodological and personal orientations to the research (see section 2.8).
- 2) 'Situating the sample' involves describing research participants to aid the reader in judging the range of persons and situations to which the findings might be relevant (see section 2.1).
- 3) 'Grounding in examples' refers to the presentation of evidence by providing raw data to determine the fit between conclusions and interpretation of the data (see Results chapter).

4) 'Providing credibility checks' involves having more than one person analysing the data to minimise bias in the analysis and involving another person in checking the interpretations made of the data (see section 2.6).

2.8 Researcher's Perspective

One important consideration within IPA is that in accessing the participants' understandings and perceptions of the world, one can never gain a complete or direct understanding of their perspective. This limits the interpretation of their verbal reports and so the dynamic process which occurs during the interviews requires the researcher to be reflexive and aware of their own assumptions and the effect these may have on the analysis. It is therefore good practice for the researcher to clearly set out their values, expectations and the framework of understanding they bring to the research so that readers may evaluate the study in light of this information (Elliot et al., 1999).

In an attempt to make explicit my theoretical orientation and standpoint in relation to this research, it should be highlighted that I am a female, white, British, 27 year old, trainee clinical psychologist with a keen interest in the psychology of physical health problems. My interest developed as an undergraduate psychology student when I studied a health psychology module and conducted research in the area of health psychology. My interest has been further developed as a trainee clinical psychologist where I have undertaken two specialist placements working with people with physical health problems. I have an interest in how people cope with physical health problems and what helps them to manage their illness. During these placements, I have undertaken clinical work with people with chronic fatigue syndrome using a cognitive

behavioural approach. This model of working may have influenced my thinking in this research and in particular, may have impacted upon my interpretations of the participants reports.

In addition to the possible bias of this personal orientation, there is also an inherent bias in all qualitative work wherein the research questions are undoubtedly focused on revealing certain experiences. Given my knowledge of this area of research, it is possible that it may have influenced the aspects of participants' accounts which were of interest to me. However, an awareness of this possible bias will hopefully have allowed me to approach the analysis with reflexivity in order to consider whether my personal beliefs were narrowing my interpretation of the data.

3. Results

The following chapter will comment on the feasibility and acceptability of the expressive writing intervention for people with Chronic Fatigue Syndrome (CFS). It will report the background data from participants' self report measures, as well as provide a brief overview of their writing topics. The main focus of the chapter will be the results following the analysis of the transcripts. It will present the master themes that emerged through the interpretative phenomenological analysis and will provide quotes from participants to reflect each of these master themes, as well as quotes for the subordinate themes that emerged under each master theme.

3.1 Feasibility and Acceptability

Adherence

The expressive writing intervention appeared to be both feasible and acceptable to the people with CFS who participated in this study. All participants reported adhering to the writing protocol at interview and did not report any difficulties. Postal instructions were able to convey the intervention accurately and participants completed each of the measures at the appropriate time points. One participant's questionnaire data was not received at the second time point (immediately after the intervention), due to being lost in the post. A few of the participants also required a single phone call to remind them to complete the final set of questionnaires. All participants gave positive feedback regarding completing the intervention in their own home and reported no disruptions or problems with this set up.

Writing Topics

Participants' manuscripts were checked to determine adherence to the writing instructions. All participants wrote about emotionally upsetting or traumatic events. Five of the participants wrote about the same or similar topics for each writing session, the remaining four participants wrote about different topics. The majority of participants reported that the topics they wrote about were emotional for them and approximately half also reported that they had not disclosed these to others:

'I had written specifically about things that caused me very deep emotional distress'.

(1:2:24)

'...certain things that I probably hadn't really told anyone else at all'. (7:3:9)

This provided further support that they had adhered to the writing instructions.

The table below (Table 2) identifies the general topic areas participants wrote about across each of the four writing sessions. Where the participant number is in bold type, this indicates those who wrote about the same or similar topics on each occasion.

Table 2: Table of Participants Writing Topics and Writing Sessions

Pp	Session 1	Session 2	Session 3	Session 4
1	Dep/CSA	CSA	Suicide/CSA	Dep/CSA
2	Abortion	Abortion	Affair	Abortion
3	Writing	CFS	CFS	CFS
4	Police Break In	Police Break In	Police Break In	Police Break In
5	Divorce	Abandonment	Moving House	CFS
6	CFS	Mothers Death	Family Problems	Writing
7	Pregnancy	Pregnancy	Anorexia	Panic Attack
8	Infertility/Divorce	Affair/ Divorce	Childhood	Divorce
9	Childhood DV	Infertility	Family Problems	Childhood

(Pp-participant; Dep-depression; CSA-childhood sexual abuse; DV-domestic violence)

Uptake

General uptake of the expressive writing intervention at assessment by CFS patients seemed poor and recruitment difficulties were encountered. Exact uptake information can not be calculated as this data was not recorded by recruiting therapists. However, no more than approximately one hundred patients will have been approached to participate. The issue of recruitment difficulties will be further addressed in the discussion chapter.

Drop Outs

Six people dropped out of the research prior to commencing the study. Five had been given an information sheet by the recruiting therapist and had agreed to be contacted by the researcher, but dropped out when they were telephoned. One person dropped out after completing the assessment for the writing intervention. Reasons for their dropping out have been presented in the method section (e.g. being too unwell to participate) and will be further addressed in the discussion chapter. One important point is that none of the participants dropped out once they had started the writing intervention, suggesting it was acceptable to them.

3.2 Background Data

To pilot the outcome measures (The Fatigue Scale, the Hospital Anxiety and Depression Scale: HADS, and the Work and Social Adjustment Scale: WSAS), participants completed them at three time points; prior to the intervention, immediately after the intervention and two weeks later. Participants' scores on these questionnaires demonstrated aspects of homogeneity and heterogeneity within the sample and are

reported here to provide further information regarding the characteristics of this particular group of people with CFS (see appendix 8).

Participants' scores on the Fatigue scale prior to completing the writing intervention, had a mean of 28 (range: 24-32; highest possible score = 33), indicating a chronic level of fatigue across all participants (Table (i), appendix 8).

Their scores on the HADS prior to completing the intervention had a mean of 10 for the anxiety sub-scale (range: 2-15; highest possible score = 21) and a mean of 9 for the depression sub-scale (range: 2-16; highest possible score = 21). Five participants had scores indicating anxiety disorder (11 or above) and four participants had scores indicating depression (11 or above). These scores suggest a fair amount of variability of emotional disorder among participants (Table (ii), appendix 8).

Scores on the WSAS prior to completing the writing intervention had a mean of 30 (range: 17-37; highest score = 40), indicating a fairly high degree of functional impairment among participants, but also indicating some variability (Table (iii) in appendix 8).

The sample size is too small to make quantitative analyses on these data worthwhile and it was not the purpose of this study to determine the efficacy of the intervention.

However, it is worth noting that only a slight decrease in the mean scores can be seen for each of the measures over time (appendix 8). This is at odds with participants subjective reports of the intervention (detailed later in the chapter) and could suggest that the measures used may not be the most appropriate in measuring outcome in future research.

This point will be further addressed in the discussion chapter.

3.3 Interpretative Phenomenological Analysis

The remainder of this chapter will focus on the analysis of the interview transcripts. It will report the master themes identified, as well as the subordinate themes that emerged under each master theme.

The table overleaf (Table 3) shows the master themes, subordinate themes and the prevalence of each of these themes in respondents accounts. Prevalence of the themes is reported to demonstrate the degree to which participants reported similar experiences and has been categorised as the majority of accounts (greater than or equal to two thirds; $\geq 2/3$), a moderate number of accounts (between one third and two thirds; $1/3 - 2/3$) and a minority of accounts (less than a third; $< 1/3$). A complete set of quotations for each of the themes can be found in appendix 7. (Quotes are labelled by the participant number, page number and line number in brackets at the end of each quote).

Six master themes regarding participants' experience of the expressive writing intervention emerged from the analysis, incorporating the twenty-three subordinate themes identified. These master themes can be further organised into three higher groupings:

- a) *Overall Experience* ('Expectations and Concerns' and 'The Experience of Writing').
- b) *Mechanisms of Action* ('Emotional Expression', 'Behavioural Activation' and 'Cognitive Organisation').
- c) *Perceived Outcomes*.

Table 3: Master and subordinate themes

Master Themes	Subordinate Themes	Prevalence of Themes
Expectations & Concerns	Open-minded	$\geq \frac{2}{3}$
	Uncertainty	$\frac{1}{3} - \frac{2}{3}$
	Fear of Emotional Impact	$\frac{1}{3} - \frac{2}{3}$
The Experience of Writing	Getting Going	$\geq \frac{2}{3}$
	Focusing on self	$\frac{1}{3} - \frac{2}{3}$
	Confronting the Problem	$\frac{1}{3} - \frac{2}{3}$
	Writing an easier medium	$\geq \frac{2}{3}$
	Re-reading the writing	$\geq \frac{2}{3}$
	Practical Aspects	$\geq \frac{2}{3}$
	Negative Aspects	$\geq \frac{2}{3}$
Emotional Expression	Reliving Emotions	$\frac{1}{3} - \frac{2}{3}$
	Emotional Release	$\geq \frac{2}{3}$
Behavioural Activation	Behavioural Activation	$\frac{1}{3} - \frac{2}{3}$
Cognitive Organisation	Clearer on Paper	$\geq \frac{2}{3}$
	Taking a different perspective	$\geq \frac{2}{3}$
	Coherence	$\frac{1}{3} - \frac{2}{3}$
	Reflection	$\frac{1}{3} - \frac{2}{3}$
	Helpful	$\geq \frac{2}{3}$
Perceived Outcomes	Emotional Impact	$\frac{1}{3} - \frac{2}{3}$
	Cognitive Impact	$\geq \frac{2}{3}$
	Behavioural Impact	$\frac{1}{3} - \frac{2}{3}$
	Physical Impact	$< \frac{1}{3}$

Each higher grouping, master theme and subordinate theme will now be explained and illustrated by relevant quotes from the participants. Although themes have been clustered by the researcher, it is important to note that some of the themes are inter-related and there is overlap between themes in some cases.

3.3.1 Overall Experience

The first higher grouping includes two master themes. It focuses on participants initial views with regards to the expressive writing intervention (Expectations and Concerns) and their actual experience of writing during the intervention (The Experience of Writing).

Expectations and Concerns

This first master theme provides an overview of how participants felt about writing to help with their CFS and highlights concerns they had about the intervention prior to taking part.

Open-minded

Participants seemed to adopt an open minded attitude to the writing intervention. They generally felt that it might have something to offer and saw it as a new technique to try:

'I was fairly open-minded to it actually. I mean, I completely accepted very early on that stress and worry were fundamental to how I was feeling and therefore I was open-minded to new techniques'. (8:1:10)

They stated they did not know what to expect from the intervention but expressed the view that they were prepared to try anything to help with their CFS. They gave the impression that they saw the intervention as offering an opportunity to help cope with their CFS rather than as a cure for it:

'... anything that can help to find a...not cure but perhaps can help chronic fatigue syndrome I think is a good idea'. (7:1:14)

Uncertainty

A moderate number of participants were unclear as to how writing might be beneficial for them and expressed uncertainty regarding the interventions likely effects. However, despite this they expressed curiosity about whether it would help:

'Puzzlement of what it could actually do, you know whether there would be any benefit...I couldn't quite see how it would work'. (2:1:7)

They seemed to be unsure about the intervention, particularly with regard to the likely impact it would have on their physical symptoms. Participants also reported uncertainty about whether they would actually be able to write for twenty minutes, both in terms of being physically able to, as well as having things to say:

'Gosh, I've got to write for twenty minutes, what am I going to put?'. (6:5:27)

Fear of Emotional Impact

There was concern among a moderate number of participants that writing about emotional experiences might result in them becoming upset. They expressed reservations about doing the writing because of this sense that it would be difficult emotionally:

'I was a bit concerned...That it would raise things that would just be there and just be to the surface again'. (1:1:21)

'...it sounded like heavy weather'. (6:1:22)

They also felt it might impact on their ability to carry on with life afterwards:

'I'm afraid that... I probably would feel very upset and bruised and tired and I think it would be difficult to then pick myself back up the next day and pretend everything is fine'. (3:16:4)

This first theme highlights that despite a number of concerns and uncertainty about the writing intervention, this group of participants were open to trying something new that might help with their CFS.

The Experience of Writing

The second master theme is concerned with how participants found the writing intervention. It provides some additional information that can be linked to the feasibility and acceptability of writing as an intervention, as well as insights into the personal experiences of this group of participants.

Getting Going

Despite initial concerns regarding their ability to do the writing, the majority of participants reported that once they started writing, it was easy:

'...once you get into it and are going with the flow and you become more absorbed by it, then you know it was fairly easy to do'. (2:2:29)

In fact, they expressed surprise at how easy it was, and at the things that came up whilst writing. Two participants stated once they got going it was actually difficult to stop and they ran over time slightly:

'...when it started to flow. It's like a train. I'm gathering up speed and then oh my goodness, couldn't find the breaks'. (6:6:28)

Focusing on Self

A moderate number of participants felt the writing gave them some time and space for focusing on themselves. They stated it enabled them to switch off from their surroundings and forget about everything else. They were able to concentrate on doing something for themselves which they were in control of:

'...allowing myself time to ... indulging myself really, time to think about issues that were worrying me, whereas normally you just put it to the back of your mind and get on with life. It was actually allowing me time to think about the things that I knew were troubling me'. (8:1:25)

Confronting the Problem

Connected to the previous theme, a moderate number of participants described the writing as giving them the space to address their problems. They felt the writing gave

them the opportunity to think about and face their difficulties, as illustrated by the previous quote, as well as the following one:

'...think about things as opposed to just pushing them inwards and not really dealing with them'. (2:12:26)

Two of the participants, however, felt unable to face their difficulties and seemed to engage in cognitive avoidance to a degree. One participant found the writing difficult and felt they could not focus on the negatives or think about their problems, as this would interfere with their ability to cope with them. Another participant felt it would be unsafe to think about them:

'I kind of felt I can't afford to think about admitting how difficult I find coping or thinking about the illness, because I have to manage these things this week. For this week I feel as if I have to keep pushing it all back and pretending it's not there, it's not a problem simply because I've got to cope'. (3:15:17)

'I don't want to think about it. I have to push it away. Dangerous.' (6:5:25)

Writing an easier medium

Participants reported writing to be an easier medium than talking, and made comparisons with talking to others and talking in therapy. They felt writing allowed them to write whatever they wanted, without fear of being judged by others. There was a sense of freedom, that they could write about things they could not talk about and didn't have to

hold back or monitor the reactions of others as they might in therapy or when talking to other people:

'I found it an easier medium. I think than the counselling because if anything came back to me from the counselling it didn't let my thoughts run. Whereas, if I was just writing myself, thoughts could run where I wanted them to and I wasn't stopped at any way along the procedure or made to account for it or asked to think – well why do you think that. Except for myself thinking well why do you think that?' (8:17:15)

*'...you can sort of write things that perhaps you wouldn't perhaps tell someone else'.
(7:4:5)*

'...you can say things to people and they make all the right noises...but I think you always slightly gauge what you'd say to them as to how you think they might react. Whereas writing it down, I didn't have any of that. I could write down whatever I wanted'. (2:7:11)

Re-reading the Writing

All but one of the participants reported re-reading their writing, either a short time after the session or a couple of days after writing, before posting it back to the researcher.

Participants had not been instructed to do this but decided to independently, and reported that they found it helpful. Re-reading was seen as providing an opportunity to reflect on what they had written and to get in touch with their emotions. It was also described as validating:

'...it's a very good channel for communication from me to me. To look back on because you can't remember how you think from day to day'. (1:9:9)

'...it was good to, in the cold light of day, have a look at it'. (2:7:5)

'I think by re-reading it, it was like feeling the emotions again, so for me it was quite important I think to do'. (7:21:3)

'...there are things that have happened that are incredibly bad and incredibly big and it in a sense validated that, so for me it was validating. When I've read it now...I'm coming to terms with it all'. (1:11:10)

Practical Aspects

The majority of participants were happy with the practical aspects of the writing intervention, providing further support for its feasibility and acceptability. They felt that the length of the writing exercise and the frequency of it were appropriate, and appreciated the flexibility of doing it when they felt it was most convenient to them. They also felt comfortable doing it in their own home and speculated that they were more able to focus on the writing in their own home, than if they had been in a clinic:

'...the fact that it was twenty minutes I thought was a perfect amount of time'. (3:2:3)

'Once a week it was just right, enough'. (4:5:30)

'...not being fixed to an exact time, I think is helpful. Because, I think you do have to be in the right frame of mind to do it'. (8:24:1)

'I think it was quite nice because you... feel quite at home. And you don't worry about your surroundings... That made me feel quite comfortable... and I think because there was no worries about the surrounding or anything or any people around. That I could just concentrate on the writing'. (7:9:9)

Negative Aspects

Participants reported finding the writing emotionally distressing in the short term and a moderate number said they were tearful during the writing sessions. Their initial concerns regarding the emotional impact of the writing therefore seemed somewhat justified. For the majority there was a sense that the writing left them emotionally drained and tired, although this was reported to be short lived:

'...extremely upsetting and tiring to actually pour it all out'. (3:10:15)

'...sometimes I felt sort of quite down for about an hour afterwards. Um, but then it sort of disappeared'. (7:6:16)

One participant said the writing was a painful experience which they dreaded. Unlike other participants, they said the negative emotional impact of writing about traumatic experiences was long lasting and it made them feel worse physically:

'... by the time it was time for the following weeks session, it was like, oh gosh I've only just recovered from the last lot'. (6:8:18)

They described each writing episode as re-exposing themselves to the trauma:

'...it's just like picking a scab. You just keep exposing that wound again'. (6:15:15)

However, they continued with the writing despite finding it very difficult, as they hoped it would be helpful:

'I will do anything if it's all part of the healing process'. (6:5:11)

'I felt like I was dealing with a course of medicine. Just objecting my mind that I've got to start this, got to get through the course. Pretend it's chemotherapy or something. Got to do it cos it's horrible, it's make you sick. It's a necessary evil.' (6:9:7)

Only one participant did not report finding the writing emotionally distressing. They stated that the part they did find difficult was physically writing and this aspect was mirrored by a moderate number of participants:

'I actually found that the hard labour was actually writing'. (5:3:6)

The participant felt it would have been easy if typing had been allowed, but instead they reported frustration at finding writing physically difficult and felt this increased their frustration about having CFS:

'...it would have been easy to sit down and type for twenty minutes'. (5:13:30)

'R: Can you think of any ways that the writing has not been helpful? P: Um, only in increasing my frustration about my condition.' (5:17:1)

Overall, participants' reports provide support that the writing intervention was feasible and acceptable to them, particularly with regards to the practical aspects. Providing space to confront problems and an easier medium than talking, are highlighted as beneficial aspects of this approach. However, negative aspects that have been described suggest there may be some limitations. These points will be further addressed in the discussion.

3.3.2 Mechanisms of Action

There were a number of suggestions reported for how the writing intervention made a difference to participants; these suggestions form the basis for this higher grouping. Participants often reported more than one idea about how expressive writing helped them, suggesting the possibility of more than one underlying mechanism providing the benefits.

Emotional Expression

This was the third master theme to emerge from the analysis and is concerned with the idea that the writing intervention facilitated the re-experience of emotions and emotional release.

Reliving Emotions

There were differences in participants reports associated with this aspect of the writing. A moderate number reported reliving and re-experiencing the emotions associated with the traumatic events they were writing about:

'I wrote and it's like it's come back in full force, as though you're living the thing again. It's like you are reliving it'. (4:8:9)

'...when you actually start writing it down, you know I feel fear, you know you really sort of feel those emotions. Um, and I know when I was writing things, quite often I sort of, my tears were rolling down my, my face. I would really feel these feelings'. (7:5:30)

Some participants found this beneficial:

'It seemed to be the more upset I got the better I felt afterwards'. (2:3:24)

One participant, however, reported this to be aversive:

'All those emotions. I was broken again.. It's like it just happened, it was fresh...it was very disturbing how dark I was feeling. I understand why I emotionally crashed. It was terrible'. (6:3:24)

One participant found she did not re-experience negative emotions at all throughout the writing process:

'I was able to remain detached'. (8:3:20)

Emotional Release

Despite the differences in participants views regarding reliving the emotions, there was a general consensus that the writing helped them to express negative feelings and to release repressed emotion. This emotional release was seen as positive and the writing was viewed as cathartic:

'...to write and get it out of your system, that was what was really helpful'. (2:7:7)

'...I have quite a lot of things, perhaps bottled up inside, just sort of writing it all down and letting it all out. It was quite nice. Um. Definitely'. (7:5:20)

'I felt when I'd written all about the anger I felt, I felt that I had released it. So I felt better. I felt that I'd let go of that particular thing'. (8:25:12)

One participant felt they had been unable to release the negative emotions associated with their writing topic and saw this as disappointing:

'I really wish that I could have been able to...put down things, because I really feel as if, um, kind of like, it's just all bottled up inside of me'. (3:10:20)

In summary, this theme of 'emotional expression' provides a possible mechanism for understanding some of the positive aspects associated with expressive writing (these are described in more detail in the final master theme). It is also linked to the earlier theme 'negative aspects of writing', with a moderate number of participants experiencing emotional distress in the short term and one participant experiencing slightly longer lasting negative effects.

Behavioural Activation

Behavioural activation is the fourth master theme, reported by a minority of participants. They seemed to suggest that the writing had motivated them to do something, either specifically relating to the writing topic or more in general with regard to their daily life:

'What I writ the other day...it pushed me to go and...get my rights' (4:9:28)

'...by doing the writing, I have no idea what has triggered off but I actually get up on Saturday. I actually put some routine in my non-routine days...By doing it, uh, it's a switch. It's put on a switch'. (5:15:20)

'I could do something that might help it. Or, at least by just knowing it perhaps I should sort of, take certain action'. (7:18:1)

Although this idea was not identified by all of the participants, it provided an understanding for how writing helped some of the group. It is also linked to the idea of cognitive organisation.

Cognitive Organisation

This fifth master theme clusters participants' ideas about the processes that may underlie the effects of expressive writing. Cognitive themes emerged repeatedly in interviews with participants.

Clearer on Paper

This first idea was supported by the majority of participants. There was a sense that problems seemed clearer written down on paper and less muddled or confused, as opposed to being a jumble of thoughts being mulled over in the mind and getting out of control:

'... when you write things down you can see it on paper. It's clearer it's not all, sort of, swimming around in your head'. (3:1:17)

'Um , when you are not thinking clearly, in your mind, you know, it becomes a bit of a muddle and things tend to get out of control. You know, you do think things are worse than they are'. (7:16:20)

'If you're in the middle of it all and just reacting to it you don't necessarily think about it clearly whereas it can either take someone else to look in or its yourself to stand back from the issue to see the wood from the trees really'. (8:22:13)

Taking a different perspective

Writing was seen to enable participants to take a different perspective with regards to their experiences. The majority of participants felt problems looked different written down, they were able to be more objective and analytical, and things did not seem as bad:

'...it enables you to look at things almost dispassionately in a slightly different way. Almost like looking in at yourself really from the outside.' (8:21:26)

'...it feels terrible when it's in my mind, but when (it's) actually down on paper then you can start to look at it objectively and make sense of it'. (3:9:25)

'...give you the opportunity afterwards to realise that maybe you are not being rational... Or things aren't quite as bad as you think they are'. (2:16:2)

This seemed to link with the previous subordinate theme 'clearer on paper', the implication being that when things were clearer on paper it enabled participants to see things differently. In addition, it is possible to relate this back to the previous master theme 'behavioural activation'. Participants who reported the writing activated them to do something differently related it to being able to take a different perspective and seeing things differently, implying that this may have mediated the behavioural effects:

'I think it's had an impact on how I view things, mostly'. (5:22:10)

Coherence

A moderate number of participants felt the writing had allowed them to describe their emotional experiences in an understandable, coherent way. In order to do this, they said they had to provide structure to their experience and organise the information. This enabled them to make links and make sense of their experience:

'I suppose I had to structure myself, isn't it. In a way, I had to have structure of what to write'. (4:7:4)

'I chose to write about those things in a particular way with references to my past' (1:5:19)

'I'd decided on what I was going to write about and then actually put it down in a coherent form' (5:3:5)

One participant also indicated that because someone else would be reading their writing, they needed to make themselves understood:

'I sort of felt because I was writing to someone that didn't know me, for some reason I sort of felt as though I had to explain myself'. (7:2:7)

Reflection

Writing was described by a moderate number of participants as allowing them time to think about their experiences in more detail and to look at how they were thinking:

'...it was actually a useful time to reflect on that, on what was stuff that was actually buzzing round my head that week'. (1:2:8)

'It's nice to look back and see where you once were and where you are now'. (1:9:30)

'When I did the writing, I had to think about things more. So you go into the depths of things'. (4:10:10)

In summary, by offering the space for reflection, writing seemed to provide participants with the opportunity to see things more clearly, take a different perspective and develop a coherent narrative, therefore allowing cognitive organisation of their experiences.

3.3.3 Perceived Outcomes

This final master theme (also considered a higher grouping on its own) assimilates all the outcomes reported by participants as a result of participating in the writing intervention. The majority of feedback highlighted positive consequences of writing, however there are a few exceptions to this.

Helpful

Writing was reported to be a beneficial experience for the majority of participants. They felt writing was a good idea, something they wouldn't have thought to do and reported that it had provided them with another coping mechanism for the future:

'It was very helpful. I found it a very positive thing'. (8:6:29)

'...given me another avenue that I can go down'. (2:8:9)

'I think it's a very good idea and it's something that I would like to carry on in my own time'. (3:9:11)

It seemed to provide participants with an experience of making progress and they described it as being the start of their situation improving:

'...doing the writing is a beginning'. (4:13:12)

'...this has opened a door, it's now stepping on the path'. (5:23:27)

One exception was someone who reported that the experience had been unpleasant:

'...reliving my life on paper. It just wasn't nice. There's nothing I liked about it'.

(6:12:3)

They reported no immediate benefit from writing, however, they were still hoping writing might have some beneficial outcome in the future:

'I think I'm yet to find out if it has been beneficial'. (6:5:12)

'I can hope, maybe in a few weeks time, a months time, I'll think oh that was good doing that. But at the moment it just... It hurt a lot. And it's stuff that I already know and stuff that I'd already handed over to her. I just mustn't think about it. Just get on with it'.

(6:16:2)

This participant seemed to indicate that the emotional distress caused by writing about their experience meant they should try to avoid thinking about it.

Emotional Impact

A moderate number of participants felt the main benefit of the writing had been on improving their mood. There was a sense that the writing had been therapeutic and had contributed to their improved general well-being:

'...I've actually I think been a little bit more relaxed and not feeling everything so intense...my whole mood sort of lifted'. (2:13:12)

'I've become a lot more calm about, about those kind of things really and less anxious the whole time'. (8:18:8)

Cognitive Impact

Participants reported a variety of cognitive benefits. Almost all of the participants reported a positive cognitive impact, with the exception of one participant who reported no benefit from participating in the writing intervention. Participants reported slightly different types of benefits however. These benefits included a change in their thinking and perception of their difficulties, as highlighted in the earlier master theme 'cognitive organisation'. This was a suggested underlying mechanism for the effects of writing:

'It doesn't bother me as much. My attitude has changed'. (1:12:31)

*'...didn't seem to be as intense the thoughts. You know, or make me feel as bad'.
(2:15:12)*

'I think doing the writing has helped, um, changed the way I think about the actual condition'. (5:23:29)

The writing provided an increased awareness of difficulties:

'I identified issues that clearly have troubled me but I didn't realize. I wrote an awful lot about my childhood and I hadn't realized it's a problem...it suddenly became clear actually how much of a problem it had been and perhaps how it shaped me and I didn't really acknowledge that until I did the writing'. (8:14:11)

A sense of being able to cope was described as a result of the writing, which was linked to being able to put things in perspective and therefore seeing problems as manageable:

'...it made me feel within myself stronger in myself and give me strength to feel I can, the situation I'm talking about, cope with it'. (4:7:10)

'...puts it more in perspective I suppose. Cope with it maybe more'. (9:6:30)

One participant in particular reported increased self esteem and confidence, which was supported in others' accounts:

'...it makes you feel more confident in yourself because a lot of the problems weren't of your making'. (9:13:13)

'I quite like me now, I didn't used to like me and I used to say nobody likes me'. (9:11:19)

Participants also described a sense of achievement as a result of completing the writing intervention:

'...actually doing, uh, fulfilling a task. It is almost like an achievement, even if it is just a little one'. (7:26:6)

'I have got this sense of achievement. I am damned if I'm going to let go of it, to be honest. Because I haven't felt this way. I mean it's a major step forward'. (5:23:24)

These numerous positive cognitive outcomes were repeatedly described by participants. One possible negative outcome was identified though. Four participants reported contrasting views with regards to their attitude towards themselves as a result of the writing. Two participants expressed the positive view that writing enabled them to be kinder to themselves:

'... if anything was just a message to, all this is happening emotionally, take it a bit easy on yourself. It was that kind of approach, so being a bit kinder'. (1:11:19)

'...I couldn't believe some of the things I'd written and I thought well, you know, maybe I am being a bit hard there and a bit judgmental'. (2:11:23)

Whereas, two other participants felt self critical towards themselves as a consequence of writing which clearly had a negative impact:

'If I looked at what I had written, I'd think well, that just sounds silly because I should be able to look at the positive side'. (3:3:9)

'I'm disgusted with myself being such a blubbering mess when I get to that topic'.

(6:19:2)

The participants who reported being kinder to themselves reported more positive outcomes on the whole as a result of writing, compared with the participants who expressed self criticism. In fact, both participants who were critical of their writing felt the intervention had not been particularly helpful. One of the participants was still able to report some positive aspects, but the other participant felt it had not been helpful at all.

Behavioural Impact

The behavioural impact of the writing can be related back to the master theme 'behavioural activation', in which participants reported that writing activated them to do something. This theme includes the changes in behaviour reported since completing the writing intervention. Participants reported increased activity levels as a result of the writing intervention compared with their prior levels. There was a sense of being able to do slightly more of the things that they used to:

'...actually probably in the last two or three weeks I have probably been doing a little bit more my normal things that I used to do. Perhaps not thinking so much and actually doing things'. (7:24:29)

*'I feel much better in myself and I've started doing some things that I didn't do before'.
(before doing the writing) (9:13:6)*

A number of participants also reported that writing facilitated problem solving and showed them a way forward:

'It clarifies everything so that you can identify what the problem is and then start to figure out, well what am I going to do about it'. (3:10:1)

'I know from the writing what I'm going to do'. (4:9:18)

This was the complete opposite for the participant who did not find the writing intervention helpful. They felt there was no option for solving the problem and this was the frustrating part for them:

'I can't do anything about this particular thing so I just drag myself around'. (6:14:12)

Other interesting comments participants made included one participant who felt they no longer felt the urge to talk about their experiences, as having disclosed them in the writing had made them feel it had been dealt with:

'...it's probably made me not want to talk about it. Because I feel probably, perhaps by writing it all down I have sort of dealt with it on my own in a way. And I don't need to talk about it so much'. (7:23:27)

Another participant felt they had consciously changed their behaviour:

'...because I understand more about why I feel the way I do or why I behave the way I do. I think I now behave slightly differently...with my parents, I'm interacting with them differently...I'm able to modify my behaviour'. (8:15:1)

In addition, two participants reported the writing had facilitated their communication with others:

'Actually in the last few weeks I have done quite a lot more. Particularly contacting people. Speaking to people. Sending e-mails and things like that. Communicating...by writing things down, um perhaps you sort of felt that it helps you with communicating perhaps a little bit'. (7:25:9)

Physical Impact

Participants made little reference to the physical impact of the writing. There was a sense that the main benefits of writing were not changes in their physical symptoms or fatigue levels. However, one participant stated the writing did help them physically:

'I was just amazed at how much better I felt the next day. You know and the good nights sleep that I got, that's what really struck me'. (2:18:26)

Despite this, the general consensus among participants was that writing helped them to cope with their difficulties but had no impact physically:

'I think its done a lot to help me, um, mentally if you like, in dealing with the issues but I don't think physically it made any difference'. (8:10:29)

Overall, the benefits of writing reported in interviews were widespread and varied for different participants. These benefits seemed less related to improvements in their physical condition and more closely associated with their psychological well-being.

Results Summary

The results of the study indicate that the expressive writing intervention was both feasible and acceptable to this group of participants. All participants adhered to the writing instructions and wrote about emotionally distressing experiences. None of the participants dropped out during the intervention and they completed all the necessary questionnaires.

Interpretative Phenomenological Analysis of the interview transcripts identified three higher groupings which incorporated the six master themes that emerged:

- 1) Participants 'overall experience' of the expressive writing intervention including their preliminary expectations and concerns and their actual experience of the writing.
- 2) 'Mechanisms of action' underlying expressive writing proposed by participants including emotional expression, behavioural activation and cognitive organisation.
- 3) 'Perceived outcomes' of the expressive writing intervention by participants.

These results will be further addressed in the next chapter.

4. Discussion

This chapter will begin with a review of the aims, method and main findings of the current study. It will present a discussion of these findings and will relate them to the existing literature. Methodological issues which may have influenced the quality of the data obtained and the interpretation of these data will then be considered, along with issues of good practice in qualitative research. Finally, the clinical implications of this study will be discussed and suggestions for further research will be made.

4.1 Review of the aims, method and main findings

The aim of this study was to pilot an expressive writing intervention for people with Chronic Fatigue Syndrome (CFS) and to explore their experience of it. It aimed to investigate the feasibility, acceptability and perceived helpfulness of the expressive writing intervention for people with CFS. It also aimed to shed light on the possible mechanism of action underlying the effects of the expressive writing paradigm.

Nine patients were recruited from the cognitive behaviour therapy (CBT) waiting list of a specialist CFS clinic to participate in the expressive writing intervention. They were asked to write about their deepest thoughts and feelings regarding a traumatic or emotionally upsetting experience for twenty minutes, once a week, for four weeks. Following the intervention, the participants took part in a semi-structured interview to explore their experience of the writing intervention. The main areas they were asked about were: initial reactions to the idea of expressive writing, how they found the writing

intervention, whether it was helpful and how they thought it might be helping. The interviews were then analysed using interpretative phenomenological analysis (IPA).

The results of this study indicate that the expressive writing intervention was both feasible and acceptable to this group of participants. All participants reported adhering to the writing protocol at interview and their manuscripts showed they wrote about emotionally distressing experiences. In addition, they reported no problems with the practical aspects of the writing intervention. None of the participants dropped out during the intervention and they completed the questionnaires at each time point.

Analysis of the interview transcripts using IPA identified six master themes.

‘Expectations and concerns’ and ‘The experience of writing’ together formed the higher grouping ‘Overall experience’; ‘Emotional expression’, ‘Behavioural activation’ and ‘Cognitive organisation’ together formed the higher grouping ‘Mechanisms of Action’; and ‘Perceived outcomes’ remained a separate group.

Despite initial concerns about the expressive writing intervention, participants reported it to be helpful. It was generally considered to be psychologically beneficial, but was not perceived to have any direct impact on the physical symptoms of their CFS. A single mechanism to account for the reported positive outcomes of the writing intervention was not identified. Instead, participants’ reports lent support to three possible pathways: emotional, behavioural and cognitive. Cognitive organisation appeared to be the most consistently supported mechanism by participants, as suggested by the variety of cognitive benefits they reported and the prevalence of quotes for this theme.

4.2 Further Discussion of Results

4.2.1 Feasibility and Acceptability

Participants reported no problems with adhering to the writing protocol, none of them dropped out during the intervention period and eight out of nine of the participants reported it to be helpful. Taken together this suggests the writing intervention was both feasible and acceptable to this particular group of CFS patients. However, initial uptake of the writing intervention seemed to be low. A large number of people with CFS were asked to participate and only a small proportion agreed, possibly as low as 10%. It is unfortunate that an exact figure can not be determined due to lack of data, as this would provided further information regarding the acceptability of the intervention. Given this apparent low uptake, it seems likely that the writing intervention appealed to a particular group of people with CFS.

A number of hypotheses can be considered to account for the low uptake. For example, as patients were being assessed for CBT, they may have been less interested in participating in research into alternative interventions in the interim. It may be that they were concerned that participating in the research would delay their therapy or that they did not feel the need for a different intervention given their forthcoming CBT. In addition, it may be that after a two hour assessment at the clinic, they were particularly fatigued and viewed participating in the research as an additional burden.

The original design of the intervention may also have discouraged participation. It was initially planned to carry out the writing intervention in line with previous research, by having participants attend the clinic to do the writing. However, after two months of

trying to recruit this was changed as none of the people asked to participate were interested. Therapists reported that the reason given most frequently by participants was that it would be too tiring for them to travel to the clinic weekly, particularly given the long distances some patients were travelling. As a result it was decided to change the expressive writing to a home-based intervention, so that it would be more acceptable to participants. Altering treatment for people with CFS has also been necessary in the past in order to engage them with services. An example of this is the adaptation of standard CBT to a combined self-help and telephone intervention for people with CFS, who reported being too fatigued to travel to out-patient appointments (Burgess & Chalder, 2001). This adaptation proved successful and resulted in improved outcomes for participants. Similarly, the adaptation of the expressive writing intervention in this study improved uptake, suggesting a home-based intervention was more acceptable for these patients.

People with CFS also tend to minimise the psychological contributions to their condition and often attribute their illness to physical causes (Afari & Buchwald, 2003). This suggests that the psychological focus of the expressive writing intervention may not have been acceptable to patients, thus reducing uptake. However, this seems unlikely given that patients were being assessed for CBT, suggesting these CFS patients were able to consider psychological aspects of their condition. Alternatively, it may have been that CBT was viewed as an activity based intervention aimed at reducing fatigue, whereas writing about general emotional experiences may have been viewed as solely emotional. Participants may have perceived this to have less face validity and to be unlikely to help them. Norman and colleagues (2004) suggest that writing about stress

secondary to a condition, is more likely to be acceptable to patients, than writing about general stress. It may be that uptake of the intervention would have been improved by having participants write specifically about their CFS. Finally, it could be that CBT, as the most well supported treatment approach to date (Afari & Buchwald, 2003), was seen as recommended, whereas writing has not yet been shown to be helpful for people with CFS. Therefore, patients may not have wished to invest energy in something that might not help, that did not provide a clear explanation of its effects and likely outcomes, and that might result in greater cost than benefit.

A final point worth considering with regards to the low uptake in this study is the reliance on other professionals for recruiting participants. Verbal reports from professionals indicated that they sometimes forgot to inform participants about the research due to lengthy assessment sessions. In addition, there was some confusion regarding the procedure to follow if people were interested, which meant some patients who expressed interest in participating in the study were not followed up. As a result, it is possible that if recruitment had been the responsibility of the researcher alone, uptake may have been improved.

4.2.2 Overall Experience

Expectations and concerns

Participants appeared open-minded and curious about the expressive writing intervention as it was an unfamiliar approach to them. They did not know what to expect from the writing and reported uncertainty regarding its likely benefit. They also reported concern about the emotional impact of the writing and anticipated possible difficulties with doing

it, such as whether they would be able to write for the full twenty minutes. This may further explain why the take up rate of the intervention was poor. It may be that for some people the initial uncertainty about how the writing might help, as well as concern regarding its emotional impact, was sufficient to discourage them from participation. Crockett and colleagues (2003) suggest that a more positive response to expressive writing as an intervention might be obtained if there was a greater understanding of how the intervention worked which could be shared with potential participants. It might, therefore, be helpful to alter the information sheet given to participants in future research to take into account this idea. An additional point is that the group of participants in this study were open-minded to a psychological intervention, whereas, as previously mentioned, people with CFS often minimise the psychological contributions to their condition. This implies that expressive writing as an intervention may only be acceptable to a limited group of people with CFS.

The Experience of Writing

Overall, participants described finding the writing intervention fairly easy once they became engaged in it. They said it gave them space, to focus on themselves and to think about things that they often tried to put out of their minds. They seemed to find writing easier than talking and they reported additional benefit associated with re-reading their writing afterwards. Participants evaluated the practical aspects of the intervention in a generally positive light. Negative aspects of writing were also identified, in particular, the experience of emotional distress whilst writing and for a short time afterwards.

The idea of 'getting going' with the writing and becoming absorbed by it highlighted a potential difficulty with ensuring complete adherence to the writing protocol. Two participants reported that they found it difficult to stop after the twenty minutes on one occasion as they felt they had not finished, so they carried on writing for a short time until they had. As this was only for an additional 10-15 minutes on one occasion, it is unlikely to have made a difference to the overall effects of the writing. Research suggests there is little impact of length of writing time on outcome (Smyth, 1998); however, it is still a consideration for future research that might look at the efficacy of the writing intervention with people with CFS in a controlled study. The flexibility allowed in this study for participants to do the writing at their convenience might need to be reconsidered. The original idea for the researcher to telephone participants both before and after the writing might reduce the likelihood that they would continue writing for longer than the specified time. Although not feasible in this study, it would be an important issue to address in future research.

Confronting the problem was considered by most participants to be a benefit of the writing, allowing them space to think about their difficulties. Pennebaker (2004) states this is an important aspect of writing as it forces people to think about their emotional upheavals and their lives in general. However, one participant reported they found it extremely hard to confront their difficult experiences. Although they did write about these experiences, they reported doing so in an unemotional way and felt because of this they received less benefit from the intervention. Research supports this idea as Pennebaker & Beall (1986) found no positive effects of writing about traumatic experiences when emotional content was avoided. The participant expressed concern

that thinking about their difficulties might impair their ability to cope and felt they could not risk this occurring. This has implications for the use of the expressive writing intervention as it may be unsuitable for people who engage in extensive avoidance. In the study by Stanton and colleagues (2002), who investigated the use of expressive writing with women with breast cancer, it was reported that those low in avoidance benefited most from expressive writing. In contrast, women who exhibited high levels of avoidance were found to benefit most by focusing on the positive aspects of their breast cancer experience. They suggest that asking people to explore their deepest thoughts and feelings about a negative experience may be threatening when they have devoted considerable effort to avoiding those experiences. The conclusion they draw is that level of avoidance may moderate the effects of writing, indicating that people with high levels of avoidance would not be suited to this intervention.

Writing was reported by the majority of participants to be an easier medium than talking to others. They felt able to write about things they could not talk about and said they did not have to hold back for fear of being judged by others. This potential advantage of writing about emotions over talking about them was highlighted by Kelly and McKillop (1996), who stated that writing provided the opportunity for individuals to express emotions without the risk of negative or inappropriate reactions. Participants' reports in this study seem to support this claim. One participant said they found the writing intervention better than previous counselling they had received. This was reported to be because they were not interrupted when writing, so their thoughts were able to run and they were able to question things themselves. This suggests that for some people writing about emotional experiences might be better than talking about them.

A comparison of writing and talking has been investigated in previous research. Donnelly & Murray (1991) examined differences in oral and written expression in undergraduate students who were randomly assigned to one of three conditions: writing about a traumatic event, writing about a trivial life event or talking to a therapist about a traumatic event. Participants wrote or talked for thirty minutes over the course of four sessions. Both writing and talking to a therapist were found to result in reduced negative mood and increased self-esteem. But, immediately following the writing session participants showed an increase in negative mood and a decline in positive mood; this was not the case for those who had talked with a therapist. In another study, Murray & Segal (1994) examined differences between writing and talking into a tape recorder about a traumatic experience. Undergraduate students wrote or talked into a tape recorder for twenty minutes per day over a four day period. Participants in both the writing and talking groups reported improved self-esteem, feeling significantly better about their traumatic experience and an increased use of adaptive coping strategies. Participants in both conditions also showed an increase in negative mood after each session.

Whilst this experience of negative mood following writing has been consistently found in expressive writing research (Pennebaker & Beall, 1986; Smyth, 1998), it seems from the above research that talking to a therapist does not result in this effect. The implication is that although both writing and talking to a therapist result in positive outcomes, the presence of a therapist during the emotional expression of a traumatic experience moderates the occurrence of negative mood immediately afterwards. This is an important difference between expressive writing and talking to a therapist, and is

likely to have clinical implications with regards to who this intervention might best be suited. In the above research, participants are healthy undergraduates and the induction of negative mood immediately following writing is a short-term effect. In clinical populations, however, the induction of negative mood following writing might be longer lasting or could affect the longer-term outcome. It seems that although the majority of participants in this study reported writing to be easier than talking, writing may have some limitations that talking does not.

Unsurprisingly, participants in this study also experienced emotional distress in response to the writing intervention and reported it to be one of the negative aspects of their experience. They described experiencing emotional distress during the writing sessions and for a short time post-writing, as is consistent with previous expressive writing research (Pennebaker & Beall, 1986; Smyth, 1998). Most participants felt this was a difficult but helpful part of the writing and reported that the negative feelings dissipated after a short time. One participant, however, described the writing intervention as a painful experience and felt they received no benefit from it. In fact, they reported prolonged distress following the writing, difficulty managing this distress and said that overall the experience had been aversive. It was noted this participant scored in the case range for depression on the HADS pre and post-writing and at follow up. This may indicate that for people with high negative affect, addressing emotional experiences through writing may not be an appropriate intervention without the support of a therapist.

This idea is supported by Norman and colleagues (2004), who reported that many of the participants in their study of expressive writing with women with chronic pelvic pain had current or lifetime depression. They suggest that depression may have led some of the women to have difficulty managing the negative affect aroused by the writing task and this may have contributed to the limited effects of writing. In addition, the mixed findings in expressive writing research with clinical populations could be attributable to this variability in emotional disorder, suggesting that the writing paradigm may work best for those with low to moderate levels of symptomatology and may only serve to increase emotional associations for those with more severe levels of psychopathology (Sloan & Marx, 2004).

However, in this study, four participants in total had scores in the case range for depression on the HADS pre-writing. These include: the participant who experienced prolonged distress in response to the writing, the participant who expressed difficulties with the intervention in terms of confronting emotional experiences, and two more participants who did not experience any difficulties. These last two participants reported a positive experience of the writing intervention and described beneficial outcomes as a result. In addition, their HADS depression score had moved into the normal range at follow up. This seems to contradict the idea that people with high negative affect cannot benefit from the expressive writing intervention. It is clear, therefore, that further research is needed to understand for whom expressive writing can be helpful and for whom it may not have the desired effects.

One additional aspect of the writing that was identified as a negative aspect for a minority of participants, was the difficulty associated with physically writing. One participant, in particular, reported that this difficulty increased their frustration with their CFS. This participant felt that it would have been easier if they had been allowed to type, as they were more used to using a computer than writing long hand. Interestingly, research by Brewin and Lennard (1999) who compared the experience of writing long hand with typing, found that those who typed obtained less benefit. They suggested that the ability to type competently affected the ability to benefit from the writing intervention, because typing is not fully routinised for most adults and it therefore carries an additional cognitive burden. It may be that the reverse was true for the participant in this study, who reported they had to concentrate on trying to make their writing legible throughout each writing session, as well as combat the fatigue associated with writing. Had the participant been allowed to type, which they reported would have been easier, they may not have experienced as much frustration with their condition and may have been able to focus more on what they were writing than on how they were writing. This in turn may have further increased their benefit from the writing intervention. This suggests that matching the appropriate format of the writing to the individual should be considered in future research in order to maximise their gains.

4.2.3 Mechanisms of Action and Perceived Outcomes

In this section, mechanisms of action and perceived outcomes of the expressive writing intervention will be discussed together. These are directly linked because discussion of participants' positive outcomes in the interviews generated ideas about how the intervention worked.

Emotional Expression

Participants' reports highlighted reliving emotions and emotional release as ways in which expressive writing helped them. Specifically they said that they re-experienced the emotions associated with the experiences they were writing about and that they were able to express negative emotions and release repressed emotion. Emotional expression was seen as a positive experience on the whole, even though it seemed to increase emotional distress in the short term. Some of the participants suggested that this process resulted in improvements in their mood and emotional well-being, allowing them to feel more relaxed.

This idea relates to Pennebaker's (1989) theory of inhibition which suggests that the reduction of active inhibition of emotion results in decreased autonomic arousal. One participant's view that the writing helped them to release emotions they had 'bottled up' thus helping them to feel more relaxed, supports this notion of reduced inhibition. In fact, this participant suggested that the more negative emotion they expressed, the better they felt afterwards. This participant and a moderate number of others also felt they were able to write about experiences they could not talk about and were able to write whatever they wanted. This also contributes to the idea that writing reduced the inhibition of negative emotion associated with traumatic experiences. One participant who reported limited benefit from the intervention attributed this to being unable to express their negative emotions and 'bottling up' their feelings. This lends further support to the idea that emotional expression is required to benefit from the intervention.

An inconsistency here, however, is that the participant that reported prolonged distress following the writing also reported re-experiencing the emotions associated with the experience they wrote about. They felt that this re-experiencing of emotions was in no way helpful and if anything reliving the trauma made them feel worse across all of the writing sessions. This might suggest that emotional expression is necessary but not sufficient to produce positive outcomes.

This might also be questionable though, as another participant who reported benefit from the intervention did not report experiencing emotional distress. They claimed they were able to stay detached whilst writing and felt this had been helpful. This participant had received counselling in the past and felt it had been an emotional experience but had not resolved the issue, whereas they felt that being detached during the writing had helped them to 'let go' of the experience. It seems, therefore, that different people experienced different benefits from the writing suggesting that different mechanisms may have been working for each of them. Or that a number of mechanisms were working simultaneously and that one mechanism may have been more helpful to one person than to another.

An additional point regarding emotional expression is that participants did not specify whether there was a reduction in intensity of emotion experienced across writing sessions. In some cases it was clear there was no reduction in the emotional distress experienced. As this was not explicitly stated there does not seem to be any direct support for the exposure hypothesis from participants' reports. It is important to note though that not all participants wrote about the same experiences across each of the

writing sessions, which means repeated exposure to the same distressing situation did not occur. Participants' reports in this study therefore cannot really shed light on the idea of exposure as a mechanism underlying expressive writing.

Behavioural Activation

Behavioural activation was reported by a minority of participants. Their reports suggested that the writing motivated them to do something about the experience they wrote about or triggered something which led directly to behavioural change, for example, seeking their rights or changing their routine. One participant, in particular, endorsed this view suggesting the writing had 'put on a switch' and had a knock on effect on their life in general.

Other participants also reported behavioural change as a result of writing. For example, consciously interacting with people differently, increased communication with others via a number of mediums and being able to do more of the things they used to. However, these participants did not suggest this as a way in which the writing worked. Instead they explained these behavioural changes as resulting from cognitive change. For example, one participant said that because the writing enabled them to see things differently, they felt more confident and so began doing activities they used to do prior to their diagnosis of CFS. It may be then, that the theme 'behavioural activation' is not an independent mechanism of action, but that behavioural change is actually mediated by cognitive organisation.

Cognitive Organisation

Cognitive organisation includes a number of cognitive aspects that participants thought might account for the positive effects of the writing. There was a sense that experiences seemed clearer on paper and looked different written down, as opposed to being a jumble of thoughts in their mind. This enabled participants to take a different perspective with regards to their experiences, to be more objective and analytical and to reappraise things. Participants reported that writing forced them to structure their experiences by having to write in a coherent way and organising the information with the audience in mind. It also allowed participants to think about their experiences and their life in more detail. In addition, a number of cognitive benefits were reported. Participants described a change in their thinking, an increased awareness of their difficulties, a sense of being able to cope, increased self-esteem and confidence, a sense of achievement and less self criticism.

Previous research can be linked to these ideas of cognitive organisation and provides support for this as a mechanism underlying the effects of writing. Participants in other studies have reported that writing enabled them to view past experiences differently (Pennebaker, 1989) suggesting participants' views in this study are similar. Most of the participants in this study endorsed this view and gave examples of how their views had changed as a result of writing and the positive effect this had. An interesting contrast regarding this aspect of the writing was noted with the participant who did not report any benefit from the intervention. This participant implied there was no other way to view their experience. It could, therefore, be hypothesised that the reason for the lack of benefit they experienced was due to this inability to see things differently.

The suggestion of coherence as a key factor in expressive writing (Pennebaker & Segal, 1999) is also supported by participants' understanding of the expressive writing intervention in this study. Research suggests that writing about an event and its emotions, making sense of it and structuring it into a narrative promotes assimilation and enables resolution of the experience (Pennebaker & Segal, 1999). One participant in this study reported telling their life story over the course of the writing and this was verified by checking the manuscript. They reported great benefit from doing this and reported that it enabled them to understand themselves better and to make sense of their experiences. However, many of the other participants' manuscripts did not seem to tell a story, nor did they report actively trying to do this. This might suggest that coherence was of less importance for this group of participants, than being able to take a different perspective of their past experiences and being objective. Claims cannot really be made about the development of coherence and a narrative across writing sessions though, as detailed analysis of the manuscripts was not carried out. Many of the participants wrote about different topics each writing session suggesting this might make it hard to develop a narrative across the sessions. The manuscripts in this study would require further analysis before statements regarding the development of a narrative were made.

The integration of both cognitive and emotional processes may be indicated from the findings of this study. The majority of participants seemed to attribute the benefits of the writing intervention to releasing negative emotion as well as to cognitive organisation. It would appear, however, that participants need not only to express emotions but also to reappraise their cognitions related to the event. This is based on the finding that the participant who reported no benefit in this study was able to express

negative emotion, suggesting this alone was not sufficient to produce a beneficial outcome. This is supported by research which has demonstrated that those who are highly emotional across all four days of writing but who do not show cognitive change do not experience any health benefits (Pennebaker, 1997a). Therefore, it could be hypothesised that it is the cognitive reappraisal of the event not just the expression of feelings that allows for improvements in mood and well-being. In addition, the reports of one of the participants who endorsed a sense of behavioural activation as a result of writing, also highlights this possibility that cognitive organisation is the most important mechanism at work. This participant related their behavioural activation to being able to take a different perspective towards their condition, implying this cognitive shift mediated the behavioural effects they experienced.

Overall, participants' reports have provided insight into how the expressive writing intervention may have helped them. Although conclusions regarding the precise mechanisms cannot be made, the identification of emotional expression, behavioural activation and cognitive organisation might indicate areas for further research. There was a great deal of support in particular for the idea of cognitive change. This supports current research. It could be that emotional expression plays an important part of the writing intervention for some individuals, whereas the crucial factor in obtaining positive outcomes could be cognitive change.

4.3 Methodological Issues

This section will consider methodological issues in this research and the impact these issues may have had on the quality of the data obtained and the interpretation of this data.

Sample

The findings of this study are based on the reports of nine participants with CFS. The small sample size clearly limits the extent to which conclusions can be drawn about the expressive writing intervention in relation to the wider population of people with CFS. Demographic data (reported in the method chapter) reveal a number of biases suggesting participants in this research may not have been representative of the CFS population in general. All but one of the participants were female and the majority of the sample were white British. Research suggests there is an increased prevalence of CFS among white people in clinic populations attributable to health care access and utilization (Afar & Buchwald, 2003). This may account for the bias in this study.

In addition, participants were recruited from a specialist service suggesting they may have had different characteristics to people with CFS in other settings. Patients seen in specialist clinics tend to have a longer duration of fatigue, higher levels of fatigue, more somatic symptoms and more functional impairment than those seen in primary care (Wessely et al., 1998a). It is clear from participants' scores on the Fatigue scale in this study that a chronic level of fatigue was present across all participants. This may have contributed to the negligible impact of the writing intervention on the physical symptoms of participants in this sample.

Variability within the sample can be seen, with respect to age, duration of illness, medication use, previous therapy, presence of emotional disorder and functional impairment. This variability further limits the general claims that can be made from the findings of this study. In qualitative research, some degree of homogeneity within the sample is considered an advantage so that statements can be made about the group of people interviewed as a whole. Whilst these findings are not generalisable, it is hoped that they reflect the experience of the sample interviewed and that they allow for meaningful suggestions to be made relating to the expressive writing intervention for people with CFS. Further research including a wider variety of people with CFS and a larger number of participants would be needed to make claims about the writing intervention for people with CFS in general.

Measures

Three measures were piloted in this study: the Fatigue Scale (Chalder et al., 1993), the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) and the Work and Social Adjustment Scale (WSAS; Marks, 1986). Participants' scores on these measures have been presented in the Results chapter. These measures provide information regarding variability within the sample and the suitability of the measures themselves. Characteristics of the participants have been considered in the discussion of the sample above; this section will further address the suitability of the measures.

From the questionnaire scores in appendix 8, it can be seen that there was only a slight mean decrease in participants' scores across all three of the measures used, which is at odds with participants' verbal reports. This could be due to the length of the follow up

period, which was only two weeks after the intervention, compared with a few months in much of the expressive writing research. Previous research has found that improvement as a result of expressive writing was not evident until the four month follow up assessment for some patient groups (Pennebaker, 2004). It is unfortunate that the follow up period could not have been longer in this study but two factors prevented this. The time constraints of the research meant a longer follow up was not possible. In addition, participants were waiting to begin their CBT and a longer follow up would have resulted in delaying their therapy. It was felt that this would be unethical, as well as unacceptable to participants.

Another consideration would be the use of self-report questionnaires alone as outcome measures. Pennebaker (2004) suggests that self-reports give us an insight into people's theories of themselves, but these are often only modestly related to real world behaviours. In light of this, it may be useful to include actual activity levels as a behavioural outcome measure in addition to self-report measures in future research. For example, participants' subjective perception of their level of fatigue may not be any different in the short term, but they may be able to do more (as is reported in this study) which might be missed as an improved outcome if not directly measured. Similarly, in future research a measure of immune functioning or another physical health measure would provide an additional objective way to measure outcome.

Quality of Interview Data

The quality of the interview data in this research may have been affected by a number of factors. First, the inexperience of the researcher in semi-structured interviewing may

have resulted in leading questions, clumsy or directive utterances at times and the occasional use of hypothetical questions. The lack of opportunity to pilot the interview schedule means that early interviews may have been of a poorer quality than later interviews. Indeed, the researcher noticed her interviewing techniques improving over the course of the study suggesting this was the case. A second factor is that how articulate participants were may have impacted on the responses they were able to provide. The researcher noticed that some participants were less able than others to explain how they thought the writing intervention helped them, which may have biased the findings towards the responses given by those who were better able to communicate their ideas. Third, social desirability may have played a role in participants' responses. It is possible that as participants were aware that this was a trainee project to develop the writing intervention, they may have wanted to give positive feedback. In an attempt to minimise this, the researcher specifically asked participants for aspects they disliked about the writing intervention. All the participants gave some negative feedback, suggesting they did not feel the need to report only positive aspects of the writing and were able to be critical at least some of the time.

Overall, despite these limitations the variability of themes identified and the quality of the textual illustrations drawn from across transcripts (including earlier interviews), indicate that data obtained were of high enough quality to provide valid information about participants experience of the expressive writing intervention.

Good Practice in Qualitative Research

This research has attempted to adhere to good practice guidelines for qualitative research (Elliot et al., 1999) in order to maximise reliability and validity, and to minimise the impact of researcher bias. The researcher's perspective has been made clear in the method chapter and a separate section discussing the possible impact of this on the research is provided below. Care has been taken to situate the sample by describing the characteristics of participants (including their age, gender, ethnicity, duration of their illness, employment status, prescribed medication and experience of therapy) and to be open about the process of recruitment; these are detailed in the method chapter.

Similarly, care has been taken to ground all themes in examples by providing a balance of narrative text with associated quotes from the participants' transcripts. This is to ensure transparency so that the fit between the quotes and the researcher's interpretation can be determined. The analysis involved an experienced qualitative researcher to provide credibility checks to ensure the validity of interpretations of the data. This researcher served as an auditor in ascertaining the goodness of fit of emerging themes.

One good practice guideline that could not be followed was giving the themes to participants following the analysis. The idea behind this is to see whether the themes identified by the researcher resonate with the participants. Unfortunately the time constraints of this research meant this particular recommendation could not be carried out. This final procedure would have strengthened the findings of this research and would have improved its validity by presenting a more collaborative analysis utilising the feedback of the participants themselves.

Analysis

The method of data analysis used in this research can be discussed in terms of strengths and limitations. IPA is concerned with individual's lived experience and their perceptions of the phenomena under investigation. It allows detailed analysis of rich material from the participants' narratives and offers a systematic procedure by which the researcher can interpret the emerging data. This approach offers clear benefits to this study, which sought to elicit participants' own views about the expressive writing intervention and their individual perceptions of how it was working.

However, this method has been criticised for failing to consider that accessing individuals' experience is not straightforward. Willig (2001) argues that attempts to access an individual's experience are biased by the researcher's own assumptions and beliefs. Therefore, in this study, in accordance with good practice guidelines, consideration of the researcher's perspective was included. Willig (2001) also argues that IPA equates an individual's account of their experience with the experience itself, thus failing to recognise the ways in which language constructs rather than describes experience. She criticises IPA for adopting a descriptive stance to analysis, arguing that appearances of experiences do not reflect their origins. She also proposes that the language individuals use informs us about how and why they talk in particular ways, rather than telling us about the experience itself. It is perhaps relevant then, to question the extent to which the participants' accounts in this study reflect a particular construction of their experience for a particular purpose in a particular context.

A final aspect of IPA to consider is the emphasis on the expertise of the researcher in judging whether something is a valid inference. The ability to make these judgements may be difficult when new to this method of research, thus affecting the quality of the findings. In this study, the inexperience of the researcher was addressed by involving an experienced qualitative researcher in the analysis, as mentioned earlier. It is hoped that this will have minimised the impact of the researcher's inexperience in using IPA on the interpretation of data.

Researcher's Perspective

Researcher bias may compromise the validity of findings in qualitative research because the interpretation of the data is inevitably done through the lens of the researcher's own experience. An important aspect of this approach to research, therefore, is to reflect on the process of analysis and think about how one's own assumptions and beliefs might influence the research process. It is for this reason that the researcher's perspective section was included in the method chapter. The impact of my therapeutic orientation as described in the method chapter and my background knowledge of expressive writing shall now be considered further.

My predominant use of cognitive behavioural models in my clinical practice is likely to have influenced my thinking about the experience of participants both within the interview and during the process of analysis. Coming from this perspective, I was perhaps most interested in how participants made sense of their experience and how the writing intervention impacted upon their thoughts, feelings and behaviour. It is likely that I would have been looking for those aspects in participants' reports and as a result

may have neglected other things participants were communicating. In addition, my knowledge of theories regarding the possible mechanisms of action underlying the expressive writing intervention may have influenced the interviews and analysis. Again, it is likely that I may have paid attention to ideas generated by participants that fitted with these hypotheses, at the expense of other suggestions they were making.

However, my commitment to hearing participants' own opinions and accepting their views as important and valuable will hopefully have minimised these influences. I was open with participants that an underlying mechanism had not yet been identified and that there was uncertainty regarding the likely benefits of expressive writing. I made it clear, therefore, that I was interested in both good and bad aspects of the intervention and was genuinely interested in their understanding of how it did or did not help them.

4.4 Clinical Implications

The findings from this study indicate that a home-based expressive writing intervention can be helpful for some people with CFS. This suggests that it may provide a promising avenue for people with CFS who cannot utilise other approaches, such as CBT and graded exercise. However, the promotion of expressive writing as a stand alone intervention for people with CFS is premature. In fact, there seem to be a number of possible contraindications for the use of this method, given the apparent difficulties experienced by some of the participants in this study.

The first is the use of this intervention with people suffering from depression. In this study, one of the participants who scored in the case range for depression on the HADS

reported experiencing prolonged distress following the writing sessions. Although this was not the case for the other participants who also scored in the case range for depression, it does highlight a concern with inducing negative mood through expressive writing in individuals who already experience a high level of negative affect. This may indicate that screening should be carried out to determine participants' emotional well-being before the expressive writing intervention is used, particularly with clinical populations.

The second possible contraindication is the use of expressive writing with people who exhibit high levels of avoidance. People vary in the extent to which they are comfortable expressing emotion and individuals who are uncomfortable with it, tend to avoid it. Being forced to confront these emotions through the writing intervention may result in the experience of overwhelming emotions that have previously been avoided, as was the case for the participant mentioned earlier. Another participant in this study also reported extensive avoidance, but this did not appear to lead to overwhelming emotion. Instead, it seemed to threaten their existing coping strategy and resulted in limited benefits from the writing intervention.

These two observations of participants' difficulties suggest that further research is required to determine whether individuals who suffer from depression or who engage in extensive avoidance are appropriate candidates for the expressive writing intervention. At present, the findings from this study and from previous research with other clinical populations (Stanton et al., 2002; Norman et al., 2004) suggest these two factors may contraindicate the use of the writing intervention.

The idea of integrating the expressive writing intervention with therapy was suggested by one participant in this study, as she felt it would have been helpful to have a follow up to discuss issues that had been raised through the writing. This would be an interesting adaptation of the writing intervention and would promote the subsequent therapeutic discussion of written material. It would also ensure that participants who experienced negative effects in response to writing would have an option to discuss these in a contained environment. The support from this study for cognitive organisation as a possible mechanism of action underlying expressive writing, as well as support from previous research, suggests that cognitive behavioural therapies or narrative approaches might best be suited to the integration of expressive writing. In the long term, if writing were to be integrated into clinical interventions, there would need to be a clear understanding of the mechanisms through which it worked in order to allow people to weigh up the benefits of participation with its costs.

One other clinical consideration with regards to expressive writing is the use of it as a form of self-help. In this study participants completed the writing at home, which required limited supervision and they exerted a degree of control over it. Smyth & Helm (2003) highlight that expressive writing does not require trained professionals, nor does it require expensive equipment. Taken together, this suggests that writing might lend itself to this format of therapeutic intervention. Future research would need to be conducted to provide support for this idea.

4.5 Suggestions for Further Research

Suggestions for improvements to this study and for further research have been highlighted at various points in the discussion. Here, these shall be drawn together to identify the most useful avenues for future research.

There are a number of improvements that could be made to this study. The first change would be to alter the recruitment strategy. It was initially decided that therapists at the clinic would approach patients about participation in the study to maximise patient confidentiality. This procedure was not very successful and in hindsight it would have been better for the researcher to contact patients directly so that the rationale of the study could be fully explained. This approach would also have meant that the researcher could have effectively recorded information regarding uptake to be able to further comment on the feasibility and acceptability of the intervention.

Piloting of the semi-structured interview would also be carried out to provide the researcher with experience of this style of interviewing. This might improve the quality of the data obtained, as well as the quality of the subsequent analysis. Following the analysis, in a future study the researcher would ensure that participants were given the themes identified to provide testimonial validity and allow for a collaborative process of analysis. This might further reduce researcher bias and increase the validity of the research as a whole.

In light of the findings from this study, future research using this intervention with people with CFS, might be better emphasising the possible psychological benefits of the

intervention. Participants in this study reported a number of psychological benefits from the writing but minimal physical benefits. Alteration to the information sheet given to participants, to include this information and to provide a preliminary explanation of how the writing might work, might also reduce uncertainty about the intervention thus improving uptake.

This study piloted the expressive writing intervention with a group of people with CFS and they reported a number of benefits from it. However, no claims can be made regarding the efficacy of the intervention or about generalisability due to the small sample size and the qualitative nature of the study. A randomised controlled trial (RCT) would need to be conducted to determine the efficacy of this intervention for people with CFS in general. In an RCT, adherence to the writing protocol would need to be monitored closely. In this study two participants ran over the writing time on one occasion. Therefore, to ensure participants were limiting their writing to the prescribed time they could be telephoned both before and after their writing. A longer term follow up would be required to identify the extent of the writing's effects and the use of objective measures as well as subjective measures would also be necessary.

Two participants in this study reported difficulties associated with the expressive writing intervention, highlighting the importance of identifying individual characteristics that may mediate its effects. It is important that future research determine for whom expressive writing has the desired effects and for whom it might actually be harmful. This study also shed light on the mechanisms of action underlying the effects of writing from the perspective of individuals with CFS, emphasising the likelihood for more than

one mechanism. It provided considerable support for existing hypotheses of cognitive organisation and highlights the need for further research of this mechanism. The findings from this study cannot in any way provide conclusive evidence for these suggested mechanisms, however, it has contributed to an understanding of the ways in which the writing intervention may have helped the participants in this study. Specific investigations of the mechanisms associated with writing are required, in particular, to simultaneously examine the possible hypotheses in relation to one another. This might help to elucidate whether there are a number of processes at work or whether one mechanism is responsible for the positive outcomes associated with expressive writing.

It seems there is much scope for further study of the expressive writing intervention in terms of its effectiveness with different clinical populations, in identifying potential individual difference moderators and in further elucidating its underlying mechanisms.

Conclusion

The findings from this exploratory study suggest that the expressive writing intervention was feasible and acceptable to the majority of participants with CFS in this study. The extent to which conclusions can be drawn about the expressive writing intervention in relation to the wider population of people with CFS is limited, however, due to the small sample size. Poor uptake of the intervention may also indicate that the sample in this study was biased and suggests that the intervention may only be acceptable to a particular group of people with CFS.

The results suggest that most of the participants in the study found the intervention helpful and reported numerous positive outcomes. It was generally considered by participants to be psychologically beneficial, but was not perceived to have any direct impact on the physical symptoms of their CFS. Two exceptions to the positive outcomes generally reported were noted, suggesting the use of the writing intervention might be contraindicated in people with high levels of negative affect or high levels of avoidance.

Finally, participants' reports in this study provided support for three mechanisms of action underlying the effects of expressive writing: emotional expression, behavioural activation and cognitive organisation. Emotional expression was considered to be an important aspect of the writing but not necessarily sufficient to result in positive outcomes. Behavioural activation received less support and was thought to perhaps be mediated by cognitive organisation. Cognitive organisation seemed to be the main mechanism endorsed by participants' in this study.

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Appendix 1: Ethical Committee Letter of Approval

**Institute of
Psychiatry**

at The Maudsley

Ethical Committee
(Research)
Research Ethics Co-ordinator
Margaret M Chambers Msc

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University of London

ETHICAL COMMITTEE (RESEARCH)

3 November 2003

Dr T Chalder
Dept of Psychological Medicine
103 Denmark Hill

Dear Dr Chalder

Re: Developing a therapeutic writing intervention for people with Chronic Fatigue Syndrome (142/03)

The Chair of the Ethical Committee (Research) has taken action to approve this study from an ethical point of view.


Please note that this approval is subject to confirmation by the full Committee when it meets on 21 November 2003. Initial approval is given for one year. This will be extended automatically only on completion of annual progress reports on the study when requested by the EC(R). Please note that as Principal Investigator you are responsible for ensuring these reports are sent to us.

Please note that projects which have not commenced within two years of original approval must be re-submitted to the EC(R).

Any serious adverse events which occur in connection with this study should be reported to the Committee using the attached form.

Please quote Study No. 142/03 in all future correspondence.

Yours sincerely,


Margaret M Chambers
Research Ethics Coordinator

Appendix 2: Information Sheet

You are being invited to take part in a research study being conducted by a trainee clinical psychologist. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and ask us if there is anything that is not clear.

Why am I being asked to take part?

The aim of this research project is to help us understand more about how to treat chronic fatigue syndrome (CFS). We would like to recruit patients with this condition to investigate a writing intervention, to see whether writing about emotional experiences has any impact on CFS in terms of symptoms and disability. There is evidence to suggest that writing can produce benefits for other patient populations (e.g. Rheumatoid Arthritis and Asthma) and can reduce disease activity and improve immunological markers. We are therefore interested to see whether this is also the case for people with CFS.

What will I have to do?

If you choose to take part in the study, you will be asked to *write* about emotionally upsetting and traumatic events, for twenty minutes once a week for four consecutive weeks. At the beginning of the study, you will be asked to complete an assessment over the telephone, as well as to fill out some questionnaires. You will then be asked to complete the four writing sessions in your own home. At the end of the final writing session and at two weeks follow up, you will be asked to complete another set of questionnaires. These will include questions relating to your symptoms and how they affect you and usually take about 10 minutes to complete. You will then be asked to attend the clinic *once*, two to four weeks after the end of the writing sessions, to take part in an interview which will be tape recorded. This will be to find out about your individual experience of the writing intervention and to hear what you thought was helpful or unhelpful. The tapes will be destroyed at the end of the study.

What will happen if I do not want to take part?

Involvement in the study is voluntary and if you do not want to take part in the research it will not affect the treatment you are offered. Similarly, if you initially agree to participate in the study but then decide you no longer wish to be involved, this will not affect your treatment.

Who will be able to see my forms?

The people who will be able to see your manuscripts are only those who are directly involved in the research. You will be given an ID number and asked to write this number on all your forms so that your forms remain anonymous.

Will I be able to find out the results of the research?

Yes. Once the study has finished and we know what the results are, you can ask for information which we will provide in a brief handout.

Where can I find out more information?

By contacting Clare Domenech (trainee clinical psychologist) on 07736 724154, or by contacting Dr Trudie Chalder (cognitive behavioural psychotherapist) on 020 7848 0406.

Appendix 3: Consent Form

Project Title: Developing an expressive writing intervention for people with chronic fatigue syndrome.

- **A member of the research team has explained why this study is being carried out and what I have to do, if I agree to take part.**
- **I have had a chance to ask questions about the study and understand why the study is being carried out and what I have to do, if I agree to take part.**
- **I understand that if I agree to take part, the follow-up interview will be audio-taped. Only the research team will have access to this and the tape will be destroyed at the end of the study.**
- **I understand that I do not have to take part and that should I decide not to, any ongoing or future treatment will not be affected.**
- **I understand that I can withdraw from the study at any time (before, during or after the intervention) and understand that this will not affect any ongoing or future treatment that I may receive.**
- **I have read the above information and agree to take part in the study.**

Signature

Date

Researcher's Signature:

- **I have provided the participant with the opportunity to ask questions and have made it clear that he/she may withdraw from the study at any time.**

Signature

Date

Appendix 4: Interview Excerpt

(P: Participant; R: Researcher)

Extract taken from interview with participant no. 7:

P: Um, yes actually writing it down made me feel that it wasn't so bad. Not as bad as you thought they were probably. Um, when you are not thinking clearly, in your mind, you know, it becomes a bit of a muddle and things tend to get out of control. You know, you do think things are worse than they are. When you wrote it down, um, and actually reading it back, it's more sort of, structural and um structured, it just becomes less, less of a problem somehow. It doesn't seem so serious, in a way.

R: So something about writing it down, makes it seem not so bad.

P: Mm. Yeah. I hadn't actually thought of that but now you asked me that question, I suddenly realised (laughing).

R: Mm. So have you any ideas about how that might work?

P: Mm. I think it's quite often, um, when you, particularly in my mind perhaps because of the ME, that sometimes I get terribly muddled in my mind and I can't think things clearly. Um, whether it's something I have to do or shopping or anything like that and I think it's probably the same with this. By writing it all down, it just became clearer, became clearer in my mind what the problem was. Um, and perhaps even you know, looking at something, like I did find, a sort of, um, a common problem in all of them. I thought oh, this is very interesting. I could actually see perhaps a bit more what the problem was. It wasn't such a muddle in my mind anymore. What had happened and what, you know my emotions and everything. It was sort of, it was all on a piece of paper and it was sort of clearer I think.

(Participant 7, Page 16)

Appendix 5: Writing Instructions

GENERAL INSTRUCTIONS

Project Title: Developing an expressive writing intervention for people with chronic fatigue syndrome: a pilot study

Thank you for agreeing to participate in this study. If you have any questions once these instructions have been given, please do not hesitate to ask the researcher prior to beginning the writing session.

It is important to the process of writing that you set up the following conditions before starting to write:

1. Find a quiet, undisturbed place to write and a time that you are unlikely to be interrupted.
2. Turn the ringer down or unplug the phone and if there are others in the house, let them know that this is your writing time.
3. Prepare the room before you start, making sure you have a pen, a comfortable chair, sufficient light and this booklet.
4. Do not eat or drink while you are writing so that you can focus all your attention on the writing.

The researcher will ring you just before the allotted time for your writing to go through the instructions and answer any questions. Once the writing time is over, the researcher will ring again to discuss any difficulties you may have had and to confirm the arrangements for the next writing session.

When you finish your writing, ensure your ID number is on the top of the manuscript, place it in the stamped addressed envelope provided for day 1 and post it to us. Alternatively keep it sealed and bring it with you on your follow up visit.

If you have any questions before, during or after the end of your four days of writing, please do not hesitate to contact Clare Domenech on 07736 724154. Leave a message and contact number if you get through to the answer machine.

Appendix 5: Writing Instructions (continued)

WRITING INSTRUCTIONS

You should use these sessions to write about your inner most thoughts and feelings about emotionally upsetting or traumatic experiences that have occurred in your life. Over the next twenty minutes, you should try to 'really let go' and explore your deepest thoughts and feelings. You can write about major conflicts or problems that you have experienced or are currently experiencing, particularly those you have not discussed in great detail with others. It may be one event or several. Remember that you have four days to write. For each writing episode you can write about the same experience or different experiences.

The only rule is to write continuously for the entire twenty minutes. If you run out of things to say, repeat what you have already written. Whilst writing, do not worry about grammar, spelling or sentence structure.

Scripts will remain strictly confidential. They will be identifiable only by your ID number and will remain anonymous. The only exception to this will be if the writing indicates that a participant intends to harm themselves or others. In this situation, the researcher is legally bound to match the ID number with the name of the participant.

Sometimes people feel a little upset after writing, which is completely normal and most people say these feelings go away after an hour or so. However, should you experience continued distress, you should contact the therapist that conducted your initial assessment or your G. P.

Appendix 6: Interview Schedule

Interviews began with a brief introduction given by the researcher to provide participants with information about the structure of the interview (e.g. likely duration) and the procedure after interview (e.g. re: follow up questionnaires).

1. I would like you to think back to the meeting when you were told about the writing study. What were your initial reactions to the idea of writing to help with your Chronic Fatigue Syndrome (CFS)?
(Prompt- what were your first thoughts about what the writing intervention might be able to offer you)
2. What did you like about the idea of writing?
(Prompt- What were your reasons for participating?)
3. What did you dislike about the idea of writing?
(Prompt- Did you have any reservations?)
4. Can you tell me about *how* you found the actual experience of writing during this exercise?
(Prompt- Was it easy/difficult? Did you enjoy it or find it hard?)
5. How able were you to identify a topic to write about?
(Prompt- Did you have many ideas or did you struggle to come up with something?)
6. What was the length of the writing exercise like?
(Prompt- Was it too much time, not enough or just right?)
7. What was the frequency of writing like?
(Prompt- was it too often, not often enough, about right?)
8. How did you find doing the writing at home?
(Prompt- were you easily distracted/interrupted being at home or did you find it better than when writing at the clinic?)
9. Can you think of any ways in which the writing was helpful to you?
(Prompt- did you find it a useful exercise to do?)
10. Can you think of any ways that the writing was NOT helpful to you?
(Prompt- is there anything about writing that you feel made your condition worse?)
11. Have you any ideas/suggestions about *how* the writing may have helped you?
(Prompt- what difference do you think the writing has made to you?)

Appendix 6: Interview Schedule (continued)

12. Do you think the writing exercise had any impact on your thoughts:

- about the topic you wrote about
- about your CFS
- about yourself as a person?

(Prompt- Has it changed your attitude towards the topic/s about which you wrote or towards your CFS? Or have you noticed yourself thinking about things in a different way?)

13. Do you think the writing has had any impact either on your feelings or on how you respond to things emotionally?

(Prompt- Did how you think or feel about yourself change over the course of writing?)

14. Did the writing have any impact on your behaviour? E.g. how you interacted with others.

(Prompt- do you do anything different as result of the writing? E.g. tackling problems or planning activities?)

15. Have you thought about the topic/s you wrote about following the intervention period?

(Prompt- after completing the writing did you forget about it or did you continue to think about it what you wrote about?)

16. What are your thoughts about using the writing in the future to help you?

(Prompt- do you think it could be helpful to you as a regular part of your life?)

17. How might you do this?

(Prompt- Would you set aside regular times or use it as and when you felt the need?)

18. What would you tell others about the writing intervention?

(Prompt- Would you recommend it to people?)

Appendix 7: Quotes Supporting Themes

(1:4:18 = participant 1: page 4: line 18)

OVERALL EXPERIENCE

1. EXPECTATIONS AND CONCERNS

Open-minded

‘I think it’s worth any kind of research to explore anything basically. And if it will help, then that’s great and I was curious’. (1:1:15)

‘...if there is anything that can be done that might help I’m prepared to give it a go’. (2:1:17)

‘...in terms of dealing with those ME symptoms and their impact I thought it would be a really good way of coping with that’. (3:1:9)

‘I was open minded to see where it would go’ (5:1:11)

‘I will do anything if it’s all part of the healing process’. (6:5:11)

‘...anything that can help to find a, sort of, not cure but perhaps can help chronic fatigue syndrome I think is a good idea’. (7:1:14)

‘I was fairly open-minded to it actually. I mean, I completely accepted very early on that stress and worry were fundamental to how I was feeling and therefore I was open-minded to new techniques really’. (8:1:10)

‘...I thought well why not, you know. Try anything once sort of thing’. (9:1:6)

Uncertainty

‘Puzzlement of what it could actually do, you know whether there would be any benefit...I couldn’t quite see how it would work’. (2:1:7)

‘I wasn’t sure how the writing therapy would affect my actual ME symptoms’. (3:1:8)

‘...I was thinking can I do it again?...when I was first told that it was twenty minutes, I thought, ah, it seems like long’. (4:2:23)

‘I didn’t really know what to expect’. (5:20:15)

‘I was a little bit worried because you have to write personal things and also you’ve got to send it off to someone you don’t know and um, it was a little bit of a worry’. (7:1:9)

‘I couldn’t see how writing would make it any different’. (8:2:29)

Fear of Emotional Impact

‘I was a bit concerned...That it would raise things that would just be there and just be to the surface again’. (1:1:21)

‘I’m afraid that if I felt that upset that knowing I have to do whatever tomorrow would make that very difficult to go on. I think I probably would feel very upset and bruised and tired and I think it would be difficult to then pick myself back up the next day and pretend everything is fine’. (3:16:4)

‘...it sounded like heavy weather’. (6:1:22)

Appendix 7: Quotes Supporting Themes (continued)

2. THE EXPERIENCE OF WRITING

Getting Going

- '...it was just harder to sit down and discipline myself but then it came'. (1:2:19)
- '...once you get into it and are going with the flow and you become more absorbed by it, then you know it was fairly easy to do'. (2:2:29)
- '...once you get into the writing, it's not as long as it seemed'. (4:2:27)
- '...when it started to flow. It's like a train. I'm gathering up speed and then oh my goodness, couldn't find the breaks'. (6:6:28)
- '...once you actually started, um, it was sort of flowing. And it was sort of, things coming up that you didn't expect'. (7:1:21)
- '...it was actually before I sat down to do it that I found hard. Once I actually sat down to do it I found it very easy and I was surprised at how easy I found it'. (8:2:9)
- 'I just started writing and first of all I thought oh gosh there's lots of pages I'm never going to fill all that up but I found once you started you couldn't stop'. (9:2:1)

Focusing on self

- '...it just gives a space and some time'. (1:9:30)
- '...just switching off from everything else as well, as opposed to focusing on everything else. And for a while thinking 'sod everybody else, I'm going to concentrate on me'. (2:17:27)
- '...something that I could do for myself'. (3:1:15)
- 'I just relaxed then and just forget about everything and just focus in on that'. (4:6:4)
- 'I could just concentrate on the writing'. (7:9:13)
- '...allowing myself time to ... indulging myself really, time to think about issues that were worrying me, whereas normally you just put it to the back of your mind and get on with life. It was actually allowing me time to think about the things that I knew were troubling me'. (8:1:25)

Facing the Problem

- 'I used the writing to help me work through some of those things, that I'd not exactly stifled but that I'd had to cope with at the time'. (1:5:31)
- 'I've allowed myself the time to be. You know sort of think about things as opposed to just pushing them inwards and not really dealing with them'. (2:12:26)
- 'In my diary I bend the truth so that I only record positive things. Whereas this (writing) was sort of the opposite because I was really trying to look at negatives that I would normally forget about or push out of the way'. (3:7:11)
- 'But since I could sit down and write about something...that means I face it'. (4:12:25)

Exception: Avoidance of the problem

- 'I kind of felt I can't afford to think about admitting how difficult I find coping or thinking about the illness, because I *have* to manage these things this week. For this week I feel as if I have to keep pushing it all back and pretending it's not there, it's not a problem simply because I've got to cope'. (3:15:17)
- 'I don't want to think about it. I have to push it away. Dangerous.' (6:5:25)

Appendix 7: Quotes Supporting Themes (continued)

Writing an Easier Medium

‘...to me it’s easier than talking’ (1:10:18)

‘It’s easier to write it down as well than actually talking about it’. (7:3:16)

‘I found it an easier medium. I think than the counselling because if anything came back to me from the counselling it didn’t let my thoughts run. Whereas, if I was just writing myself, thoughts could run where I wanted them to and I wasn’t stopped at any way along the procedure or made to account for it or asked to think – well why do you think that. Except for myself thinking well why do you think that?’ (8:17:15)

Able to write anything

‘...it was things that you wouldn’t necessarily talk about that you were writing about’. (2:2:25)

‘...you can sort of write things that perhaps you wouldn’t perhaps tell someone else’. (7:4:5)

‘...because I wasn’t having to talk to somebody and see their reactions, I felt much easier about talking about things or saying exactly what I wanted to without being judged in a way’. (8:6:7)

‘...when I had the counselling, of course I knew the girl that I was going to talk to each week and I knew I’d have to face her the following week. So, in a way I always held back slightly’. (8:8:5)

‘...you can put what you want to and it’s all confidential. Sort of different doing that than talking to someone’. (9:2:28)

No judgement when writing

‘...you can say things to people and they make all the right noises...but I think you always slightly gauge what you’d say to them as to how you think they might react. Whereas writing it down, I didn’t have any of that. I could write down whatever I wanted’. (2:7:11)

‘...you think well they’re going to judge me. You sort of tell them something personal and you think they’re always going to know this. Whereas I think when you write it down like that and you’re just sending it off...whoever is going to read it, they don’t really know me. So they can’t judge me’. (7:4:5)

‘I suppose there’s no sort of embarrassment or worrying about what somebody else is going to think’. (8:7:30)

‘...when you’re sort of talking to someone...sometimes you don’t like to talk about things, you feel awkward or whatever’. C: What do you think it is about talking to someone else that makes you feel awkward? P: Um, well they might think you’re pathetic or they think you’re making it up or whatever’. (9:8:5)

Benefit of re-reading the writing

‘Just reading through it, it makes sense out of it’. (1:5:21)

‘...there are things that have happened that are incredibly bad and incredibly big and it in a sense validated that, so for me it was validating. When I’ve read it now...I’m coming to terms with it all’. (1:11:10)

‘...it’s a very good channel for communication from me to me. To look back on because you can’t remember how you think from day to day’. (1:9:9)

‘...it was good to, in the cold light of day, have a look at it’. (2:7:5)

Appendix 7: Quotes Supporting Themes (continued)

'...the next day, two days down the line, I can look at it and think, well OK, now I can see that I have that problem'. (3:7:24)

'...when I went back and read what I had written and was writing, I felt strong, that I shouldn't give up'. (4:7:12)

'I think by re-reading it, it was like feeling the emotions again, so for me it was quite important I think to do'. (7:21:3)

'I was just skimming through it as you'd skim through, you know, a magazine article or something, just seeing the way the thoughts went. Just as if to summarise'. (8:10:5)

'...sit and read through it after I'd finished, um, I found was helpful'. (9:3:12)

'...well I suppose when you read it back to yourself it probably sinks in more'. (9:8:4)

'I've been able to read it all back and look at and analyse problems more and perhaps there not as bad as what they'd always seemed to be'. (9:1:14)

Practical Aspects

Time

'It was long enough, it was just about right. And the only time was the last time that I finished a few minutes early. There were no problems with that at all' (1:4:4)

'...the fact that it was twenty minutes I thought was a perfect amount of time'. (3:2:3)

'It wasn't too short and when I got into it, it was just enough'. (4:5:18)

'All that emotion you can dredge up in twenty minutes. It's more than enough'. (6:8:9)

'Yes, you know at the end of the 20 minutes I was starting to think O.k. I've not got much else to say about this now and there wasn't much more I could have gone on to say. I wasn't looking up at 10 minutes thinking "oh God I've got another 10 minutes to go", I think it was just right actually.' (8:4:5)

Exception

'I found that... I got a bit carried away and it took me much longer. Every time it took what 20 minutes and I didn't think that was long enough. Need more like half an hour... 20 minutes you're stopping in mid-air'. (9:1:21)

Frequency

'Every other day would have been too much, by the nature of the things that I was writing about. It might have been Ok if I'd chosen different content but that would have been too much. Every week, that seemed fine. Every other week, maybe I'd have lost the plot a little bit with it and maybe would have forgotten.' (1:4:21)

'...once a week? I thought that was fine' (3: 5: 3)

'Once a week it was just right, enough'. (4:5:30)

'...that was sort of just about right I think. Perhaps someone whose got more time might want to write everyday but for me I did find that once a week was just enough.' (7:9:1)

Exception

'...twice a week might have got more into the flow of it if you see what I mean'. (9:5:19)

Appendix 7: Quotes Supporting Themes (continued)

Frustration

‘C: Can you think of any ways that the writing has not been helpful? P: Um, only in increasing my frustration about my condition.’ (5:17:1)

MECHANISMS OF ACTION

3. EMOTIONAL EXPRESSION

Emotional Release

‘It was cathartic’. (1:2:26)

‘...to write and get it out of your system, that was what was really helpful’. (2:7:7)

‘...get the emotions out of me and put them onto paper’. (3:8:24)

‘...when I get it out it’s better for me’. (4:17:23)

‘...it’s got a lot, a lot of it out’. (6:2:31)

‘...I have quite a lot of things, perhaps bottled up inside, just sort of writing it all down and letting it all out. It was quite nice. Um. Definitely’. (7:5:20)

‘I felt when I’d written all about the anger I felt, I felt that I had released it. So I felt better. I felt that I’d let go of that particular thing’. (8:25:12)

Exception: Unable to release emotion

‘I really wish that I could have been able to...put down things, because I really feel as if, um, kind of like, it’s just all bottled up inside of me’. (3:10:20)

Reliving Emotions

‘It seemed to be the more upset I got the better I felt afterwards’. (2:3:24)

‘I wrote and it’s like it’s come back in full force, as though you’re living the thing again. It’s like you are reliving it’. (4:8:9)

‘...it just brought it to the surface...When it is like fresh in my mind...back again, like yesterday. Like it happened yesterday’. (6:3:3)

‘...when you actually start writing it down, you know I feel fear, you know you really sort of feel those emotions. Um, and I know when I was writing things, quite often I sort of, my tears were rolling down my, my face. I would really feel these feelings’. (7:5:30)

4. BEHAVIOURAL ACTIVATION

‘What I write the other day, again it pushed me to go and you know try and get my rights’ (4:9:28)

‘...by doing the writing, I have no idea what has triggered off but I actually get up on Saturday. I actually put some routine in my non-routine days...By doing it, uh, it’s a switch. It’s put on a switch’. (5:15:20)

‘I could do something that might help it. Or, at least by just knowing it perhaps I should sort of, take certain action’. (7:18:1)

Appendix 7: Quotes Supporting Themes (continued)

5. COGNITIVE ORGANISATION

Clearer on paper

‘You might remember how you feel sometimes but you don’t actually put those together on paper’. (1:9:11)

‘...it was quite good in a way to get it off your chest if you like. Rather than having it up in your head the whole time’. (2:2:26)

‘...good way of, you know, when you write things down you can see it on paper. It’s clearer, it’s not all, sort of, swimming around in your head’. (3:1:17)

‘When it’s actually on paper it’s easier to deal with than when it is in your mind’ (3:9:23)

‘...when I write it down, I can look at it and see it more’. (4:17:11)

‘...writing it all down, it just became clearer, became clearer in my mind what the problem was...It wasn’t such a muddle in my mind anymore’. (7:17:4)

‘Um , when you are not thinking clearly, in your mind, you know, it becomes a bit of a muddle and things tend to get out of control. You know, you do think things are worse than they are’. (7:16:20)

‘...to see the wood from the trees really’. (8:22:15)

‘...you can think thoughts but they tend to jumble themselves up...but I think when you’ve got it in black and white you can see it’s more as it was rather than just wandering around in your head’. (9:6:7)

Taking a different Perspective

‘...enabled me to, to write about those things differently’. (1:3:18)

‘...it may well be that I look at it in a different light’. (2:8:18)

‘...give you the opportunity afterwards to realise that maybe you are not being rational about something you thought about. Or things aren’t quite as bad as you think they are’. (2:16:2)

‘...it feels terrible when it’s in my mind, but when I’ve actually down on paper then you can start to look at it objectively and make sense of it’. (3:9:25)

‘...looking at it, it doesn’t seem so bad when you have, sort of, written it down’. (3:6:30)

‘I can think things out more logically when I write things down sometimes’. (4:17:11)

‘I think it’s had an impact on how I view things, mostly’. (5:22:10)

‘...by the third it’s like, right let’s be objective now’. (6:2:26)

‘...writing it down made me feel that it wasn’t so bad. Not as bad as you thought they were.’ (7:16:19)

‘...it enables you to look at things almost dispassionately in a slightly different way. Almost like looking in at yourself really from the outside.’ (8:21:26)

‘I’ve been able to read it all back and look at and analyse problems more and perhaps there not as bad as what they’d always seemed to be’. (9:1:14)

‘...things looked different written down to um, swinging about in your head I suppose. You know when you see it written down you sort of read it back to yourself and things can look different’. (9:1:19)

‘...it wasn’t my fault. I was put upon which shouldn’t have happened’. (9:7:15)

Appendix 7: Quotes Supporting Themes (continued)

Coherence

‘The way things came together enabled me to, to write about those things differently’. (1:3:18)

‘...actually putting things down on paper, um, things, I can be more structured’. (3:6:28)

‘I suppose I had to structure myself, isn’t it. In a way, I had to have structure of what to write’. (4:7:4)

‘I’d decided on what I was going to write about and then actually put it down in a coherent form’ (5:3:5)

‘When you wrote it down, um, and actually reading it back, it’s more sort of, structural and um structured, it just becomes less, less of a problem somehow’. (7:16:20)

Reflection

‘It’s nice to look back and see where you once were and where you are now’. (1:9:30)

‘...it was actually a useful time to reflect on that, on what was stuff that was actually buzzing round my head that week’. (1:2:8)

‘...it triggered off other things’. (2:4:27)

‘...thinking about my writing therapy sessions made me think about it in a lot more detail than I normally would’. (3:13:25)

‘When I did the writing, I had to think about things more. So you go into the depths of things’. (4:10:10)

‘...by writing it all down, you look back at it and you’re sort of reading how you felt and what you’re reactions are to situations and sometimes you nearly feel embarrassed about, gosh, this is what I’m thinking. Um, so it was quite interesting in that sense to see what you were thinking in a way and what your thoughts were. And you really, you felt really, you were reading someone else’s nearly. (7:19:19)

PERCEIVED OUTCOMES

Helpful

‘I’m not saying it was a cure or, at all but it just helped’. (1:6:5)

‘...given me another avenue that I can go down’. (2:8:9)

‘...to write and get it out of your system, that was what was really helpful’. (2:7:4)

‘I felt that the act of writing down feelings and putting it on paper was very beneficial to me’. (3:3:20)

‘I think it’s a very good idea and it’s something that I would like to carry on in my own time’. (3:9:11)

‘...doing the writing is a beginning’. (4:13:12)

‘...this has opened a door, it’s now stepping on the path’. (5:23:27)

‘I actually found the experience useful in that, having to sit down at a period of time, on a particular, twenty minutes, day to do it, actually has a knock on effect on my life in general’. (5:1:2)

‘I do realise it probably has helped me a little bit. More than I actually thought’. (7:27:7)

‘It was very helpful. I found it a very positive thing’. (8:6:29)

Appendix 7: Quotes Supporting Themes (continued)

Exception

‘There’s nothing I liked about it’. (6:12:3)

‘I think I’m yet to find out if it has been beneficial’. (6:5:12)

Emotional Impact

‘It was useful, I wouldn’t say useful was the right word, therapeutic to write’.
(1:5:22)

‘...I’ve actually I think been a little bit more relaxed and not feeling everything so intense...my whole mood sort of lifted’. (2:13:12)

‘...relief that I was actually able to tell someone and it sort of came out I think’.
(7:2:29)

‘...felt calmer in a way. I felt more at peace with myself. I understood a bit more about myself’. (8:25:14)

‘I’ve become a lot more calm about, about those kind of things really and less anxious the whole time’. (8:18:8)

Cognitive Impact

Impact on thoughts

‘It doesn’t bother me as much. My attitude has changed’. (1:12:31)

‘...now I think I’m a bit more ‘does it really matter?’ attitude. Is it worth getting worked up over?’. (2:12: 23)

‘...didn’t seem to be as intense the thoughts. You know, or make me feel as bad’.
(2:15:12)

‘...my mind wasn’t wandering as much’ (2:14:20)

‘I think doing the writing has helped, um, changed the way I think about the actual condition’. (5:23:29)

‘I’m one of those sorts of people that things tend to go on in my mind quite a lot. And I can’t really let it go. Perhaps by writing it down it has actually helped me in that way. Um, because thinking about it, I probably have been able to perhaps think about other things a little bit more. Um, than perhaps my ME, um and what caused it, perhaps to sort of think, um what caused my ME and why have I got it and perhaps that’s been a little bit less’. (7:24:9)

‘...it’s made me a lot more positive...Um and then I think, yes, they’re good friends they’re not going to leave just because I don’t feel well enough to go out.’(8:18:6)

‘I mean if you bury them in your head it’s there for you to think about. I think once you’ve got them out you don’t dwell on them so much’. (9:9:20)

Increased Awareness

‘It has made me perhaps a little bit more aware of where my triggers are and how I am responding and why’. (1:12:1)

‘...you don’t actually really realise sometimes what you are thinking’. (2:7:1)

‘...the fact it has made me aware means that now I can actually start to deal with it’.
(3:13:23)

‘...it did make me realise and perhaps more aware’. (7:17:24)

‘I identified issues that clearly have troubled me but I didn’t realize. I wrote an awful lot about my childhood and I hadn’t realized it’s a problem...it suddenly became clear actually how much of a problem it had been and perhaps how it shaped me and I didn’t really acknowledge that until I did the writing’. (8:14:11)

Appendix 7: Quotes Supporting Themes (continued)

‘I think it makes me more aware, it has made me more aware of my emotions so that I then deal with it’. (8:20:31)

More able to cope

‘...now I can see that I have that problem I can deal with it’. (3:7:25)

‘...it made me feel within myself stronger in myself and give me strength to feel I can, the situation I’m talking about, cope with it’. (4:7:10)

‘...it made me feel I could overcome things’. (4:12:22)

‘...writing, if anything just reinforces that I can deal with those things’. (5:25:5)

‘...I don’t think it’s stopping it (negative emotion), it’s (writing) making me able to deal with it’. (8:21:3)

‘...puts it more in perspective I suppose...Cope with it maybe more’. (9:6:30)

Increased Self Esteem and Confidence

‘...writing about the traumatic problem now makes me feel strong. Makes me feel that you’ve been through these things and you’re still standing and that makes me feel good in myself’ (4:13:22)

‘I feel better about myself and I feel better that I can do, a task that I used to be able to do and not think about it’. (5:21:19)

‘...it might have just given me a little bit of confidence’. (7:26:9)

‘...it makes you feel more confident in yourself because a lot of the problems weren’t of your making’. (9:13:13)

‘I quite like me now, I didn’t used to like me and I used to say nobody likes me’. (9:11:19)

Sense of Achievement

‘It shows me that I did something that I couldn’t have done before’. (4:13:12)

‘I have got this sense of achievement. I am damned if I’m going to let go of it, to be honest. Because I haven’t felt this way. I mean it’s a major step forward’. (5:23:24)

‘...actually doing, uh, fulfilling a task. It is almost like an achievement, even if it is just a little one’. (7:26:6)

Kinder to Self

‘...a message to...take it a bit easy on yourself’. (1:11:20)

‘...I couldn’t believe some of the things I’d written and I thought well, you know, maybe I am being a bit hard there and a bit judgemental’. (2:11:23)

Exceptions: Critical of Self

‘If I looked at what I had written, I’d think well, that just sounds silly because I should be able to look at the positive side. So, I couldn’t over come that’. (3:3:9)

‘I’m disgusted with myself being such a blubbering mess when I get to that topic’. (6:19:2)

Behavioural Impact

Increased Activity

‘...certainly, the day after... I was able to do more’. (2:13:9)

Appendix 7: Quotes Supporting Themes (continued)

'...it was giving me a day where I didn't feel as bad and was able to do things'.
(2:10:21)

'I'm ready to go ahead and try and just do a little something'. (4:17:4)

'Since doing the writing I actually get up on Saturdays and do things'. (5:15:14)

'...actually probably in the last two or three weeks I have probably been doing a little bit more my normal things that I used to do. Perhaps not thinking so much and actually doing things'. (7:24:29)

'I feel much better in myself and I've started doing some things that I didn't do before'. (9:13:6)

Problem Solving

'To think about my response and maybe ultimately to readjust it'. (1:12:8)

'It clarifies everything so that you can identify what the problem is and then start to figure out, well what am I going to do about it'. (3:10:1)

'I know from the writing what I'm going to do'. (4:9:18)

'I can see that maybe there's something a little bit more that I can do to help improve myself, try and work on what I can do'. (4:19:27)

Exception: Unable to resolve problem

'I can't do anything about this particular thing so I just drag myself around'.
(6:14:12)

Decreased need to talk about the problem

'...it's probably made me not want to talk about it. Because I feel probably, perhaps by writing it all down I have sort of dealt with it on my own in a way. And I don't need to talk about it so much'. (7:23:27)

Modifying Behaviour

'...with my parents, I'm interacting with them differently...I'm able to modify my behaviour'. (8:15:7)

Facilitated Communication

'Actually in the last few weeks I have done quite a lot more. Particularly contacting people. Speaking to people. Sending e-mails and things like that.

Communicating...by writing things down, um perhaps you sort of felt that it helps you with communicating perhaps a little bit'. (7:25:9)

'...certainly I've talked to one of my friends about the things I've written about, a little bit'. (8:18:29)

Physical Impact

'I began to be physically more well. There are a lot of different things, I can't say that I feel that was because of the writing, but it was useful'. (1:7:2)

'I was just amazed at how much better I felt the next day. You know and the good nights sleep that I got, that's what really struck me'. (2:18:26)

'I think its done a lot to help me, um, mentally if you like, in dealing with the issues but I don't think physically it made any difference'. (8:10:29)

Appendix 8: Questionnaire Scores

Table (i): Participants Fatigue Scale scores

Participant	Time point 1	Time point 2	Time point 3
1	26		29
2	31	30	16
3	32	31	31
4		5	5
5	24	29	17
6	32	33	33
7	26	27	25
8	21	17	20
9	31	30	30
Mean	28	25	23

(N.B. a blank cell indicates missing data)

Table (ii): Participants HADS scores

Participant	Time point 1		Time point 2		Time point 3	
	<i>A</i>	<i>D</i>	<i>A</i>	<i>D</i>	<i>A</i>	<i>D</i>
1	7	4			5	4
2	12	13	14	11	12	9
3	14	14	7	13	11	16
4	10	5	8	5	10	5
5	2	7	8	4	5	2
6	13	16	16	14	11	14
7	12	5	12	9	12	6
8	5	2	6	1	6	1
9	15	13	13	7	13	7
Mean	10	9	10	8	9	7

(N.B. a blank cell indicates missing data)

Table (iii): Participants WSAS scores

Participant	Time point 1	Time point 2	Time point 3
1	26		21
2	32	36	32
3	37	35	38
4	27	27	30
5	20	20	19
6	37	37	35
7	34	28	33
8	17	13	12
9	37	33	33
Mean	30	29	28

(N.B. a blank cell indicates missing data)