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CHRONIC FATIGUE SYNDROME/MYALGIC ENCEPHALOMYELITIS: A
QUALITATIVE EXPLORATION

The Psychological Impact of Dependency in Adults with Chronic Fatigue Syndrome/Myalgic
Encephalomyelitis: A Qualitative Exploration

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CFS/ME is defined as a chronic condition with fluctuating symptoms that typically include persistent fatigue, muscle and/or joint pain, reduced memory and concentration, and sleep disturbances (NICE, 2007). In the UK, the National Health Service assesses more than 6000 new cases of CFS/ME each year (Collin et al., 2011). The mean age of onset for the condition is between 29 and 35 years, and women account for 75% of the CFS/ME population (Prins, van der Meer, and Bleijenberg, 2006). Much potential aetiology for CFS/ME have been investigated, including neurological, endocrine, immunological, genetic, psychiatric and infectious, however the diverse nature of the symptoms cannot yet be fully explained and a debate exists as to its causes and perpetuating factors (Kerr et al., 2008). CFS/ME can limit functional capacity, producing various degrees of disability and psychological distress (Dancy and Friend, 2008). Symptoms can impact upon the sufferers' quality of life, affecting relationships, recreation and work, and resulting in social isolation, loss of roles (Gray and Fossey, 2003; van Heck and de Vries, 2002) and suicidal ideation (Action for ME, 2009). The National Institute for Health and Care Excellence (NICE) 2007 sets guidelines for the management of CFS/ME which combines cognitive behaviour therapy (CBT), graded exercise therapy and activity management.

CFS/ME has overlapping similarities to other medically unexplained conditions, including Irritable Bowel Syndrome, Fibromyalgia Syndrome (FMS) and other types of chronic pain, collectively referred to as Functional Somatic Syndromes (FSSs) (Wessely, Nimnuan and Sharpe, 1999; White, 2010). A body of research reveals how patients with FSS's are often met with disbelief and lack of support by health professionals and people within their family and social networks. Common features of disbelief, rejection, stigmatisation, belittling, misunderstanding, and suspicion that the problem is exaggerated or psychological (Werner and Malterud, 2003) have been described as 'invalidation' (Kool et al.,

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2009). Kool et al. also found that patients with FMS experience invalidation not only in the form of a lack of understanding and denial by others, but also from a sense of being lectured to and/or overprotected by others.

Conversely, for patients with FSS, feeling validated and receiving quality social support has been found to greatly improve quality of life (Schoofs et al., 2004), especially with regards to mood, helplessness (Franks, Cronan and Oliver, 2004), symptom severity (Lacker et al., 2010), and mental and physical functionality (Jason, Witter and Torres-Harding, 2003; Jason et al., 2010b). Kool et al. (2012) found that both invalidation and social support were independently associated with mental health status of patients with FMS such that a consideration of both social support and invalidation improves health outcomes.

Interpersonal dependency, defined as a thought, belief, emotion, or behaviour that is derived from the desire to maintain close relationships with others and to seek their support (Bornstein et al., 2005), has been found to be a risk factor for both physical and psychological conditions (Arutz, 2005; Bornstein, 2012). These findings support Bornstein's (1993) theoretical interactive model of dependency which suggests that an inability to elicit help can lead to the development of depression and anxiety, which in turn can lead to complaints of physical illness.

Physical independence can be argued to be as important as social support and symptom validation. Gignac and Cott (1998) developed a conceptual model of independence and dependence relating to the onset of chronic physical illness and disability in adults. The model proposes that domains of disability (such as household tasks, personal care and employment) can have a direct impact on an individual's independence and dependence in terms of whether the individual needs help, whether the individual receives help, and in terms of the individual's subjective perceptions of their need. The model also argues that external factors, such as the physical environment and provision of illness-related information, can

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actively shape an individual's level of dependence. Gignac and Cott highlight that dependence is often portrayed negatively in society and is associated with practical helplessness, social powerlessness, need, incompetence, and the absence of independence. Independence, however, is viewed as a desirable goal attained when individuals function without assistance from others and is associated with autonomy, choice, control, and self-direction.

A rise in physical dependence is believed to have important consequences on several levels, such as poor psychological well-being and quality of life, as well as increased stigma and marginalisation (Gignac and Cot, 1998). Depression may be associated with physical dependence when all domains of disability, including personal care and employment, are affected alongside a subjective belief in the need for assistance (Dancy and Friend, 2008). Conversely, even in such circumstances, depression may only occur when accompanied by perceptions of loss of control, loss of efficacy, and helplessness (Dancy and Friend, 2008). Loss of independence in domains such as valued activities may be related to anxiety or fear about future constraints on functioning. Choosing to forgo activities instead of seeking assistance may relate to subjective perceptions of independence; however, they may also be associated with perceptions of loneliness or social isolation (Dancy and Friend, 2008).

Jason et al. (2010a) found that participants receiving help for tasks that required high levels of physical energy (such as household chores) had significantly reduced fatigue and improved vitality. One participant reported that practical help was beneficial as it allowed energy to be spent on more valued aspects of life and thereby preserving psychological well-being. Indeed, illness intrusions have been found to mediate the relationship between impairment and depression in women with CFS/ME (Dancy and Friend, 2008). Allowing individuals time and energy to fulfil other aspects of life may have a positive effect on psychological well-being.

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Previous literature highlights the physical and psychological implications for individuals with CFS/ME, and the role of significant others appears to be instrumental in helping to improve physical energy and psychological well-being. However the experience of being physically dependent on others, and the impact this may have on psychological stability has received little attention.

Exploring the potential psychological effects of the functional limitations imposed by CFS/ME and the physical dependency that may result is of importance for clinicians, patients and carers alike in order to improve the management of the condition. The aim of the research is to explore the impact of physical dependency on well-being for adults with CFS/ME.

Method

Methodological rationale and design

Due to the limited research in the area of physical dependency and psychological implications in CFS/ME, an explorative qualitative methodology was chosen in order to capture the variability in experiences and emotions (Willig, 2008). Thematic analysis, a method for identifying and reporting themes within data, was chosen to provide rich and detailed accounts (Braun and Clarke, 2006). An inductive approach was taken and themes were identified at the semantic level. The researcher adopted a realist epistemological perspective, meaning that it was assumed participants' experiences to be true (Murray and Chamberlain, 1999). The findings were conceptualised as themes that were found within the experience of being physically dependent on other people.

Participants

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Participants aged between 25 and 60 years ($M= 45.5$) were recruited from Southern England. Table 1 provides further participant demographics [INSERT]. All participants were self-selected as they responded to a mass invitation via their support group co-ordinator for participation. Participants' identification was anonymised using false names. Participants varied in illness severity, and can be categorised into three groups (NICE, 2007). People with *mild* CFS/ME are mobile and able to achieve personal care and light domestic tasks with difficulty. They may be in employment but have limited leisure and social activities in order to rest. People with *moderate* CFS/ME have reduced mobility and are restricted in all daily activities. They are often unemployed and require frequent rest periods. People with *severe* CFS/ME are only able to perform minimal daily tasks and have severe cognitive difficulties. They are likely to be house-bound or bed-bound, and suffer prolonged after-effects from increased activity. The researcher applied these guidelines to each participant from their descriptions of themselves in the interviews.

Materials

Data were collected from semi-structured telephone interviews. Each interview was recorded using a telephone recording device and a dictaphone. These were transcribed verbatim using Express Scribe transcription software. Participants were provided with an information sheet, a consent form, and a summary of the research findings.

Procedure

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Ethical approval was granted by XXX. The sample was obtained through contacting CFS/ME support groups that advertised their services on the website of ‘Action for M.E.’

(www.actionforme.com). Action for M.E is one of the leading charities for CFS/ME in the UK, providing users with information and support. The co-ordinator of each support group was contacted, whom later informed their group members of the research. Group members then contacted the researcher directly for participation.

The inclusion criteria were as follows: (1) for participants to be aged between 18 and 60 years, as the target population was adults; (2) to have had a diagnosis of CFS/ME by a registered GP for a minimum of 3 years; (3) to live with at least one other person or require help from others. A requirement of the study was that individuals should discuss how they experience needing help from others and participants must therefore be receiving regular help of some kind.

The interview schedule was generated using Spradley’s (1979) guidance in formulating research questions as well as being informed by previous literature on dependency in chronic conditions. In order to refine the interview questions, three people with CFS/ME were asked to express their thoughts regarding the research topic and the interview questions. These participants did not take part in the study. The starting questions were broad, giving participant’s opportunity to express their experiences of CFS/ME and allowing the researcher to understand their context. Specific questions were then asked in relation symptoms, diagnosis and fatigue patterns (e.g. “Can you briefly explain the symptoms you experience due to your fatigue”). The main body of the interview related to the type, quantity and quality of help participants receive in a variety of contexts, and how they feel emotionally about asking for help (e.g. “Do you ever find yourself needing help or support with anything due to your CFS/ME?” and “How do you feel emotionally when asking for help or

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assistance?"). The closing questions were designed to bring the participant out of the interview process, and express anything not already asked by the researcher.

Participants received an information sheet and a consent form by email or post. Once the researchers received the signed consent form, participants were contacted by email or telephone to arrange a time to commence the interview. Each interview was 45 minutes in duration, followed by a formal debrief reminding participants of the aims of the research. After conducting ten interviews it was considered that no new information was being elicited and so, in accordance with Braun and Clarke's (2006) guidelines, data collection ceased. Braun and Clarke (2006) indicate a number of steps that need to be followed.

Stage 1: Immersion in the data in order to become familiar with the breadth and depth of the content. This involves iterative reading of the data in an active way by searching for meaning and patterns.

Stage 2: Generate initial codes that identify features of the data.

Stage 3: Sorting codes into potential themes, and collating all the relevant coded data extracts within the identified theme.

Stage 4: Reviewing the themes, firstly at the level of the coded data extracts to assess whether they appear to form a coherent pattern, and secondly to consider the validity of the themes in relation to the data set.

Stage 5: Defining and naming the themes allowing for identifying the essence of the themes, and determining any sub-themes.

Stage 6: Producing the report.

Results

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The analysis generated six themes: (1) loss of independence and self-identity; (2) an invisible illness; (3) anxieties of today and the future; (4) Catch-22; (5) internalised anger; and (6) importance of acceptance. Each theme will be addressed separately and illustrated with supporting quotations.

Loss of independence and self-identity

Participants expressed a nostalgic view of their ‘previous life’ before the onset of the condition. A sense of loss was felt, especially with relation to being independent and fulfilling important life roles. Participants expressed this loss as impacting upon their psychological well-being in that they felt an over-ruling sense of burden and guilt to those closest to them, and a decrease in their portrayal of themselves as a valued and worthy person: “I continually mourn the person that I used to be. I feel guilty about being unable to be independent, not being able to be part of the world, not being able to fulfil the role I should be fulfilling” (Diane). This sense of burden was described as distressing, to the point in which individuals experienced suicidal ideation due to their dependency on others: “There are many days and hours that I wish I could die” (Diane).

Feeling unable to reciprocate help, often due to high levels of fatigue, was also expressed as contributing to loss of self-identity: “When you can't give anything back because you've either got no energy, no money, then it just, it does make you feel second class and very insecure about your place in the world” (Annie).

Additionally, lack of control over the ability to perform daily activities stemmed from the loss of independence. Restrictions involving such tasks create feelings of despair and have a negative impact on self-worth: “Most of the time a task will get done eventually but I have

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to be patient. Sometimes she says yes and then forgets about it, so sometimes I have to keep reminding her. I always feel guilty afterwards and I feel that I'm a burden to her" (James).

An invisible illness

CFS/ME was described as an 'invisible illness' as those with the condition can look perfectly healthy to those around them, but feel incredibly unwell: "With ME you look well, the amount of times I get the comment 'Well you look quite well' and you think 'Christ just because I can put a bit of make-up on occasionally, you didn't see me sat on the sofa barely able to breathe'" (Annie). The invisible nature of the condition can make it difficult for individuals to be recognised as needing help and to feel able to ask for help. Participants described the difficulties of having the invisible condition by using the contrasting example of having a broken limb. If the condition was visible, participants felt it would allow them the power to prove to others that help is really needed and for people to understand: "If I had a broken arm or a broken leg I can show you an x-ray that shows categorically that I can't do a task but there is nothing I can do to prove to you that I have this condition or that I can't do that kind of thing, and um it is soul destroying it *really* is soul destroying" (Annie).

The amount of activity undertaken can be misleading to others as they may judge the individual's degree of illness by activity levels, which can vary daily: "There's no consistency with the condition, and you're asking for people to understand that" (Annie). A lack of understanding due to the invisibility of the condition was reported to generate reluctance in asking for help, increasing feelings of despair and reducing self-worth: "It's really hard with other people because they don't even recognise CFS, they just say 'Everyone gets tired' and they don't see why they should give you extra help. I think it's easy to get discouraged in asking for help because people just don't understand" (Emily).

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Participants spoke of the frequent problems they face with trying to communicate with others about the condition and their needs as other people struggled to understand why they required help: “When I’m like tired and people ask me how I am and I’m just like ‘Oh I’m tired, oh I’m tired, oh I’m tired’ but it’s almost like I need to say ‘I’m absolutely exhausted and I’m *struggling to live*’, but people just *don’t understand*” (Emily). Other participants felt that communicating their needs was difficult because of how they felt about themselves, their low self-esteem and loss of self-worth playing a role in hindering their ability to communicate: “I suppose it feels a bit like feeling sorry for yourself when you have to explain it to them” (Helen); “I feel ashamed that I need the help” (Annie).

Due to problems faced with communicating the nature of the condition, some participants described attempts to go for long periods of time without asking for help. Restraining from asking for help was viewed as resulting in a deterioration of health, with the symptoms associated with exhaustion being increased: “[Asking for help] makes you feel bad, so you try even harder to go even longer to ask for help, by which point you’ve deteriorated again and therefore you’re asking for help for something you, in other people’s eyes, you should be able to cope with” (Annie). This can reinforce feelings of worthlessness and that others do not understand their needs.

Anxieties of today and the future

Many participants expressed anxiety surrounding daily life, especially in relation to being able to access the help they needed and having to rely on others to gain that help. Some participants expressed concern over whether they would be able to receive help from the ‘right’ people – people who would understand and handle the task in an appropriate manner: “When I have an appointment it’s just so difficult because there’s no-one who can take me,

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even if I asked a friend they wouldn't know how to be with me and in those sort of situations I get incredibly anxious” (Diane). Daily anxieties were often catastrophised into more dominant and overarching anxieties about future help. The question often arose of whether help received and the people currently relied upon would be available in the future, generating immense anxiety and worry: “I often think ‘What would I do if something happened for instance to my partner’, and I can't even think about how life would be” (Diane).

Catch-22

Participants expressed that they were often in a ‘Catch-22’ situation, where expressing to someone that they require help and informing them of how, when and why, is almost as exhausting as completing the task themselves without assistance. This may generate a dilemma, such that individuals often need to weigh up their energy resources in order to determine whether asking for help is the best course of action: “Having help, it's partly a debate. Is it easier on the amount of energy it takes to ask and wait for that, or is it actually going take me less energy to just do it myself” (Kirsty). The dilemma can cause frustration and anxiety, and can sometimes induce feelings of worthlessness and incompetence.

Internalised anger

A few participants reported feeling angry and frustrated by having to rely so heavily on other people in order to achieve daily tasks. Frustration was an emotion withheld from the caregiver due to fear of being mistaken as ungrateful: “I never say anything about it to anyone because at the end of the day they are helping me out, but I do feel frustrated by it, you know inside” (Emily); “Sometimes I get frustrated because there’s something I want to get or want to do,

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and I have to wait [sigh], and I don't want to snap at her because I know she's doing it for me" (James).

Importance of acceptance

Many participants provided vivid accounts of their level of acceptance of the condition, in particular its chronic nature, the physical and cognitive limitations, and their need to rely on other people for help. Some participants expressed that they longed for the life they had prior to the onset of the condition, making acceptance of the condition difficult: "Trying to portray a life that isn't there is really difficult" (Annie). Conversely, others expressed that acceptance of the condition was starting to develop, and consequently their psychological health and quality of life improved: "I did realise that the most important thing is my health, so it doesn't really matter what I'm doing or not doing, as long as I'm looking after myself" (Emily).

Other participants expressed an improvement in how they felt about living with the chronic condition. Acceptance was viewed as being able to see what is true rather than approving of the condition or endorsing their physical limitations. Acceptance was also accompanied by a reduction in emotional distress caused by resistance towards the reality of their life and limitations.

Discussion

Although previous literature has shown CFS/ME to impact greatly on people's lives, the experiences of being physically dependent on others and the influence this may have on psychological well-being, has received little attention. Understanding the psychological implications of physical dependency is important for effective management of the condition,

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and the findings of this research have provided valuable information in terms of helping improve care for this condition.

For participants in this research, the experience of needing to ask others for help with daily activities induced a sense of loss of independence and self-identity. Participants expressed that they were unable to perform daily tasks and thereby fulfil the roles in life important to them. This generated a sense of worthlessness, inadequacy, and uncertainty about their place in life. This loss of independence is supported by previous research which demonstrates how increased physical dependence increases depression, feelings of hopelessness and powerlessness, as well as reducing self-efficacy (Gignac and Cott, 1998) and self-confidence (Ahlstrom, 2006). Fatigued individuals can also have difficulty meeting the expectations of certain roles and often have to decrease or cease their commitments (Barroso et al., 2002).

Previous literature highlights a disruption in how individuals view themselves following a diagnosis of CFS/ME, with a move from an identity associated with high activity to one characterised by inactivity (Asbring, 2001). Reduced psychological well-being has been found to originate from loss of self-identity (Edwards, Thompson and Blair, 2007; Harris, Morley and Barton, 2003), which in turn can induce feelings of worthlessness (Ahlstrom, 2006), grief and despair (Gray and Fossey, 2003) in people with CFS/ME, all of which support findings from this study.

Participants stated they are no longer able to reciprocate the help received from others, and this induces a sense of worthlessness. Indeed, intense fatigue has previously been associated with increased levels of psychological distress (Greenberg, 2002). The finding regarding worthlessness due to the inability to provide help to others has not been reported previously and thus extends understanding of the psychological implications of dependency in CFS/ME.

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Worthlessness and vulnerability were also induced due to the lack of control participants felt over their lives, particularly relating to how and when tasks were carried out. According to Williams and Koocher (1998) a diagnosis of a chronic condition can disrupt the ability to predict and manage events, dramatically altering one's sense of personal control. More specifically, lack of predictability, increased physical dependence, and emotional lability can erode an individual's sense of control of their life. The present research has indicated that a feeling of loss of control can lead to a sense of inadequacy.

Many participants described CFS/ME as an 'invisible illness' which can prohibit them from seeking adequate help and inducing feelings of shame and worthlessness. As Davis (2005) argues, people with CFS/ME can appear perfectly 'normal' to people with whom they have casual interactions. When the condition is not visible to others it can be more difficult to obtain the help they need to function effectively. They may have to inform others that they have the condition and explain what help they require. Some people may have to convince others that they have physical limitations imposed by the condition, and that they are not simply seeking an unfair advantage. This is commonly experienced by people with other FSSs (Kool et al., 2009; Werned and Malterud, 2003). Stressful situations as a result of such encounters can increase fatigue and thus can have a profound effect on health and psychological well-being (Davis, 2005). This can eventuate in social withdrawal (Kralik et al., 2005). Adequate social support and validation has been shown to lessen these difficulties (Jason et al., 2010b).

Participants in this research spoke of feeling stigmatised and misunderstood by those who may be best placed to offer them physical support – another commonality to people with other FSSs (Werned and Malterud, 2003). As a result they expressed reluctance in asking for help, leading to feelings of despair and loss of self-worth. An implication of this finding is that family, carers and friends need to have a greater understanding of the condition and the

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impact on daily life. These findings relating to stigma and psychological distress are supportive of previous research which demonstrates that stigma in CFS/ME can arise from the uncertainty connected with the condition, causing psychological suffering including anxiety, doubt, shame, and reduced self-esteem (Asbring and Narvanen, 2002). In turn, the feelings induced by stigmatisation can lead to social withdrawal in an attempt to preserve self-worth. Furthermore, many participants in the present research reported feeling reluctant to seek help, a situation which Davis (2005) stresses is not only frustrating and disappointing but is a risk to physical and psychological health.

Many participants expressed that CFS/ME is difficult to explain and define, often leading to the inability to fully explain their needs. One could argue that communication of needs is important in chronic illnesses in order for individuals to maintain quality of life, especially where symptoms are often invisible to others. Previous research into the experiences of people with CFS/ME has shown that individuals can find it difficult to explain the condition and communicate their needs (Edwards, Thompson and Blair, 2007). The findings of the present research support this previous research, but also expand current understanding in that communication was found to be hindered due to stigma and a lack of understanding from others, inducing a sense of isolation and loss of self-worth. The experiences of communication in CFS/ME as a whole, however, have not yet been investigated in depth.

In previous literature regarding communication in chronic illnesses in general, patients who have engaged in open discussion with others and received attentive responses have demonstrated improvements in health outcomes (Dashiff, Hardeman and McLain, 2008; Rosland, Heisler and Piette, 2012). The present research provides evidence indicating that interventions in lifestyle and fatigue management should perhaps include education on how individuals can explain CFS/ME and effectively communicate their needs to a variety of

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people, including family, professionals and strangers, in the hope of reducing the psychological burden and stress associated with asking for help. Indeed, Christopher and Thomas (2009) provide evidence that CFS/ME patients may cluster into various sub-groupings as a result of the heterogeneous nature of their symptoms. One possible sub-grouping consists of people who exhibit a far from optimal approach when confronted by problem situations. This in part results in heightened experienced distress.

Feelings of burden and worthlessness seemed to be significant in some participants, and these feelings often forced individuals to refrain from seeking help. Going without help for a period of time left some participants in a state of desperation. When these individuals eventually decided to seek help, their desperation was often unrecognised by others. Meanwhile some participants spoke of how restraining from seeking help had increased their symptoms, ultimately impacting on their overall quality of life. This complements previous research which indicates that emotional awareness and regulation impact greatly on the lives of CFS/ME patients (Christopher and Thomas, 2009).

Several participants expressed feelings of anxiety throughout the day, often caused by the worry of not being able to manage their daily activities and receive the help they need. There was evidence of catastrophising worries into concerns about the future. Previous research demonstrates that anxiety is often prevalent in CFS/ME (Deale and Wessely, 2000; Fischler et al., 1997). High levels of anxiety and catastrophising have been found to strongly relate to fatigue (Sohl and Friedberg, 2008), and anxiety has been associated with reduced physical functioning (van Milligen et al., 2011), mirroring the findings of the present research.

Some participants often faced a Catch-22 situation when attempting to complete a task. One could either communicate their needs to someone in order to receive help, or complete the task themselves. Both options however, were expressed as difficult and energy

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consuming. Previous research demonstrates similar dilemmas faced by people with CFS/ME. Davis (2005) proposed that individuals can either forgo the assistance they need and thus bear the consequences of attempting to do things they may not be able to do safely by themselves, or endure the discomfort of subjecting themselves to interrogations by strangers regarding their condition and the reasons for requiring help.

Anger was an emotion that individuals felt they did not want to express to those close to them because of their feelings of being a burden and concerns about appearing ungrateful. A number of factors contributed to this emotion, including limited independence, the unpredictable nature of the condition, the interference with everyday activities, and the interruption with roles and personal goals. A build-up of internalised anger was reported to be distressing. This finding supports previous research which highlights how anger is a common emotion for individuals with chronic illnesses. People with CFS/ME can feel frustrated about the unpredictability of fatigue and decreased ability to think clearly (Kralik et al., 2005), as well as feeling angry about the negative effects of the condition and the perceptions of limited success in treatment (Raymond and Brown, 2000). Experiencing public scepticism concerning the validity of CFS/ME can also leave people feeling angry, misunderstood and isolated (Toussaint et al., 2009), and unexpressed anger can prevent individuals from effectively managing their emotions in relation to the condition (Christopher and Thomas, 2009).

Participants in the present research who showed signs of accepting the impact of the condition on their daily functioning expressed good psychological well-being. They reported feeling relatively positive about their life and able to interact with their environment. A few participants reported that if they were unable to achieve a task in the way in which they were once able to, they accepted that as reality and developed another way. This was said to give them a greater sense of independence, self-worth and accomplishment. Such observation

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indicates that social problem-solving skills may be important in terms of a sense of independence in everyday situations (Christopher and Thomas, 2009; Gilhooly et al., 2007).

Research into the role of acceptance has demonstrated its positive effects on psychological well-being and overall quality of life. Van Damme et al. (2006) found that acceptance is associated with lower levels of fatigue, functional impairment and psychological distress. The authors concluded that acceptance may play a protective role in aspects of psychological well-being, such as anxiety and depression, and argue that this is important because having 'problems' in psychological functioning potentially maintains the condition. Brooks, Rimes and Chalder (2011) also found that CFS/ME patients with a greater level of acceptance showed significantly reduced fatigue, and thus argue that acceptance may be important to consider within treatment.

Limitations of the research

Data analysis

Due to the nature of qualitative analysis, the researchers cannot free themselves of their epistemological stance and personal experiences, thus data cannot be coded in an entirely unbiased manner (Braun and Clarke, 2006).

Procedure

It may be argued that as participants were recruited via support groups it is likely that these individuals were higher functioning and more independent than those who are unable to attend such groups due to the severity of their symptoms. It may be that these latter

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individuals experience greater psychological distress when asking for help. However, severely affected individuals may be reluctant or unable to engage in research due to the level of energy expenditure required.

Conclusions and future research

This research has extended understanding of how dependency can impact upon psychological well-being of adults with CFS/ME. Other related constructs of invalidation and social support have been studied in people with other FSSs. Physical dependency can be viewed as a new but overlapping construct within this literature.

Due to the need to frequently ask for help with daily tasks, people diagnosed with CFS/ME can feel guilty and a burden to others, and can experience loss of self-worth and self-identity, reducing their psychological well-being. Asking for help was found to be difficult and upsetting for many, the resultant effect being a reduced sense of control over their lives. For some, however, asking for help was routine. Notably, participants discussed learning to accept their condition as pivotal to their psychological well-being. Adequate social support and validation from health professionals and family and social networks can be argued to facilitate improvements in mental and physical well-being.

Future research is required to further examine the impact of physical dependency in patients with CFS/ME, and role of acceptance in accessing appropriate physical and psychological support.

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Table 1. Participant demographics

Name	Age (Years)	Gender	Time since diagnosis (Years)	Illness severity	Employment Status
Annie	41	Female	20	Moderate	Unemployed
Diane	60	Female	7	Moderate- to-severe	Retired
Emily	29	Female	5	Mild-to- moderate	Employed part-time
Helen	40	Female	4	Moderate	Unemployed
James	25	Male	9	Moderate- to-severe	Unemployed
Jane	43	Female	4	Mild	Employed full-time
Joanna	54	Female	8	Moderate- to-severe	Unemployed
Kirsty	36	Female	18	Moderate	Unemployed
Nicola	48	Female	13	Moderate	Unemployed
Susan	59	Female	9	Moderate	Retired