



Toward a trajectory of identity reconstruction in chronic fatigue syndrome/myalgic encephalomyelitis: A longitudinal qualitative study

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Abstract

Background: Chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) is an illness associated with high levels of physical and cognitive disability over a prolonged period of time. Recovery from CFS/ME can be interspersed with relapses. Further, the legitimacy of the illness continues to be questioned within and beyond the health profession.

Aim: This paper examines the reconstruction of self-identity for those experiencing CFS/ME.

Method: This longitudinal qualitative study involved up to three in-depth interviews with 17 people with CFS/ME and family members.

Results: A trajectory that describes transitions in identity over time and the range of elements that influence these is proposed. During the acute phase of illness, characterised by total debility, people adopted the traditional sick role. The medium term phase highlighted movement between disability as part of the total self, total debility, and/or the adoption of a supernormal identity. The longer-term phase was defined for the majority of participants as the positive reconstruction of self. Identity was contingent with positive and negative experiences and responses co-existing with the potential to 'tip' the balance and perceived identity. In the longer term people's identity became more static with the development of coping strategies to maintain this. The trajectory can be described as pendular and movement between each type of identity was possible during all phases of the illness experience depending on the nature and impact of the illness and responses given to these. The proposed trajectory represents a dynamic model of identity reconstruction.

Conclusion: Understanding the patients' experience and recognising that different stages may exist is important for health professionals. This awareness can enhance shared understanding and opportunities to work with people in negotiating the impact of illness.

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Keywords: Chronic fatigue syndrome; Identity reconstruction; Nursing

What is already known about the topic?

- Chronic illness is generally linked to the experience of biographical disruption and chronic fatigue syn-

drome/myalgic encephalomyelitis represents a chronic, often highly debilitating condition.

- The impact of illness on identity is generally held as negative, yet identity reconstruction can result in positive outcomes for people with chronic fatigue syndrome/myalgic encephalomyelitis and other chronic conditions.

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- Understanding how a positive outcome can be achieved is poorly understood.

What this paper adds

- This study has found that it is possible to reconstruct a new and positive self-identity following the onset of chronic fatigue syndrome/myalgic encephalomyelitis.
- Identity reconstruction can be seen to follow a trajectory containing three phases, characterised for the majority by total debilitation in the acute phase, to disability as part of the total self in the medium term and a positive self-identity in the longer term.

1. Introduction and background

Work around identity and illness can be broadly divided into the study of the impact of illness on identity and consequent need for reconstruction and emergent identities. Key areas are the impact on biography (Bury, 1982), life story (Frank, 1995; Williams, 1984), and explanatory models (Helman, 1991; Kleinman, 1988). When the body changes, uncertainties around definitions of the self arise (Ciambrone, 2001). Individuals need to work out how to explain the illness to themselves and others (Kleinman, 1988) as well as explore the present and future impact of changes (Bury, 1991).

The impact of illness on the self has been conceptualised as a biographical disruption (Bury, 1982) where the story that a person constructs about his life, past, present and future is interpreted and changed as a result of the illness. Chronic illness represents a continuing disruption. Boundaries are challenged or erased and a focus on bodily states adopted (Bury, 1982). Because of this, the ill person rethinks their biography and self-concept, ultimately resulting in a mobilisation of resources to respond to the life disruption. For people where illness is unexpected, or not anticipated, for instance the early onset of arthritis, greater work to come to terms with this and reconstruct identity may be necessary (Bury, 1982).

An illness such as chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) imposes many losses on the individual and their family. The deterioration in mobility, energy levels and concentration, coupled with uncertainty over the course of this makes the illness particularly difficult to live and deal with (Ware, 1999). CFS/ME induces profound biographical disruption through its effects on self-image, social roles and valued occupations (Whitehead, 2004a). Financial difficulties and social isolation create additional stress acting to undermine self-esteem.

Similar impacts have been noted for people living with fibromyalgia, a condition characterised by bodily pain with transitions in identity across work, family life, social life (Söderberg, 1999) and accompanying diminishment of self-confidence (Younger, 1991).

When lives have been disrupted by particular events efforts to create continuity in life histories, or to 'reorient' oneself, can be summarised as the attempt to reconstruct personal life histories (Williams, 1984). By uncovering a means of interpreting the illness, we become better able to re-establish the relationship between the self, the world and our bodies (Williams, 1984). The narrativised reconstruction is concerned with gaining meaning and import to the illness by placing it within the context of one's own life and to reconstruct the narrative of the self (Frank, 1995). The reconstruction of one's own life story is of central importance. Narrativising the chronic illness within the framework of one's own life history makes it possible to give meaning to events that have disrupted and changed the course of one's life (Williams, 1984). When individuals are unable to achieve this, identity issues remain unresolved.

The ways in which illness effects self-change has been explored through narratives (Frank, 1995). Three types of illness narratives are proposed, restitution, chaos and quest. Restitution involves seeking to return to the former self, chaos depicts an inability to interpret and make sense of the illness and quest, seeking to achieve a new self that draws on the experience of having suffered. People are described as moving through all or some of these in interpreting their experience. Work on the narratives of people diagnosed as HIV-positive (Ezzy, 2000) and with breast cancer (Thomas-Maclean, 2004) have shown that narratives differ in terms of their focus between and within conditions. One quarter of those diagnosed as HIV positive and one third of those with breast cancer described a quest narrative, others described a restitution narrative or a chaos narrative. No notion of a process of working through different types of narratives were proposed.

A second branch of work focuses on the outcomes of identity reconstruction, taking the premise that loss of self is a fundamental consequence of chronic illness (Charmaz, 1983; Fontana and Smith, 1989). However, some studies suggest that people can, over time, develop strategies to deal with these and derive positive meaning from the illness experience (Ware, 1999; Robinson, 1990). Questions around the meaning and attainment of a successful transition are raised. A number of studies (Carricaburu and Pierret, 1995; Charmaz, 1987; Corbin and Strauss, 1988; Yoshida, 1993) have suggested that biographical work aims toward self-construction and maintenance of a self that is conceived of as either the same as before (restored self) able to take up life very much as it was, or better than before (supernormal self). This suggests a hierarchy of outcomes.

Individuals living with chronic progressive deteriorating conditions have been portrayed as aspiring to construct preferred personal and social identities with the ultimate being the supernormal social identity, an identity where extraordinary feats are commonplace in the conventional world, followed by the restored self, a reconstruction of previous identities prior to the illness, the contingent self, which is a potential, but uncertain identity because of the possibility of future illness and lastly the salvaged self, retaining a past identity based upon a valued activity or attribute while becoming physically dependent (Charmaz, 1983). In the case of progressive deteriorating illnesses this meant 'reducing identity goals and aiming for a lower level in the identity hierarchy' (Charmaz, 1987, p. 285).

A framework on identity reconstruction following spinal cord injury (Yoshida, 1993) incorporated both process and outcome elements of identity reconstruction. Five predominant identity views emerged presented as a pendulum. A general movement was mapped from the former self to the disabled identity as total self, to the supernormal identity, then the disabled identity as an aspect of the total self, then moving to the middle of the pendulum, the middle self was noted when an individual acts on both the disabled and non-disabled aspects of themselves. Not everyone experienced all of these identities and could be situated at anyone of the identities with little movement for some time. Movement along the pendulum was influenced by a number of factors including loss, sustainment, integration, continuity and development.

Earlier work around the identity transformation of women living with CFS/ME or fibromyalgia did not note a total loss of self during illness (Asbring, 2001). A partial loss of earlier identity, particularly in relation to work and social life was noted. Some made attempts to regain the former self, but "these attempts often failed and disappointment then followed" (Asbring, 2001, p. 317). It would appear that the participants in Asbring's (2001) study moved between these two identity forms in a circular motion for some time before moving onto a new identity, a new self that contained some elements of the former self but also positive gains from the illness experience. The process elements involved giving up activities that were no longer achievable, performing activities in different ways and finding alternative interests, elements noted in earlier work (Ware, 1993) where a successful, positive transition was achieved by the prioritisation of activities and pacing of these (Ware, 1998).

Clarke and James (2003) propose the emergence of two forms of identity reconstruction following the onset of CFS/ME; immediate and total loss of identity, characterised by totalising separation from the key areas of work, friends and activities; and the new self, a radicalised self that represented a new, better self.

Evidence of a wish to return to the former self or to a supernormal identity was not found, nor movement between the two identities. Once achieved it appeared that the radicalised self remained. Process elements involved in the movement from total loss of identity to a radicalised self were beliefs that one had been negatively judged by others and experiences trivialised initiating a withdrawal from social environments and subsequent isolation from daily life.

The purpose of this paper is to further illuminate the reconstruction of identity in CFS/ME with an emphasis on the experiences that facilitate this and to explore a possible trajectory.

2. The study

2.1. Methodology

The study was guided by hermeneutic phenomenology drawing on the work of Heidegger (1962) and Gadamer (1975). This methodology reflected the descriptive and interpretative quality of the research question that underpinned the study: 'What does the experience of CFS/ME mean to people who are experiencing this state of being-in-the-world and their families?'

The methodology focused the approach taken more fully on the importance of recognising and acknowledging the preunderstandings that the researcher brought to the study and the impact of these in generating the data. The methodology further highlighted the significance of the temporality of understandings elicited and the evolution of these, particularly relevant to a longitudinal qualitative study and one with a focus on exploring the evolution of identity reconstruction.

2.2. Sample

Seventeen people with CFS/ME were interviewed and purposive sample drawn in order to include people from a number of different settings. Ten people attended a CFS/ME clinic at a local hospital. Three people were recruited through local CFS/ME support groups and four people through a snowballing approach. People with CFS/ME participating in the study ranged in age from 13 years to 63 years and comprised of 6 men with CFS/ME and 11 women. A range of family situations were represented from those with children at home, with older children living away, geographically dispersed families, separated families, and those in retirement.

A diagnosis of CFS/ME from a member of the medical profession was not part of the inclusion criteria where it is known that this can be affected by a number of factors (Sharpe et al., 1997; Woodward et al., 1995). Where this study focussed on the lived experience of

CFS/ME the most important factor was an individual's belief that they had CFS/ME. In addition, as will become evident in the paper, the search for a diagnosis of CFS/ME can constitute a significant factor in the illness experience.

2.3. Data collection

In-depth interviews were conducted mainly in participant's own homes with follow-up interviews conducted over a two and a half year period. All interviews were tape-recorded and transcribed verbatim. Where the aim of the study was to explore the meaning of the experience of living with CFS/ME the interview schedule was unstructured, starting with one question 'can you describe the onset of symptoms?' with minimal probes through out the interview.

2.4. Enhancing the credibility of the study

In hermeneutic phenomenological research an ability to follow the decision trail relating to theoretical, methodological and analytic choices is an important indicator of trustworthiness. Attention to the way in which the researcher's preunderstandings and horizons operate is essential (Koch, 1994). The author reflected on the influences that informed the decision trial and so the credibility of the study, with an emphasis on the potential effects of personal and social characteristics on data collection, discussed in more depth in a further paper (Whitehead, 2004b).

2.5. Ethical considerations

The study gained approval from the local research ethics committee. All potential participants were contacted through a third party who provided study information informing people of their right not to take part in the study and to withdraw from the study. Those who were interested in taking part returned a reply slip agreeing to be contacted about the study. Informed consent was obtained from all participants. To protect the anonymity of the families that took part in the study, information that may lead to identification has been removed and all participants have been given a pseudonym.

2.6. Data analysis

Verbatim transcriptions of the interviews were made. These were sent back to participants to review the content and accuracy. The data were imported into NUD*IST Vivo® 1.2 computer software. Iterative reading of the interview transcripts was an integral and ongoing part of the interpretive process. Analysis began by identifying key words and concepts that

emerged. Themes were created based on segments of data and drawing from conceptual literature until a decision to leave the hermeneutic circle of analysis was made. Codes were mostly descriptive at first; Developing into interpretative themes through in-depth reflection.

3. Findings

The analysis presents the reconstruction of self-identity following the form of a trajectory with three stages, the acute, medium and longer term.

3.1. Disruption and identity in the acute phase of the illness experience

The acute phase of the illness experience was characterised by total disablement lasting between 2 weeks and 3 months. During this phase all participants reported ubiquitous loss. Typically, the symptoms began suddenly and without warning. People were thrown from a world defined by activity to a period of complete immobility, remaining house or bed-bound, worlds dramatically constricted. Everyone had to take time away from work or school. The dramatic loss in self-esteem and identity represented a disabled self as the total identity.

I couldn't get further than the door and that was it. I used to go in there to make a sandwich, and everything went haywire, bread, jam, I said this is too much, I couldn't get my breath, I was on the settee and half off it. Alan

People described being unable to wash, dress or move around the house unaided. The initial loss reflected people's sudden inability to function in any of the areas that had given their lives meaning, structure and purpose. Participants frequently felt isolated and separated from the daily requirements of life, work, family and recreation. They became outsiders, distant from the activities of every day.

I went home to stay with my parents for what was going to be a few days, just to have mummy nursing sort of thing but the pain was so bad that I ended up staying there over a month. Lucy

At this stage no-one had a confirmed diagnosis of CFS/ME, the majority believing they were experiencing a bad bout of flu. Following a period of time of total disablement, people attempted to move on, triggered by a variety of beliefs, described in more depth elsewhere (Whitehead, 2005) but overwhelmingly governed by the need to return to work and take up previous roles. This movement characterised the reconstruction of identity in the medium term.

3.2. Identity reconstruction in the medium term

Identity reconstruction in the medium term was characterised by attempts to return to aspects of the former self with the emergence of three types of identity outcome: (1) disabled identity as the total self, (2) disabled identity as part of the total self, and (3) supernormal identity. A circular movement between experiencing the disabled identity as total self and the disabled identity as part of the total self was noted as people attempted to regain aspects of the former self and relapses were experienced. A number of coping strategies were employed including a restructuring of the pace and organisation of activities, resisting marginalisation from society, finding alternative interests and activities and seeking a diagnosis.

Following the experience of total disablement in the acute phase, people attempted to undertake everyday tasks themselves, to return to work or school. No-one resumed all former activities. Everyone described times when they felt they had attempted to achieve too much and experienced a relapse and total disability.

Some people were able to regain aspects of their former identity by restructuring and pacing. This allowed involvement in key activities whilst balancing the severity of symptoms. Two people described taking 'naps' in order to get through the day, one by arrangement with the college, another during quiet times:

They were very good and arranged a room with a bed in for me... so I used to nap between lectures, that was the only way that I could get through the day.
Helen

I was lucky really because the girls there knew that I wasn't so good and I used to go in and I used to have to sleep before I could open the branch. Linda

Everyone in the study described breaking tasks into stages in order to limit the concentration or physical exertion required in a continuous period. People described 'slowing down', exhibited through a slower pace of movement, undertaking one activity or commitment at a time rather than several:

I have to pace myself very carefully, I have to look in my diary and see what is around on a particular day before I agree to something, so that I've not got a crowded programme, make sure that if I feel what is a stressful day that I have a completely free day the next day either just to rest or just to potter so that's the style of living at the moment. Coral

People felt that they had stopped 'pushing themselves' and limited activity where they linked over-exertion to 'physical pay back' in terms of exhaustion and muscle pain. The fear of inciting a deterioration in health was

strong for the majority of the group. Only one person described himself as actively 'pushing' himself to achieve activities to aid recovery:

I've always actively fought it, tried to push back.
Joseph

Joseph took on a semi-supernormal identity. He pushed himself in relation to maintaining a high powered job, but had to relinquish social roles as a result:

People walking past must have thought 'look at that lazy slob', because I came home from work and lay on that sofa there and spent most of my weekend there too...because I had a family to support, I couldn't stop working, but it meant I couldn't do much with the family. Joseph

This pathway, pushing yourself to achieve normal functioning in one domain was rejected by all other participants.

Not all experiences could be described as losses and outside of people's control. Resisting marginalisation was evidenced through the choice of activities continued and in finding alternative interests and activities.

People prioritised and chose to undertake some activities over others. Coral described structuring her diary, not undertaking more than one thing in a day to allow her sufficient rest, prioritising the activities she would undertake. Amy continued to play in the orchestra and Moira attended a school disco when they could not attend full-time schooling. This highlights that people with CFS/ME also have a degree of control over the way in which they negotiate social interaction. There was strong evidence that people heavily structured their activity in order to maximise the activities they were able to undertake in the context of the constraints of their illness. Furthermore, activities undertaken were chosen to maximise the ability to maintain socialisation in areas felt to be valuable.

New, alternative activities were taken up by some. Two people took up study after giving up work, something they would not have considered before. Studying at home gave them the flexibility they needed. Active sports such as swimming and running were given up, but could be replaced by less physically demanding activities such as QiGong and meditation.

The decision to consciously 'slow down' was supported by their own experience of relapses following over-exertion and also the experiences of others who 'over did it' and suffered the consequences:

...now, she's inclined to push herself, and push herself so far that she ends up in bed and I don't think that's good, I really don't... . Margaret

Over exerting oneself was felt to cause an inevitable and unnecessary deterioration in health.

As a result of the experience of relapses through attempts to maintain employment or study, 10 of the 14 people in work/study when the illness first began had to give up work/study. Four people carried on working, although everyone but Joseph had to take prolonged periods of time away from work.

Seeking a diagnosis was a major factor in this stage of identity reconstruction. The majority of the group had to live with the symptoms for 2 years before a diagnosis of CFS/ME was made. Living with an illness that remained undiagnosed created uncertainty. Negative interactions with clinicians over the diagnosis could also be mentally debilitating. Gaining a diagnosis even when this did not always open up treatment options was described by everyone as important. It allowed people to move on, to understand better what they must deal with. Nine people gained a diagnosis CFS/ME their GP or a hospital consultant, most within 2 years. Eight people had to live with further uncertainty and spent several years, up to 30 years in one case, seeking a diagnosis, this being the main focus of identity reconstruction. When people had generated enough evidence that their symptoms were those of CFS/ME they approached their GP with the diagnosis and this was conceded by the GP in all cases. A diagnosis of CFS/ME allowed people to put the search for a label behind them and move onto managing the symptoms. Without a diagnosis people did not move into the next phase of identity reconstruction.

3.3. *Identity reconstruction in the longer term*

The third phase of identity reconstruction involved the emergence of a newly constructed self. For the majority ($n = 15$) this was characterised by the creation of a positive self. Having been confronted with the loss of the former self, of a functioning body, of friends and even of a legitimate place in society, people with CFS/ME tended to develop a new sense of the normal. People talked of becoming new selves; selves that they say they value more than previous selves. A return to the self before the illness was not sought, nor did people “settle” for an existence that was subordinate to their life before illness. Instead, the majority invented, or were in the process of creating, new and, they believed, better selves.

The majority felt that they had transcended the illness, underpinned by a deeper understanding of themselves, others and life in general.

It *makes you* evaluate life and decide what’s really important. Richard.

I think I’m a different person for having come through it, I think it’s made me a lot stronger than I was, made me face up to things. Angela

Basic everyday day matters were valued more greatly and materialistic needs diminished. People became experts in understanding and managing their symptoms.

A minority ($n = 2$) held the illness experience as entirely negative. This group remained highly disabled and appeared to be unable to reinvent themselves. They continued to mourn the loss of a career they had enjoyed and at times described feelings of worthlessness attached to their current role:

A few years back I could still use my catering skills, I’ve done a few weddings for family, but now I can’t even ice a cake, that’s frustrating. Alan

The interviews showed that the majority of people had entered a process of coming to terms with the situation, but had reached different levels of reconciliation. The length of time that it took to reconcile oneself with the illness varied and did not appear to be linked to the length of time since the onset of the symptoms or diagnosis although both people who remained highly debilitated had lived with symptoms for many years before a diagnosis was given. Yet three other participants who had also lived with CFS/ME for many years and without a diagnosis for most of this time had reconstructed their identity.

The positive reconstruction of identity remained relatively fragile. Everyone believed in, and were alert to, the possibility of relapses in health in the future. To this end they monitored the balance between rest and activity for the foreseeable future

I’d be very careful to limit myself, I’d be very careful to pace myself because there’s no way I’d want to go back to what it was. Paula

Steve who believes he has almost fully recovered from CFS/ME described his fear of relapses:

I’m going to keep an eye on myself, I’m scared of relapses and I catch things easily. It does scare me when I’m ill because I do get tired and I think ‘oh no, I’m going back’. Steve

The possibility of relapses was not a fear that haunted people on a daily basis, but did continually influence the type and amount of activity undertaken:

...and a friend said come along to the baths with us, you know because I love swimming, but I said no because although I felt alright, I’d already agreed to go round to a friends and I can’t overdo it. Linda

Fears of a relapse emerged when symptoms associated with a common cold or flu-like illness were experienced. As such this group could be described as having illness ‘hanging’ over them. They believed that a ‘vestige of the virus’ remained inside them waiting to attack the body if

they became run down and believed that they had a propensity to catch the illness again:

People who described a positive self-identity had not necessarily fully recovered, many still experienced symptoms and all were unsure as to whether CFS/ME would ever be over for them. This group had attained a balance between living with and accepting the long-term implications of CFS/ME and creating a positive outcome in terms of their achievements and lifestyle. They were no longer devoted to searching for a diagnosis or treatments that would return them to their former selves.

4. Discussion

The study has resulted in the mapping of a trajectory that reflects elements of earlier work but also many differences. Unlike the trajectory of identity noted for chronic progressive conditions (Charmaz, 1983) that found deterioration in identity, the current study found both that different priorities were set and that identity became progressively more positive. The trajectory reflected Yoshida's work that identities were pendular and could move backwards to a past identity and forwards to a new identity with people potentially staying at one point on the pendulum for some time, before moving on.

All participants in the study described biographical disruption in their lives after illness onset, moving from an identity associated with a high level of activity to one characterised by inactivity (Charmaz, 1983). The initial phase was marked by total disruption described as widespread suffering and disturbance, reflecting work on spinal cord injury (Yoshida, 1993) and CFS/ME (Clarke and James, 2003) but not the initial supernormal identity described by those experiencing chronic and progressive conditions (Charmaz, 1983) nor a partial identity disruption as found in work with people with CFS/ME (Asbring, 2001).

Following the initial period of acute and severe disruption, the medium term was characterised by three identity outcomes, disability as the total self, disability as part of the total self and for one person, the supernormal self. The trajectory was not linear, a circular movement was noted between the first two identities as noted in earlier work (Asbring, 2001) and relapses were experienced. The analysis did not portray attempts to return to the former self as noted in the work with CFS (Asbring, 2001), HIV (Carricaburu and Pierret, 1995) and chronic deteriorating conditions (Charmaz, 1983), more, a strategic approach to maintain aspects of the former self. Nor does it support earlier findings that people with CFS/ME reject all aspects of the former self (Clarke and James, 2003). One person adopted a supernormal identity, also noted in the

work around spinal cord injury (Yoshida, 1993) and progressive deteriorating conditions (Charmaz, 1983) but not in the literature on CFS/ME.

The medium term phase highlighted a testing of boundaries. Symptoms were still disabling and the impact felt most acutely in relation to career identity reflecting the high priority given to work during illness (Charmaz, 1991; Ware, 1998). Social identity was partially disrupted for most participants, some activities were maintained but others were given-up reflecting a degree of choice in the activities people maintained and gave up. People performed activities in a different way and found alternative interests, in line with previous research (Asbring and Narvanen, 2002). It further develops the notion that people with CFS/ME are not passive in the illness process (Ware, 1993). People still have some control over the course of their lives and the focus of the disruption of the illness, reflecting the strategic mobilisation of resources to advantage (Locker, 1983; Williams, 1984).

The search for a diagnosis was an important element in identity reconstruction in the medium term identity. The importance of gaining a diagnosis of CFS/ME and many other conditions is well known (e.g. Sharpe, 1998; Woodward et al., 1995), however, this event has not been placed in the context of an identity trajectory and found to impede movement onto a more positive phase of identity reconstruction.

Longer term identity reconstruction reflected progress to a new self for the majority of people. The illness experience brought with it positive changes in identity for most, linked to new insights into their previous lifestyle and reflecting earlier work on CFS/ME (Ware and Kleinman, 1992) and fibromyalgia (Schaefer, 1995a), also noted in studies on the experience of living with other chronic illnesses (Royer, 1995; Schaefer, 1995b; Lindsey, 1996; Morse, 1997).

Two key elements of the new self were that this contained elements of the former self as well as new aspects and that this was a contingent self. That the new identity for people with CFS/ME contains part of the former self has been noted (Asbring, 2001) and was described more positively than being a salvaging of parts of the former identity (Charmaz, 1983). For people with CFS/ME, losing the identity of one's earlier self does not appear to be necessarily more advanced than for those living with other forms of chronic illness as suggested (Clarke and James, 2003). Although people experienced an absence of former patterns and meanings and norms lacked clarity (Foucault, 1982), especially in the acute phase of the illness, people did not completely lose sight of social norms and how they 'fitted' into the system, half of the group received a diagnosis within 2 years. It would seem a tautology to suggest that people reject everything related to their former self, no-one can forget and fail to draw on previous experience (Gadamer,

1975). The disruption of many things that formerly made life and self meaningful can act negatively, however, where the individual recognises the need to become more autonomous and self-governing (Robertson, 2000) often working outside of conventional frameworks of the illness experience, the development of a new self becomes a fruitful and useful adaptation (Foucault, 1982). Exactly how this level of insight is achieved and why some do not achieve this remains speculative.

5. Conclusion

This study has revealed that the lived experience of CFS/ME can be seen to follow a trajectory in relation to the reconstruction of self-identity and that individuals and families narratives may be different at each stage of the illness. This level of understanding is important in promoting shared understanding and so the engagement of nurses and health care professionals in the assessment and management of people with CFS/ME. Whilst this work has a wider resonance not only with work into CFS/ME but with other chronic conditions, conflicts exist. Further work to explore both disease specific and broader, common themes, through the chronic illness experience is needed to further enhance understanding and meaning support and interventions.

6. Limitations of the study

There are a number of limitations to this study. The sample selected was drawn from an area in which a CFS/ME clinic was available. Referral to the clinic often took some time, but it did provide a means of validating a diagnosis of CFS/ME. This may make the experiences of this group different to those without access to a CFS clinic, although only a proportion of the sample had been referred to the clinic. In order to qualify some of the concepts put forward in the paper, further work with people with CFS/ME and other chronic illnesses needs to be undertaken to explore the resonance of a trajectory of identity reconstruction.

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