

**Title: Third Sector Responses to Health Care Challenges of ‘difficult to manage diagnoses’: a case study of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis**

**Forrester-Jones, R. Tizard Centre, SSPSSR, University of Kent**

**Krotofil, J. Tizard Centre, SSPSSR, University of Kent**

**Oliver, D. Tizard Centre, SSPSSR, University of Kent**

**Corresponding author: R.V.E.Forrester-Jones, Tizard Centre, SSPSSR, University of Kent, Woodlands, Giles Lane, Canterbury, Kent, CT2 7LR, UK**

**e-mail [r.v.e.forrester-jones@kent.ac.uk](mailto:r.v.e.forrester-jones@kent.ac.uk)**

**NB: this paper is currently under journal peer review**

## **Abstract**

The Health and Social Care Act 2012 stipulated: clinically led commissioning; provider regulation to support innovative services; greater patient voice; Public Health England to drive improved health; greater accountability; and the removal of unnecessary bureaucracy. The Care Act 2014 (implemented in April 2015) further aimed to formulate a single, consistent national minimum eligibility threshold, establishing an entitlement to public care and support for all adults with eligible needs and their carers. The mantra for these legislative changes appears to be fairer eligibility criteria and provision of health and social care. Councils are now supposed to take on new duties of wellbeing and independence promotion and provision of information/advice to increase independent living as well as planning ahead for future needs. It is unclear however as to what impact this new entitlement benchmark will mean to individuals with high needs but diagnostically contentious diagnoses (conceptualised here as non-traditional) such as Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME).

The management of CFS/ME has been controversial, with both medical and psychiatric approaches to care being advocated within the health profession. Many people with CFS/ME have reported feeling that their symptoms and problems are either minimised or simply not accepted by health and social care professionals. In this small-scale quasi-experimental longitudinal study we used both quantitative and qualitative methods to find out what patients with CFS/ME thought about a multi-modal holistic care package including spiritual support provided by a private/charitable status hospital specialising in CFS/ME. Fifteen patients with CFS/ME were interviewed at two time points: T1 during hospital admission and T4 twelve months post hospital discharge (each patient had on average stayed in the hospital for two weeks). We found significant improvements in fatigue symptoms as well as perceived improvements in quality of life, and a probable improvement in depression for the study

group 12 months post-hospital discharge. Whilst for individual participants, each of these factors had its own unique meaning shaped by their personal experiences and unique histories, with a few exceptions, the majority of research participants were able to conclude at 12 months follow up that being cared for in the hospital had been a good decision and that they benefited from it. All of the patients were funded and cared for by the third sector as a result of an inability of the current NHS to sustain their care needs. The paper ends on a call to question what will happen to similar ‘non-traditional’ patients?

## Introduction

Chronic fatigue syndrome/Myalgic encephalomyelitis (CFS/ME) is classified as a disorder characterised by symptoms of severe and prolonged fatigue (for a minimum of six months) with accompanying muscular and joint pain, headaches, sleep disturbances and cognitive difficulties which are not due to ongoing exertion, not substantially relieved by rest, nor caused by other medical conditions (ICD-10, WHO 2010, CDCP 2015). Patients with a diagnosis of CFS/ME have also reported secondary negative experiences and feelings; these being largely due to responses from medical practitioners and the wider community about the condition, such as trivialisation, scepticism or disbelief (Dickson *et al.* 2007) and/or characterising people with CFS/ME in judgemental ways, using stigmatising terms to describe them such as ‘illness focused’ or ‘illness fixated’ and ‘medicalising’ (Åsbring & Närvänen 2003:718). In Åsbring & Närvänen’s study, physicians reported ‘*feelings of doubt and irritation*’ towards their patients with CFS/ME (ibid, 178). Such a lack of empathy for the patient can lead to negative stereotyping, especially the psychologising of symptoms amongst female patients (Åsbring & Närvänen 2002). People with CFS/ME have also reported financial and occupational consequences of CFS/ME (Assefi *et al.* 2003) as well as disrupted home relationships and, as a result of being disbelieved, vulnerability to identity crisis (see; Larun & Malterud 2007). Whilst ‘*prevalence depends substantially on the case definition*’ of CFS/ME used (Bates *et al.* 1993), incidence rates of CFS/ME are estimated at between 0.2 and 2.6% within adult populations in the United Kingdom and the United States (Prins *et al.*, 2006).

The medical and social needs of the UK population patients are diverse and shaped by a range of factors including medical uncertainty of diagnosis (Deary *et al.*, 2007) severity and length of illness, social support available to patients, (Band *et al.*, 2014) age, and material

situation. A systematic review of studies on CFS/ME which included the views of over 2500 patients with mainly moderate or severe CFS/ME, identified that people with CFS/ME sought to gain: an understanding of their symptoms; the diagnosis of CFS/ME and information about it; respect and empathy from service providers as well as positive attitudes and support from family and friends; the opportunity to alter their own views and priorities; and the development of strategies to cope with their disabilities whilst maintaining or recovering social participation (Drachler *et al.*, 2009).

### *Policy*

The management of CFS/ME has also been controversial, with both medical and psychiatric approaches to care being advocated within the health profession. These have polarised patient groups with in particular, those who believe that CFS/ME has direct physical causes fervently critiquing those who approach the condition from a psychiatric perspective with many people with CFS/ME, feeling frustrated that funding has tended to focus on psychiatric models of treatment (see Hawkes 2011). This is despite the Report of the Working Group on CFS/ME (2002) to the UK Chief Medical Officer which highlighted the need for patients with CFS/ME to be assessed appropriately and supported to manage the condition. The Health and Social Care Act 2012 stipulated that Public Health England should drive improved health with greater accountability and the removal of unnecessary bureaucracy, together with greater patient voice in terms of types of provision of care. Where diagnosis is uncertain or/and contentious (conceptualised here as non-traditional) such as Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME), however, the question remains as to whether appropriate health and social care is really available? Further, do individuals with such conditions really have a 'voice' or a 'choice' of health or/and social care? The individuals who feature in this study had all experienced treatment models which had led to feelings of being misunderstood. Statutory services were viewed with distrust and misgivings

with little support being provided, leaving individuals to cope on their own with severe disability and often distress, corroborating previous research reviewed above. The purpose of this study was to find out whether a more holistic form of treatment which incorporated *both* health and social care and which included extensive dialogue between professionals and patients was a) helpful to patients with CFS/ME and b) an exemplar of a health and social care model which might be replicated elsewhere.

### *Previous research on treatment for CFS/ME*

Quantitative research including random controlled trials have sought to evaluate various assessment tests for cognitive functioning in patients with CFS/ME (e.g. Cockshell & Mathias 2014) as well as intervention treatments and therapies including pharmacological treatments (e.g. Olson *et al.*, 2003), supplements (e.g. Vermeulen & Scholte 2004), homeopathy (see Weatherly-Jones *et al.*, 2004) cognitive behaviour therapies (see Moss-Morris *et al.*, 2005), and Qigong Exercise (see Ho *et al.*, 2012). Qualitative studies have tended to focus on the perspectives of patients about their illness (e.g. Larun & Malterud 2007), how doctors view CFS/ME (e.g. Anderson *et al.*, 2012) as well as the experiences of families (e.g. Donalek 2009) and significant others caring for a patient with CFS/ME (e.g. Brooks *et al.*, 2013, Band *et al.*, 2014). What is apparent from previous empirical studies is: a) the lack of multi-model approaches to treatment for patients with CFS/ME, and b) a general lack of provision specific to CFS/ME sufferers; we found only one hospital in the UK which emphasises such particular care. Previous studies also lack a longitudinal aspect to the research; tending only to chart results at one particular time period. This study adds to the knowledge of CFS/ME by providing an in-depth exploration of a multi-disciplinary approach to care and treatment provided in an independent hospital.

### *Aim and objective*

The aim of the research was to examine whether a particular holistic (health and social) model of care was related to improved quality of life and fatigue symptoms one year after discharge. The objective was to identify key areas of good practice in relation to care and support of people with CFS/ME.

## **Methods**

### *Study design*

The study was a quasi-experimental longitudinal design aimed at measuring a range of data over time to find out the extent to which patients with CFS/ME viewed the specialist holistic care provided by a particular hospital to make a positive contribution to their health. This design has been successfully used in previous studies measuring the impact of care on patients (see Forrester-Jones *et al.*, 2006, 2012). Data from staff and patients at the hospital were collected during 2011-2014 with patient data collected at four time points: during hospital admission (T1) (patients received on average two weeks of in-patient treatment), 3 months post-hospital discharge (T2), six months post-discharge (T3) and 12 months post-hospital discharge (T4).

### *Study location, site and holistic model of care*

The 40-bed non-surgical hospital provided in-patient medical and nursing care with integrated input from counsellors, physiotherapists, Christian chaplains and support staff. Whilst not exclusively caring for CFS/ME patients, the hospital offered an holistic care and treatment package (including medication, a range of counselling including spiritual support, hydrotherapy, physiotherapy) designed to meet most or all of the needs of someone with CFS/ME, in the context of a supportive, Christian ethos, although there was no compulsion to be involved in any worship or Christian ritual. A third sector organisation, the hospital was

a registered charity and received no direct government funding, relying on income from fees, donations, profits from its trading activities and fundraising initiatives as well as for specific capital projects. Although some patients paid for their care, many were funded by the NHS or Social Services or on occasions by sponsorship from the hospital itself. The general approach used in the hospital to aid CFS/ME recovery followed the model advocated by Worthy (unpublished). This eight stage model of therapeutic alliance between the doctor and patient is based around trust and envelops seven basic elements including: humanity, genuineness and integrity, compassion, non-judgemental listening, believing the patient's story, respecting the patient's needs and aspirations, and going at the patient's speed.

The hospital was set in 100 acres of farm and woodland, with 10 acres of formal gardens and ponds. All rooms were en-suite and there was a chapel, hydrotherapy pool and public café. A guest house within the grounds of the hospital as well as several guest suites within the main building offered rooms for relatives and friends of patients to stay or for those seeking a focussed period of physical, spiritual or emotional support, or simply to experience the on-site facilities such as Healing Services, Massage, the Book shop, Gift shop and Tea Room.

#### *Sampling and recruitment*

A homogeneous purposive sampling technique was used since we wished to study a particular group of patients, namely those with CFS/ME who were being treated using the same holistic, multi-modal method. Therefore, recruitment was based on all those people admitted to the hospital between August 2011 and August 2012 for the assessment and management of CFS/ME (n=17).

#### *Ethical considerations*

The study was peer reviewed and gained UK NHS ethical approval. Each patient was informed of the project both verbally and by letter by the researcher, and written consent was obtained. Mindful of the particular symptoms patients with CFS/ME tend to experience, we were careful to make sure that data collection took place during one or two split sessions, normally with breaks for rest, depending on participants' presentation and ability to engage in data collection procedures. Data collection at times 2-4 took place mainly in participants' homes and one was carried out in a café of the participant's choice.

### *Measures*

A mixed-methods approach was used with both quantitative measures and a bespoke qualitative interview. This paper reports on the quantitative findings of the study only; the qualitative part of the study is reported elsewhere (Krotofil, Forrester-Jones and Oliver *et al.* (in progress)).

#### *Quantitative measures included:*

- *Hospital Anxiety and Depression Scale (HADS)* (Zigmond & Snaith, 1983);
- *Chalder Fatigue Scale* (Chalder *et al.* 1993): an 11-item questionnaire, with each item scored on a Likert scale (0, 1, 2, 3), that produces a total score between 0 and 33 assessing both physical and mental fatigue;
- *The Schedule for the Evaluation of Individual Quality of Life (SeiQuol)* (O'Boyle *et al.* 1993): a mixed-method interview-based instrument allowing individuals to describe their lives in terms of those factors which they consider important in relation to their quality of life. The qualitative data is subjected to a manifest content analysis which provides a global score of the aspects of life which are most important to the individual; measures of these were taken at each time point in the study to indicate any changes in priority aspects to individual's quality of life.

- *Social Network Guide* (Forrester-Jones and Broadhurst 2007): mapping the size of individuals' social networks as well as the types of social support provided by network members;

Data were analysed using parametric paired one tailed t-tests and non-parametric Wilcoxon tests via SPSS Version 22.

## **Findings**

### **Participants**

All participants had their diagnosis of CFS/ME confirmed by a physician during their admission using a range of assessments including the Canadian Clinical Criteria (see Carruthers *et al.* 2003). All 17 patients who met the research criteria consented to be involved in the project but two withdrew at an early stage of the study before base line data had been collected. This left a total of 15 study participants. All were female, aged between 20 and 87, with a mean age of 42 years and mode of 33 years at the date of admission. Seven of the participants lived with their spouse, five were living with their parents (four of whom were being cared for full-time by their mothers) and three lived on their own with only sporadic help from neighbours and friends. Six of the participants had children. None of the study group were employed at baseline, although three periodically engaged in voluntary work. Before the onset of their condition, five had been health care professionals and four had worked either in retail or administration jobs. The rest had never been in paid employment. Hence the majority were receiving Disability Living Allowance (renamed Personal Independence Allowance from 8 April 2013). Two of the group had educational qualifications up to GCSE level and seven at University level. Whilst each participant had symptoms particular to themselves, symptoms experienced by the whole group included

sensory impairments (sensitivity to light, noise and food), headaches, and feeling weak/fatigued. Six had difficulties walking and one expressed severe spiritual anxieties.

We collected data at all four time points wherever possible though it proved difficult to gain full data sets for the purposes of statistical analysis at times 2 and 3, during which individuals reported an ‘*adjustment period*’ after their discharge, often with some sort of relapse. We therefore present changes in symptoms from T1 and T4 only (T4 being hospital treatment). The group showed signs of symptom recovery at T4 indicated in the findings below.

### *Fatigue*

We had complete data sets about fatigue for eleven participants at T1 and T4. On average participants reported a significant reduction in the level of fatigue at 12 months follow up, as compared to base line  $t(10) = 2.68, p < 0.05$ . The reduction in mean Chalder Fatigue score at 12 months was 6.0 (95% confidence interval (CI) [1.02 – 10.98]) (see Figure 1).

### **Insert Figure 1 here**

### *Anxiety and depression*

No significant difference was found in levels of anxiety experienced during admission (M=7.82, SE = 1.52) and at 12 months follow up (M=6.55, SE= 1.30) (n=11). However the mean difference in depression scores at T1 (M=7.55, SE= 1.13) and T4 (M=5.55, SE=0.99) were statistically significantly lower  $t(10) = 2.44, p < 0.05$ . These results should however be interpreted in terms of their clinical significance as it is important to note that of the 11 participants who completed the HADS for T1 and T4 only 3 individuals reached a threshold at T1 which suggested possible diagnosis of clinical depression or anxiety disorder. Of those, 2 participants reported being diagnosed with depression and/or anxiety disorders in the past and were taking prescribed medication. These two individuals remained above the diagnostic

threshold at the 12 month follow up. The third person with no previous diagnosis reported clinically significant reduction of anxiety and depression symptoms after 12 months.

### *Quality of life*

The majority of participants reported a better quality of life at 12 months follow up as compared to the time of admission. In the sample of 12 participants who completed the SEIQoL questionnaire at both time points, there was a significant difference between the global SEIQoL index score at T1 (M= 39.43, SE= 6.50) and the global SEIQoL index score at T4 (M=66.56, SE= 6.45),  $t(11) = 4.55$ ,  $p < 0.05$  (see Figure 2). The areas of life identified as important factors influencing quality of life appeared to be relatively universal despite the group being diverse in terms of age, severity of CFS/ME and other coexisting conditions. Thus very similar factors seemed to influence the group's quality of life: relationships with family and friends, ability to undertake work (or study) and related to this factor, financial situation, church membership, ability to socialise, meet new people and spend quality time outside of home, and ability to carry out everyday life activities, including house chores and self-care. These were the areas of life that participants reported as being the most affected by CFS/ME, and at the same time influenced the way the condition and its symptoms were experienced by themselves. These were also the areas of life in which participants were striving to make positive changes while recovering from CFS/ME. These included: hanging the frequency of contacts with close family; starting part-time work; and re-negotiating the division of work and responsibilities in the family. Table 1 shows the areas of life which were identified as having the strongest impact on participants' quality of life and the meaning ascribed to each of them: the most important being family, friends and ability to lead a normal life.

**Insert Figure 2 here**

## *Social networks*

### *Size*

#### **Insert Figure 3 here**

After removing one outlier, we had social network information for 10 participants at both time points (T1 and T4) (see Figure 3). Although the data at both time points was found to be normally distributed (using Kolmogorov-Smirnov test for distribution) a Wilcoxon-Signed Rank test was carried out due to the small sample size.

No significant changes in average social network size of the group were found. At T1 the average network size of the group was 19 members (median 19.5, SD 3.82) with a range of 12-25. At T4, average network size remained at 19 members, with a median of 17 (SD of 5.83; range of 11-31). Figure 3 shows that social network size increased for over half (n=6) of the group. One participant's network size stayed the same whilst three participants experienced a decrease in network size (one participant's social network had halved in size by T4).

### *Area of life*

At Time 1, just under half of all network members came from community contexts separate from CFS/ME or health services. These included clubs, church, neighbourhoods, other friendship groups and acquaintances. A quarter of all network members came from participant's families (excluding family members living within individuals' households). Work contexts provided 9% of all network members with the rest being derived from CFS/ME related contexts including the hospital. At the follow-up T4, the number of social contacts derived from CFS/ME related contexts i.e. the hospital and CFS/ME network had increased, as had friends without CFS/ME but overall, network members derived from all

other possible social contexts had decreased. These changes were however, not statistically significant.

### *Network membership*

Table 3 shows that at both time points, just over half of the participants as a whole had social networks mainly made up of family or friends. Hospital and other paid carers made up just over an eighth and clubs/church around an eighth of all network members. Fewer network members were work colleagues or neighbours and very few network members were people who participants would regard as social acquaintances or people they knew from local shops. After 12 months post-discharge from hospital treatment for CFS/ME, a few more friends, family members and church/club contacts made up individuals' social networks but these changes were not significant.

### **Social support**

#### **Insert Table 4 here**

Table 4 provides a breakdown of the types of support reported by participants showing whether or not they were provided by all network members. For almost every category of support, less than one third of all potential network members provided it to participants. The exception was 'household' support which included help with domestic chores such as cooking, washing dishes and cleaning, although less than half (36%) of the potential providers provided this type of support. Overall then, the participants were receiving minimal support from their network members. Surprisingly, only 3% at T1 and 2% at T4 of all potential network members provided personal support (help with dressing, bathing etc.) despite participants reporting that they generally found these tasks to be the most difficult to perform, especially when they were feeling really poorly. There were no significant changes

at Time 4. Whilst family members made up the highest proportion overall (about a third of all family members) providing social support at both T1 and T4 (see Table 5), proportionately more friends provided decision making and feedback, confiding and companionship to individuals compared to the other network membership groups.

### **Insert Table 5 here**

Less than half of all network members (48%) were in contact with participants on a daily/weekly basis and this proportion decreased to 34% by T4 (Table 4). Family members were in contact with individuals most frequently at both time points though at T1, just under a quarter of all network members in contact with participants on a daily/weekly basis were church or club social contacts (Table 5) though this proportion dropped to only 14% by T4. Similarly, whilst just over a quarter of all network members in contact with participants at T1 were neighbours this proportion decreased to 13% by T4 despite all of the participants returning to their homes by T4. Less than half (42%) of all ties between participants and their network members were reported as “reciprocal” although participants felt “close” to 78% of all their social contacts (mainly family and friends), this figure rising to 82% at T4 (see Tables 4 and 5).

## **Discussion**

The longitudinal study design, which followed the guidelines of Sharpe *et al.*, (1991), proved useful in demonstrating long term changes of CFS/ME. Whilst the number of instruments used (n=5) meant that the research process was arguably intense for the subject group and researcher to navigate, the fieldwork took place in a piecemeal, flexible way which allowed individuals to participate at their own pace, taking breaks for rests. Studies of other client groups (e.g. intellectual disabilities (see Booth & Booth 1996) and mental health (see Forrester-Jones & Barnes 2008) in addition to guidelines for researching people with

CFS/ME (Sharpe *et al.* 1991) have indicated that participant unresponsiveness may lead to the exclusion of particular methods (e.g. the SeiQuol interviews ). However, this study has shown that such methods are successful if carried out sensitively.

On average participants reported a significant reduction in the level of fatigue at 12 months follow-up. Given that ‘fatigue’ within a diagnosis of CFS/ME envelops a myriad of symptoms for diagnosis including concurrently 4 or more of the following 8: post-exertion malaise lasting more than 24 hours; unrefreshing sleep; significant impairment of short-term memory or concentration; muscle pain; multi-joint pain without swelling or redness; headaches of a new type, pattern, or severity; tender cervical or axillary lymph nodes; a sore throat that is frequently recurring (Centres for Disease Control and Prevention 2015) then this is a positive result indicating that symptomology for this cohort of patients had decreased. However, a random controlled trial (which was not possible within the remit of this research) would need to be carried out (see Deale *et al.*, (2001) for examples) in order to draw firm conclusions as to what exactly may have contributed to overall fatigue reduction.

At time 4, the majority of participants were still reporting anxiety but there was a probable improvement in depression scores. Since many studies including Brown *et al.*, (2001), Taylor *et al.*, (2003), and Fuller-Thomson & Nimigon (2008), all argue that depression is a concomitant of CFS/ME our findings are hopeful.

Relationships with family and friends, and the ability to participate in everyday living activities were the areas of life most affected by CFS/ME for this cohort at both baseline and 12 months after leaving hospital and also influenced the way symptoms were experienced, corroborating previous findings (see Band *et al.*, 2014). These were also aspects of life which participants were actively trying to change positively; being viewed as central to recovery. Whilst each of these components of quality of life had their own unique meaning shaped by

each individual personal experiences and unique histories, they generally correspond with the self-improvement needs of CFS/ME patients identified by Drachler, *et al.*, (2009). Holistic hospital treatment, including spiritual and emotional counselling as described earlier in the paper, as well as on-going telephone support post-hospital discharge was aimed at actively helping individuals change aspects of their lives that *they* perceived as being barriers to recovery. This pro-active person-centred and individualised type of support was something which patients reported as beneficial as exemplified in the following quote:

*“I feel that every decision I have made here has been an informed choice, because they have given me the information and I have then chosen whether to take that on board, or whether to take another thing that I think will work. [...] Because they deal with the emotional side and the physical side and if people want, with the spiritual side, it is all kind of coming together now. In the last few days it started to make sense how it all links together. So that has been quite good. I find all the areas really helpful.” (CFS\_10)*

The qualitative data is presented elsewhere but with a few exceptions, the views expressed in interviews corresponded with the quantitative results provided here, indicating a decrease of the average fatigue level and significant improvement in terms of participants’ quality of life.

Average social network size ( $m=19$ ) for the group was found to be small compared to ordinary populations ( $m=124$  Hill & Dunbar 2003) and slightly smaller than other client groups including people with mental health problems and people with intellectual disabilities where longitudinal studies have also used the same measure and where average network size has consistently been found to be 22 (see Forrester-Jones, *et al.*, 2004; Forrester-Jones *et al.*, 2006; Forrester-Jones *et al.*, 2012; White & Forrester-Jones (*under review*)). At Time 1, ‘family’ was the main social context for individuals, with few people accessing a ‘work’ context. Whilst at one year post-hospital discharge, all areas of life apart from ‘family’ and ‘friends’ had decreased as contexts from which to gain network members, the hospital and

CFS/ME network had become more important as routes to possible social relationships. Previous research has demonstrated how reduced social contact, and shifting roles within the family can contribute to the maintenance of CFS/ME (Deary *et al.*, 2007). The limited social context and network membership of participants' social worlds, together with the QoL finding that CFS/ME had impacted on their relationships with family and friends is important in relation to long-term recovery. A wide social network with a range of network members arguably places fewer demands on informal carers (in this case family members) as well as paid staff (see Forrester-Jones *et al.*, 2006). Helping individuals develop their social networks may well improve their overall recovery trajectory. As it stood, for this group of individuals, overall social support was limited with relatively infrequent social interaction with network members which decreased post discharge and the finding that the relationships participants did have tended not to be reciprocal may have reflected a lack of opportunity to move out of a dependency model where by others do things 'for' individuals with CFS/ME rather than 'with' them.

### **Limitations of the study**

The fact that we were unable to gather full data sets for every participant at T2 and T3 meant that we could not provide a complete picture of milestone changes in recovery. This necessarily limits the findings but also reflects the fluctuating nature of CFS/ME which can impact on participant reliability to engage in research at specific times. The study was also small in terms of the sample and therefore the findings are not generalizable. Yet, the in-depth nature of the study did mean that the experiences of individuals in terms of how treatment may or may not impact on their quality of life could be explored. The study also showed that the social lives of people with CFS/ME have synergies with other client groups including those with mental health problems and those with intellectual disabilities.

Nevertheless, we would recommend that any future study is conducted within a random controlled trial.

### **Conclusion and recommendations**

The research indicated that a careful accepting assessment of the person with CFS/ME whereby the patient feels that they are ‘believed’ can aid feelings of recovery and ensuing improvement in quality of life. For many of the participants, admission to the hospital was a turning point at which they started exploring new treatments, introduced some changes into their daily routines, or looked at their problems from a different perspective. Acceptance of the CFS/ME condition, with its accompanying symptoms and, more broadly the life situation of participants by the hospital clinical, professional staff, as well as chaplains and counsellors provided an opportunity for the participants with CFS/ME to begin to reassess their lives and illness during, and after, their stay at the hospital. This in turn, prompted some of the participants to introduce some significant changes to their lives.

The hospital doctors, nurses, physiotherapists, chaplains and counsellors worked as a ‘support’ team to offer care which started with and centred around the individual with CFS/ME. Such care provision sought to empower the patient to work with the team in order to understand the illness and seek out possible strategies to combat symptoms. This type of relationship was set within a more homely than institutional environment, with a positive culture of belief in individual’s histories and experiences of their illness.

The findings from this study provide an example of how a clinical and socially supportive care environment can contribute positively to experiences of CFS/ME. In the face of continued lack of empirical understanding, uncertain diagnosis and variable interventions, as well as general negativity and pejorative stereotyping of the illness, together with the possibility of people with CFS/ME falling outside of the new eligibility threshold (see Care

Act 2014), this third sector model of care may well be a hidden pearl. Under the Care Act 2014, councils are now supposed to take on new duties of wellbeing and independence promotion and provision of information/advice to increase independent living as well as planning ahead for future needs. It will be interesting to see how this plays out in practice in relation to people with conditions such as CFS/ME and it is hoped that findings such as ours will be informative to those making decisions around eligibility. Future research which offers a comparative study of various treatment settings utilising a random control trial design would be invaluable for testing out the model on offer at this hospital, though for the particular participants in this study, it certainly looks promising and, as a third sector response to a condition that other sectors don't seem to be able to deal with (or perhaps want), it may become increasingly more important.

## References

- Anderson, V.P., Jason, L.A., Hlavaty, L.E. Porter, N. & Cudia, J. (2012) A Review and Meta-Synthesis of Qualitative Studies on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Patient Education Counselling*, 86, 147-155 [online] Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3229648/> [Accessed 11 March 2015]
- Åsbring, P., & Närvänen, A. (2002) Women's experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qualitative Health Research*, 12, 2, 148-160 [online] Available at: <http://qhr.sagepub.com/content/12/2/148.full.pdf>
- Åsbring, P., & Närvänen, A. (2003) Ideal versus reality: physicians perspectives on patients with chronic fatigue syndrome (CFS) and fibromyalgia, *Social Science & Medicine*, 57, 711-720 [online] Available at: <http://www.sciencedirect.com/science/article/pii/S0277953602004203#> [accessed 10 March 2015]
- Assefi, N.P., Coy, T.V., Uslan, D., Smith, W.R., Buchwald, D. (2004) Financial, occupational, and personal consequences of disability in patients with chronic fatigue syndrome and fibromyalgia compared to other fatiguing conditions, *The Journal of Rheumatology*, 30, 4, 804-808 [online] available at: <http://depts.washington.edu/uwccer/data/pdf/pub/070%20j%20rheumatol%202002%2030%20804-808.pdf> [accessed 10 March 2015]
- Band, R., Barrowclough, C. & Wearden, A. (2014) The Impact of significant Other Expressed Emotion on Patient Outcomes in Chronic Fatigue Syndrome, *Health Psychology*, 33, 9, 1092-1101 [online] Available at: <http://psycnet.apa.org/journals/hea/33/9/1092.pdf> [accessed 10 March 2015]
- Bates, D.W., Schmitt, W., Buchwald, D., Ware, N.C., Lee, J., Thoyer, E., Kornish, J. R., Komaroff, A.L. (1993) Prevalence of Fatigue and Chronic Fatigue Syndrome in a Primary Care Practice, *Archives of International Medicine* 153 (24) 2759-2765.
- Booth, T. & Booth, W. (1996) Sounds of Silence: narrative research with inarticulate subjects, *Disability & Society*, Vol 11, No 1, pp55-69
- Brooks, J., King, N., & Wearden, A (2013) Couples' experiences of interacting with outside others in chronic fatigue syndrome: a qualitative study, *Chronic Illness* 10, 1, 5-17 [online] downloaded from <http://www.chi.sagepub.com> downloaded Templeman Liv/The Librarian on January 9 2015
- Brown, C., Dunbar-Jacob, J., Palenchar, D.R. *et al* (2001) Primary care patients' personal illness models for depression: a preliminary investigation. *Family Practice* 18, 314-320 [online] Available at: <http://fampra.oxfordjournals.org/content/18/3/314.full.pdf+html> [Accessed 11 March 2015]
- Carruthers BM, Jain, A.K., De Meirleir, K.L. *et al*. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols (2003) *Journal of Chronic Fatigue Syndrome*, Vol. 11(1) 7-36.

Centres for Disease Control and Prevention (2015)

<http://www.cdc.gov/cfs/diagnosis/index.html> downloaded on 18/02/2015

CFS/ME Working Group (2002) Report of the CFS/ME Working Group: *Report to the Chief Medical Officer of an Independent Working Group*, Department of Health

<http://www.erythos.com/gibsonenquiry/Docs/CMOreport.pdf>

Chalder T, Berelowitz G, Pawlikowska T, Watts L, Wessely S, Wright D, Wallace EP (1993). Development of a fatigue scale. *Journal of Psychosomatic Research*, 37:147–153.

Cockshell, S.J. & Mathias, J.L. (2014) Cognitive functioning in People with Chronic Fatigue syndrome: A Comparison Between Subjective and Objective Measures, *Neuropsychology*, 28, 3, 394-405

Deale, A., Hiusain, K., Chalder, R., Wessley, S. (2001) Long-Term Outcome of Cognitive Behavior Therapy Versus Relaxation Therapy for Chronic Fatigue Syndrome: A 5-Year Follow-Up Study, *American Journal of Psychiatry*, 158, 12 2038-1498

Deary, V., Calder, T., & Sharpe, M. (2007) The cognitive behavioural model of medically unexplained symptoms: A theoretical and empirical review. *Clinical Psychology Review*, 27, 781-791 [online] Available at:

<http://www.tandfonline.com/doi/pdf/10.1080/08870440802403863> [Accessed 10 March 2015]

Dickson, A., Knussen, C. & Flowers, P. (2007) Stigma and the delegitimation experience: An interpretative phenomenological analysis of people living with chronic fatigue syndrome. *Psychology & Health*, 22, 851-867 [online] Available at:

<http://www.tandfonline.com/doi/pdf/10.1080/14768320600976224> [Accessed 10 March 2015]

Donalek, J.G. (2009) When a Parent Is Chronically Ill: Chronic Fatigue Syndrome. *Nursing Research*, 58, 5, 332-339

Drachler M, de Carvalho J, Hooper L, Hong C, Pheby D, Nacul L, Lacerda E, Campion P, Killett A, McArthur M, Poland F, (2009). The expressed needs of people with chronic fatigue syndrome/myalgic encephalomyelitis: a systematic review. *BMC Public Health*, 9: 458 [online] Available at: <http://www.biomedcentral.com/content/pdf/1471-2458-9-458.pdf>

[Accessed 10 March 2015]

Forrester-Jones, R. & Barnes, A. (2008) On being a girlfriend not a patient: The quest for an acceptable identity amongst people diagnosed with a severe mental illness, *Journal of Mental Health*, 17 (2) 153-172

Forrester-Jones, R. V. E., Broadhurst S, (2007). *Autism and loss*. London: Jessica Kingsley Publishers

Forrester-Jones, R. Cambridge, P. Carpenter, J. Tate, A. Beecham, J. Hallam, A. and Knapp, M. Coolen-Schrijner, P. and Wooff, D. (2006) The Social Networks of people with Learning Disabilities Living in the Community Twelve Years After Resettling from Long-stay hospital. *Journal of Applied Research in Intellectual Disability* 19, 285-295

Forrester-Jones, R., Carpenter, J., Cambridge, P., Tate, A., Hallam, A., Beecham, J., Knapp, J. Woof, D. (2012) Good Friends are Hard to Find? The Social Networks of People with Mental Illness 12 years after Deinstitutionalisation *Journal of Mental Health* Vol 21, 1, 4-14,

Forrester-Jones, R., Jones, S., Heason, S. & Di'Terlizzi, M. (2004) Supported Employment: a Route to Social Networks, *Journal of Applied Research in Intellectual Disabilities*, 17, 199-208

Fuller-Thomson, E. & Nimigon, J. (2008) Factors associated with depression among individuals with chronic fatigue syndrome: findings from a nationally representative study, *Family Practice*, 414-422 [online] Downloaded from <http://fampra.oxfordjournals.org/> at University of Kent on January 9 2015

Hawkes, N. (2011) The dangers of research into CFS/ME Medical Research. *British Medical Journal*, 342, 1392-1395

Hill and Dunbar Hill, R. A., & Dunbar, R. I. M. (2003). Social Network Size in Humans. *Human Nature*, 14 (1), 53-72

Ho, R.T.H., Chan, J.S.M., Wang, C-W., Lau, B.W.M., So, K.F., Yuen, L.P., Sham, J.S.T., Chan, C.L.W. (2012) A Randomized Controlled Trial of Qigong Exercise on Fatigue Symptoms, Functioning, and Telomerase Activity in Persons with Chronic Fatigue or Chronic Fatigue Syndrome, *Annals of Behavioural Medicine*, 44, 160-170 [online] Available at: <http://link.springer.com/article/10.1007/s12160-012-9381-6/fulltext.html> [Accessed 11 March 2015]

International Chronic Fatigue Syndrome Study Group (1994) The Chronic Fatigue Syndrome: A Comprehensive Approach to Its Definition and Study, *Annals of International Medicine*, 121, 12 953-959

Larun, L. & Malterud, K. (2007) Identity and coping experiences in Chronic Fatigue Syndrome: A synthesis of qualitative studies, *Patient, Education and Counselling*, 69, 20-28 [online] Available at: <http://www.sciencedirect.com/science/article/pii/S0738399107002601> [Accessed 10 March 2015]

Marks, M.R., Huws, J.C. and Whitehead, L. (2015) Working with uncertainty: A grounded theory study of health-care professionals' experiences of working with children and adolescents with chronic fatigue syndrome, *Journal of Health Psychology*, 1-10 [online] Available at [hpq.sagepub.com](http://hpq.sagepub.com) at Templeman Lib/The Librarian [Accessed 21 May 2015]

Moss-Morris, R., Sharon, C., Tobin, R., & Baldi, J. (2005) A Randomized Controlled Graded Exercise Trial for Chronic Fatigue Syndrome: Outcomes and Mechanisms of Change, *Journal of Health Psychology*, 10 (2) 245-259 [online] Available at: <http://www.hpq.sagepub.com> at Templeman Lib/The Librarian [Accessed 11 March 2015]

O'Boyle C ,McGee HM , Hickey A,et al. (1993).*The Schedule for the Evaluation of Individual Quality of Life (SEIQuoL): administration manual*. Ireland, Royal College of Surgeons

Olson, L.G., Ambrogetti, A., Sutherland, D.C. (2003) A Pilot Randomized Controlled Trial of Dexamphetamine in Patients with Chronic Fatigue Syndrome, *Psychosomatics*, 44, 1, 38-43 [online] Available at: <http://www.sciencedirect.com/science/article/pii/S0033318203703235> [Accessed 11 March 2015]

Prins, J.B., van der Meer, J.W.M. & Bleijenberg, G. (2006) Chronic fatigue syndrome. *The Lancet*, 367, 346-355 [online] Available at: <http://www.sciencedirect.com/science/article/pii/S0140673600041982> [Accessed 9 March 2015]

Sharpe, M.C., Banatvala, J.E., Borysiewicz, L.K., Clare, A.W., David, A., *et al.* A report-chronic fatigue syndrome: guidelines for research, *Journal of the Royal Society of Medicine*, 84, 118-121

Taylor, R.R., Jason, L.A., Jahn, S.C. (2003) Chronic fatigue and sociodemographic characteristics as predictors of psychiatric disorders in a community-based sample. *Psychosomatic Medicine* 65, 896-901

Vermeulen, R.C., & Scholte, H.R. (2004), Exploratory open label, randomized study of acetylcarnitine and propionylcarnitine in chronic fatigue syndrome. *Psychosomatic Medicine*, 66, 276-82

Weatherley-Jones, E. Nicholl, J.P., Thomas, K.J. Parry, G.J., McKendrick, M.W., Green, S.T., Stanley, P.J., Lynch, S.P.J. (2004) A randomised, controlled, triple-blind trial of the efficacy of homeopathic treatment for chronic fatigue syndrome *Journal of Psychosomatic Research* 56 (2004) 189–197

World Health Organisation, (2011) *International Statistical Classification of Diseases and Related Health Problems 10<sup>th</sup> Revision* World Health Organisation

Zigmond AS, Snaith RP, (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67:361–370.

**Table 1 Life domains identified as having the strongest impact on participants' quality of life and the meaning ascribed to each of them**

<b>Area of life</b>	<b>Frequency T1</b>	<b>Frequency T4</b>	<b>Meaning</b>
Family	10	11	Support and acceptance, companionship. Being able to fulfil caring responsibilities towards elderly parents, children
Friends	9	11	Mutual support and acceptance, sharing time with others. Joy and burden of doing things for others
CFS/ME network	9	8	Being able to live normal life. Controlling symptoms: pain, tiredness, lack of sleep, mobility problems.
Work/studying	6	4	Meeting with other people, having structure. Pride, sense of achievement, making a difference
Church, Spiritual life	6	5	Social aspect of church membership: friendship, companionship. Relationship with God: guidance, sense of purpose.
Socialising/going out	5	7	Meeting other people, spending quality time outside of home. Being able to access entertainment: cinema, theatre, library, restaurant.
Independence	5	3	Being able to do the housework, shopping and other daily tasks
Peaceful environment	3	1	Feeling safe, being able to rest.
Professional support	3	1	Being believed and supported by health care professionals
Finance	2	1	Being unable to earn money, relying on the spouse to provide for the family. Being forced to fight for benefits.

**Table 2 Number of network members derived from each area of life at Time 1 and Time 4**

<i>Area of life</i>	<i>n (%)</i>	
	<i>T1</i>	<i>T4</i>
Household	16 (7)	9 (5)
Health Care	17 (8)	18(10)
Work colleagues (paid/vol)	20(9)	17 (9)
Club (including CFS/ME network)	13(6)	18(10)
Church/social club	34(16)	31 (16)
Neighbourhood	21(10)	15(8)
Other family (not household)	52 (24)	44 (23)
Friends (without CFS/ME)	29 (14)	32(17)
Social Acquaintances	12(6)	3(2)
Total	214 (100)	187(100)

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**Table 3 Social Network membership at Time 1 and Time 4**

<i>Social network membership category</i>	<i>n (%)</i>	
	<i>T1</i>	<i>T4</i>
Family	51 (28)	52 (28)
Friends	45 (24)	48 (26)
Hospital and other paid carers	27 (14)	24 (13)
Clubs/church	23 (12)	28 (15)
Work colleagues	19 (10)	19 (10)
Neighbours	19 (10)	19 (10)
Retail & social acquaintances	3 (2)	0 (0)
Total	187 (100)	187 (100)

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**Table 4 Frequency of social support reported by participants at Time 1 and Time 4**  
(N=11)

	<i>Always /sometimes</i>		<i>Hardly ever/never</i>		<i>Total</i>	
	<i>n (%)</i>		<i>n (%)</i>		<i>n (%)</i>	
<i>Support behaviour</i>	<i>T1</i>	<i>T4</i>	<i>T1</i>	<i>T4</i>	<i>T1</i>	<i>T4</i>
Personal	6 (3)	4 (2)	181 (97)	183 (98)	187 (100)	187 (100)
Household	67 (36)	57 (30)	120 (64)	130 (70)	187(100)	187(100)
Material	12 (6)	12 (6)	175 (94)	175 (94)	187(100)	187(100)
Decision making & feedback	45 (24)	38 (20)	142 (76)	149 (80)	187(100)	187(100)
Confiding	52 (28)	52 (28)	135 (72)	135 (72)	187(100)	187(100)
Company	46 (25)	72 (39)	141 (75)	115 (61)	187(100)	187(100)
Invisible	55 (29)	43 (23)	132 (71)	144 (77)	187(100)	187(100)
Critical	7 (4)	4 (2)	180 (96)	183 (98)	187(100)	187(100)
<i>Interactional behaviours</i>						
Frequency	<i>Daily, Weekly</i>		<i>Monthly or less</i>			
	89 (48)	70 (37)	98 (52)	117 (63)	187 (100)	187 (100)
Reciprocity	<i>Reciprocal</i>		<i>Not reciprocal</i>			
	79 (42)	64 (34)	108 (58)	123 (66)	187(100)	187(100)
Closeness	<i>Close</i>		<i>Not close</i>			
	146(78)	153(82)	41(22)	34(18)	187(100)	187(100)

**Table 5 Support types provided by network members**

<i>Support type</i>	<i>Family</i>		<i>Friends</i>		<i>Hospital &amp; other paid carers</i>		<i>Clubs &amp; church</i>		<i>Work colleagues</i>		<i>Neighbours</i>		<i>Retail &amp; social acquaintances</i>		<i>Total</i>	
	<i>T1</i>	<i>T4</i>	<i>T1</i>	<i>T4</i>	<i>T1</i>	<i>T4</i>	<i>T1</i>	<i>T4</i>	<i>T1</i>	<i>T4</i>	<i>T1</i>	<i>T4</i>	<i>T1</i>	<i>T4</i>	<i>T1</i>	<i>T4</i>
Personal	4(66)	2(50)	0(0)	0(0)	2(33)	2(50)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	6	4
Domestic	19(28)	17(30)	12(18)	12(21)	3(4)	4(7)	9(13)	4(7)	11(16)	9(16)	12(18)	1 (19)	1(1)	0(0)	67	57
Material	12 (100)	12(100)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	0(0)	12	12
Decisions/feedback	16(35)	16(42)	20(44)	15(39)	6(13)	3(8)	2(4)	1(3)	1(2)	3(8)	0(0)	0(0)	0(0)	0(0)	45	38
Confiding	12(23)	12(23)	28(54)	24(46)	3(6)	2(5)	5(10)	7(13)	4(8)	7(13)	0(0)	0(0)	0(0)	0(0)	52	52
Companionship	10(22)	21(29)	19(41)	26(36)	1(2)	2(3)	5(11)	15(21)	8(17)	5(7)	2(4)	3(4)	1(2)	0(0)	46	72
Invisible	24(44)	20(46)	15(27)	17(39)	2(4)	2(5)	11(20)	2(5)	0(0)	1(2)	2(5)	1(2)	1(2)	0(0)	55	43
Critical	5(71)	3(75)	0(0)	0(0)	1(14)	1(2)	0(0)	0(0)	0(0)	0(0)	1(14)	0(0)	0(0)	0(0)	7	4
Total	102(35)	103(36)	94(32)	94(33)	18(6)	16(6)	32(11)	29(10)	24(8)	25(9)	17(6)	15(5)	(3)1	0(0)	290	282
<i>Interactional</i>																
Frequency; daily, weekly	25(28)	20(28)	17(19)	12(17)	8(9)	9(13)	21(23)	10(14)	0(0)	7(8)	18(26)	12(13)	0(0)	0(0)	89	70
Reciprocal	24(30)	20(31)	20(25)	21(33)	5(6)	4(6)	10(13)	6(9)	12(15)	8(12)	7(9)	5(8)	1(1)	0(0)	79	64
Closeness	43(29)	46(30)	41(28)	46(30)	6(4)	8(5)	22(15)	22(14)	19(13)	18(12)	14(9)	13(8)	1(1)	0(0)	146	153