



Quest, chaos and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis

Lisa Claire Whitehead*

University of Stirling Stornoway, UK

Abstract

Chronic illness is disruptive, threatening people's sense of identity and taken for granted assumptions. Transformations in values, expectations and life priorities are likely to be experienced and in order to regain a coherent sense of self, people must interpret their experiences. People with difficult to diagnose illnesses can find themselves living with greater uncertainty and stigma. This paper explores how people with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) describe and interpret their illness experience by applying Arthur Frank's narrative typologies to analyse interviews with 17 British people with CFS/ME. The analysis proposes that a trajectory of narrative typologies is experienced, starting with a restitution narrative, moving to a chaos narrative and, for most, back to a restitution narrative and on to a quest narrative. The presentation of narrative types put forward by people living with CFS/ME differ to those presented by people who are HIV positive and have been treated for breast cancer.

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Background

When lives have been disrupted by illness efforts to create continuity or to 'reorient' oneself, can be viewed 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 (Bury, 1982). 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 reconstructing 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.

Factors that may disrupt the reconstruction of narratives are many and varied but key issues include diagnosis, relapses and conflict with care providers. Diagnosis is integral to an individual's interpretation and management of an illness, to the theory and practice of medicine, and to social understandings of illness (Brown, 1995). Physical symptoms that are not well defined can lead to delays in interpretations of aetiology (Gale & Marsden, 1985). When these symptoms are linked to questionable conditions a diagnosis may not be

*Tel.: +44 1851 708248.

E-mail address: lw6@stir.ac.uk.

given (Broom & Woodward, 1996) and can give rise to animosity between patients and clinicians (Asbring & Narvanen, 2003; Deale & Wessely, 2001; Sharpe, 1998). Analysis of interactions between clinicians and people with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) during attendance at a CFS clinic highlighted the political nature of such interactions (Banks & Prior, 2001). Lay peoples' ideas around framing problems and the management of these were often in conflict with those of clinicians.

Narratives have been used to explore identity in CFS/ME and their role in helping to reconstruct identity. The analysis of narratives generated in a group setting found that co-narrated collectised stories were the most common form of narrative used in which people collectively narrated a story, each reinforcing and confirming the experiences of themselves and others (Bulow, 2004). This was particularly therapeutic when experiencing a contested illness such as CFS/ME. Narratives afford the opportunity to explore the ways in which people make sense of illness as a practical activity and how their identities are constructed as part of that process. Horton-Salway (2001) explored the ways in which attributional stories and identity stories on the experience of ME, connect with one another within a narrative. In ME, the narrative worked to construct ME as a physical disease whilst countering accusations of malingering or psychological illness. However, ironically, this then implicated people as inducing the illness through over-work, one of the popular theories behind the aetiology of ME (Ware, 1992). Horton-Salway (2001, p. 256) stresses the importance of moving beyond a face value analysis of narratives to explore the meanings as constructed by individuals and groups within them which are "more complex and situated discursive productions" that they may be given credit for.

Illness narratives: theory

Narrative theory is increasingly employed to understand the subjective experience of illness (McLeod, 2000) with growing recognition that narratives are the means by which we render our existence as meaningful (Polkinghorne, 1988). Earlier work sought to establish the existence of a narrative approach and theory as offering an alternative to a dominant positivistic paradigm (Sarbin, 1986) arguing that two forms of thought

existed, the scientific and the narrative (Bruner, 1990). A general principle is that within any story, a beginning, middle and end can be identified (Riessman, 1993). Furthermore, a plot or core story, containing the main points that the teller is conveying can be determined. Labov and Waletzky (1967) suggest that the key elements of a story are: abstract, orientation, complicating action, resolution, evaluation and coda. The approach lends focus on language and grammar and has been criticised as detracting from the function and importance of the narrative (Priest, Roberts, & Woods, 2002).

Recent work has explored the factors involved in shaping a story, the therapeutic value of telling stories and the ownership of these (Murray, 2000). Frank (1998) has explored how far stories are an opportunity for self-expression and influential upon self-care practices and the impact of wider power relations upon these; how far stories replicate the messages passed down by health professionals, the media and health policy. Horton-Salway (2001) proposes that in order to appreciate the complexity of narratives, three approaches can be taken in the analytic process: one based on upon a realist ontology which presupposes that the narrative reflects the world, the second based on a cognitivist approach which highlights the constructive role of the narrative and the third based upon a discursive approach which considers the interactive context within which the narrative is constructed. Murray (2000) has further described four levels of analysis, personal, interpersonal, positional and ideological, and the integration of these to highlight that a critical approach to analysis requires the recognition and synthesis of more than one level, the most commonly used being a personal approach. These issues cut across the generation of types of narrative. Narrative types are not static but rather reflect many levels of meaning.

Frank (1995, p. 76) proposes that three types of narrative exist, the restitution, chaos and quest narratives, and that in any illness narrative all three types will be told, with one type guiding the narrative at any one time.

Restitution narrative

The restitution narrative is framed as the most common narrative amongst the recently ill but least often evidenced amongst the chronically ill (Frank, 1995, p. 77). The basic plot of the restitution story is that yesterday I was healthy, today I am sick but

tomorrow I will be better (Frank, 1995, p. 77). This narrative type is about movement away from and back towards health, exploring the experiences and meaning of investigations and treatments.

The ill person's own desire for restitution is compounded by the expectation that other people want to hear restitution stories. The sick role is a master narrative in Western health care espoused in Parson's sick role (Parsons, 1951) with the ultimate expectation that an individual will get well. People learn from institutional stories the model of how illness stories should be told. Media abounds with stories of those who have recovered and continued with their lives (Kroll-Smith, 2003).

The restitution narrative reflects a modernist expectation that for every suffering there is a remedy. The emphasis is on the sufferer to solve the puzzle of illness (Frank, 1995, p. 80). This narrative type is one often used in the media to promote recovery from illness and portrays the ability to overcome anything. For people living with a chronic illness, hearing stories of recovery can be both inspiring, that there is hope of positive change, and intimidating if they are unable to see anyway of taking steps to recovery and experience social pressures to overcome illness.

The implicit genesis of illness in the restitution narrative is an unlucky breakdown in the body. The causal act is not drawn upon because the individual does not focus on illness, but rather on the recovery.

Chaos narrative

In the chaos narrative, the plot is that life will never get better; no one is in control. Sufferers describe experiencing an "emotional battering" (Frank, 1995, p. 101) stemming from their rejection of their suffering by clinicians and socially by others. In the chaos narrative, the individual makes attempts to reassert predictability but these generally fail and efforts have a cost for the individual. The stories reveal vulnerability, futility and impotence (Frank, 1995, p. 97) and can be difficult to listen to. Chaos narratives depict people "sucked into the undertow of illness" whilst restitution narratives illustrate illness as "transitory" (Frank, 1995, p. 115).

Quest narrative

In the quest narrative, individuals accept illness and seek to use this, believing that something is to

be gained through the experience. Illness is seen as a challenge and an impetus for change (Frank, 1995, p. 166). This differs from the restitution narrative where individuals are not solely seeking recovery from illness.

Three subtypes of quest narratives are proposed. The first is *memoir* in which events are related simply. The second is *manifesto* in which illness becomes a motivator for social action or change. The third is *automythology* in which illness is expanded to reveal fate or destiny (Frank, 1995, pp. 119–120).

The person whilst no longer ill remains marked by illness. A hero's status is derived from being initiated through agony to atonement. When this is the only narrative put forward the reader is encouraged to critically evaluate it where a move straight from the onset of symptoms to a quest narrative without apparent suffering appears "too clean" cut (Frank, 1995, p. 135).

Previous work using Franks' illness narratives typologies

Two studies have directly employed Frank's (1995) work (Ezzy, 2000; Thomas-Maclean, 2004), but parallels can be drawn with other studies that link with key themes from the narrative types. Ezzy (2000) interviewed 46 people living with a diagnosis of HIV. In this study, over a third of the sample told only a restitution narrative, the driving theme being seeking recovery from what is currently an incurable condition. They attempted to live a normal life by dealing with the diagnosis and future uncertainty. These groups were looking to the future and had goals, the time frame for the future ranged from 5 years to life into old age. Essential to this group was expected prognosis, which they held as good with appropriate treatment. The uses of restitution narratives are noted to be precarious for this group because they are based on the assumption of a long and healthy normal life, yet decline related to HIV can be unpredictable and some also undertook risky behaviour that may help to precipitate decline (Ezzy, 2000). Just under a quarter described themselves as being in perpetual chaos, highlighting sustained distress and vulnerability. No mention of the time since diagnosis of this group was made. It is possible to suggest that the latter group recently received a diagnosis of being HIV positive compared to the others in the study, although this is not discernible from the available information.

Ezzy (2000) describes polyphonic tragic narratives as representing a quarter of the narratives. This is classed as one narrative type not a mixture of the three narrative types. These narratives were orientated to the present and uncertainty around the future brought creativity to the present rather than fear. Future plans were not made because the future was felt to be less amenable to control. People remained orientated to the present but with an eye to longer-term consequences. Changes in values were noted. People became less materialistic. A criticism of the paper is the loss of detail through the decision to reflect the most dominant narrative by giving an overall classification of narrative type without paying attention to elements of other narrative types. The data presented show strong elements of the memoir-quest narrative but this is not acknowledged.

The expression of the social consequences of illness articulated through manifesto, quest narratives are central in the narratives of men diagnosed as HIV positive (Carricaburu & Pierret, 1995) and people with AIDS (Marshall & O'Keefe, 1995; Viney & Bousfield, 1991). The illness narrative becomes part of the social and political spheres making it a collective experience, removed from the private sphere. It is suggested that illness narratives about AIDS differ in this respect from narratives about pain, the central theme being a search for an opportunity to articulate one's experience and to find listeners.

Thomas-Maclean (2004) interviewed 12 women who had experienced breast cancer. The study revealed that three women only put forward a quest narrative. The other nine women described stories that involved a mixture of narrative types, seven women put forward a restitution narrative, eight a chaos narrative and a further four quest narratives. Seven started with a restitution narrative, moving quickly through diagnosis and treatment, reintroducing themselves as healthy in the present. The sustainability of such a narrative in the face of possible relapses is questioned (Thomas-Maclean, 2004). A chaos narrative was most likely to emerge when descriptions of the diagnosis of breast cancer were described. The quest narratives demonstrated the memoir and manifesto quest but not the automythology element of quest.

The limitations of the study involve the sample that was composed of women who did not opt for breast reconstruction following surgery and who may be seen as less likely to be seeking restitution

where breast reconstruction seeks to attain at the very least the appearance of physical normality. The failure in the analysis to link time since diagnosis to the narratives again leaves the reader unclear as to possible links between this and patterns in illness narratives.

Crouser (1997) argues that breast cancer is held as particularly transformative, this being equated to the quest narrative (Thomas-Maclean, 2004), where the desire for the breast cancer patient as a mortal individual may be to wrap up the story, encapsulating the malignancy and preventing it from infiltrating the entire life (Crouser, 1997). Nearly all participants (11/12) in Thomas-Maclean's study put forward a quest narrative at some stage, three exclusively so. However, it is unclear as to how distinctive this is to breast cancer.

Work into identity reconstruction following the onset of CFS/ME (Clarke & James, 2003) has proposed that people with CFS/ME are highly likely to construct a radicalised self that represented a new, better self, equating with Frank's (1995) notion of quest. It is proposed that people with CFS/ME do not seek a return to the former self (a restitution narrative). This is proposed to be driven by the anomie of suffering from a condition whose very reality is debated both in the medical and in the wider communities, in addition to severe symptomatology on a daily basis. As people with CFS, lacking an uncontested medical diagnosis, search for meaningful self-identities, they resist previously available narratives to take up an alternative narrative, one of a radicalised self (Clarke & James, 2003). The paper leaves the notion of how people become radicalised unknown and it may be that people do not resist previously available narratives rather these are not open to them. These areas will be explored in further detail.

Method

In depth, interviews were conducted with 17 British people with CFS/ME. Ages ranged from 13 to 63 years and the sample included six men and 11 women. Family circumstances were divergent ranging from those with children at home, older children living away, geographical dispersed families, separated families and those in retirement. Up to three interviews were conducted with each person to help to build up trust (Cornwell, 1984; Hosie, 1986). Participants were asked to start their narrative by describing the onset of symptoms and

describe their illness experience up to the present day. People were recruited from a number of settings, a CFS/ME clinic at a local hospital, a local CFS/ME support groups and through a snowballing approach to recruit people with CFS/ME who neither attended a CFS/ME clinic nor a support group. Time since diagnosis at the start of the study ranged from 1 to 8 years. Time between the start of symptoms and the interviews ranged from 2 to 40 years. Time between the start of symptoms and diagnosis ranged between 6 months and 32 years with the majority of the group gaining a diagnosis within 2 years of the onset of symptoms ($n = 10$), a further three within 10 years and four over 10 years.

The methodological principles guiding the study were drawn from hermeneutic phenomenology, particularly *Gadamer's (1975)* work. Key points were that the analysis was interpretative in orientation, and the researcher's preunderstandings were acknowledged and reflected upon with the aim of achieving a fusion of horizons (*Gadamer, 1975*). The analysis did not seek to assimilate the material into a prearranged framework and was not entered into to seek an objective valid truth. No set method of analysis was adhered to rather general principles used, making the need for transparency around the process important to allow the reader to assess the credibility of the work (*Whitehead, 2004*). Each narrative was analysed individually to identify the narrative process and events in that transcript and on to explore the emerging framework with the next narrative with the aim of producing both narrative and paradigmatic knowing to create both a narrative account and a thematic analysis (concepts and models that generalise beyond the individual case) the latter being a minority area in narrative analysis (*McLeod, 2000*).

The key procedural steps taken in the analysis drew upon the work by *McLeod and Balamoutsou (2000)* and involved reading and immersion, identification of stories, identification of topics, summarising stories and sequences, constructing a representation of the narrative as a whole, followed by micro-analysis of specific events and processes.

Findings

Everyone in the study began with a restitution narrative. The restitution narrative was evidenced in three phases: at the onset, in gaining a diagnosis and in seeking treatment. At the onset, no one was

aware that their symptoms may have been related to CFS/ME. Everyone believed that they had the flu or an acute viral illness. As such, everyone treated the symptoms as a minor acute illness. Time was taken off from work or school as necessary; people adopted the traditional 'sick role' (*Parsons, 1951*). It was not until much later that people reconstructed the onset of their symptoms and then attributed these symptoms to CFS/ME:

It was a sickness bug to start with, I was playing netball, got dizzy... Moira.

...it was the half term holidays and I had the flu like I've never had before, it was awful, for 4 days I lay in bed, I didn't get up at all, I had to have someone to look after the children because my husband was working. Angela.

At first the symptoms were tolerated and incorporated into everyday interpretations of an acute illness.

A number of participants visited their GP with apparent 'flu' or infection and in the early stages this was treated as such. Typical illness behaviours such as rest and relinquishment of roles at work and home were adopted. There was an expectancy that a level of recovery would be attained in the short-term and normal roles taken up again. The next stage identified in the narratives was the realisation that symptoms could not be attributed to an acute and familiar illness. It was at this stage that narratives moved away from the restitution narrative.

An exploration of this stage of the illness experience found that participants described a number of reasons for a transition in illness beliefs: (i) symptoms did not follow the normal pattern for flu or infection; (ii) the illness experience deviated from the experience of others around them; (iii) symptoms lasted longer than predicted by the GP; (iv) the experience included unexpected and highly distressing symptoms; (v) the experience involved progressive, deleterious functional consequences at home and/or at work.

The use of an everyday framework to explain the existence of symptoms diminished. People could no longer attribute the symptoms to an acute illness. Symptoms became more severe yet remained non-specific in origin and no explanations were forthcoming. People remained in limbo in the medical system and at this point all moved into a chaos narrative.

Chaos was marked by severe symptoms and a loss of focus on everyday life such as work and school. Sudden and debilitating attacks were frightening for all involved:

...it was very frightening because every time he had an attack I thought it was a heart attack which is not quite as frightening now because I have an idea what it is or I know when one's coming on. Margaret.

...she hyperventilated, she couldn't move she was froze solid, just, she just talked because she couldn't move a bone in her body. So I said to her what shall I do and she said just phone the doctor and the doctor came out and he just couldn't believe what had happened. Richard.

The combination of the intensity, suddenness and visible nature of these symptoms led to further medical advice being sought.

Half of the group felt that their GPs were not supportive and this set them back and in part maintained the cycle of chaos:

...although he gave the impression to me that he was very sympathetic and understood ME, apparently when he got a form from the DSS, he just filled it in with all negative replies, saying...there was nothing wrong with me, and if I couldn't walk, it was psychological, so he said I had no difficulty walking, I had no difficulty doing any of the things that he'd said...y'know, that were on this form. Maria.

One woman noted:

I would get more out of a pair of support tights than what I have out of the system. Brenda.

Emotionally, experiences like this impacted greatly and often led to self-doubt and withdrawal from services and contact with others.

The return to a chaos narrative was noted in the narratives where relapses heralded a return to debility and left people questioning their ability to ever recover. Everyone in the study had experienced at least one major relapse and many smaller relapses in health. People attempted to ward off a relapse and return to a chaotic state, illustrating their vulnerability and uncertainty about the future. A return to a chaotic state was not felt to be far away:

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.

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 second phase of the restitution narrative involved the narrative of gaining a diagnosis. The group divided into two pathways: those for whom a diagnosis was medically led and those who had to search for a diagnosis. The key difference was that those whose diagnosis was medically led presented a shorter chaos narrative than those without. This stage of the restitution narrative was interspersed with a return to chaos narratives through knock-backs, mainly characterised by interactions with clinicians, relapses in health and non-response to treatment.

On visiting the GP in the first 6 months of the onset of symptoms, three pathways were taken: (1) diagnosis initiated by a doctor ($n = 4$); (2) a referral and subsequent diagnosis from a consultant ($n = 4$); and (3) no referral or diagnosis ($n = 8$).

Four people were given a diagnosis by a doctor and referred to the CFS/ME clinic to confirm this within 12 months of the onset of symptoms. Five people were given a preliminary diagnosis of CFS/ME following a referral to a consultant. Access to the consultant was prompted by either a GP referral or following admission to hospital.

These group's symptoms were translated into a medical framework by health professionals. This was not a smooth transition, it took up to 40 years to gain a diagnosis and periods of despair and vulnerability were experienced.

Nearly half of the group ($n = 8$) remained without a diagnosis, despite further investigation and repeated visits to the GP. Remaining without a diagnosis was described as an uncomfortable place to be. Not only was it socially unacceptable to continue to adopt the sick role and remain debilitated by unexplained factors, but the situation also caused internal dissonance amongst sufferers:

You tend to start thinking well if it's not that what is it? ...people tend to go on a hunt to try to find out for themselves in the absence of any information at all from the medical profession. Dominic.

All eight people in this group used books, media publicity and complementary/alternative medicine to help interpret their symptoms and then support the diagnostic label:

Then I was reading a book 'Recovering from a viral illness' and it was listing all the different

symptoms of what they called Post Viral Fatigue then and I could identify with what it was saying...I went back to the GP and look, I can identify with this list. Brenda.

I'd heard a couple of programmes, on the wireless about ME and they described it as the same symptoms as what I'm feeling and then him that's on Wheel of Fortune, his wife came up because she's had it and what she described was exactly the same as what I had and so I went up to Dr R cause I had an appointment for results and said do you think it could be this ME because all the symptoms are there. Alan.

People waited until they had collected 'proof' from a number of sources before approaching the GP with a possible diagnosis:

I was going to acupuncture to ease the pain but I was worried that I was losing the ability to do things that I'd done before and it was my acupuncture man that suggested that I had ME and I'd seen bits, clips from things, I'd seen a programme on the television and thought oh they're just my symptoms that's just like me and it was actually the man that said to me I think you've got ME. Paula.

I saw a chiropractor once a week, years ago now and he was the first one to say that my symptoms were ME and he knew someone that I could see, but I didn't act on it, I don't know why now, but I didn't and it was only years later that I picked up on this again when I was reading a book about viral fatigue. Linda.

All eight people in this group 'forced' the issue of a diagnosis of CFS/ME by presenting the GP with a self-made diagnosis supported by the evidence they had acquired to back these assertions, a process that took most several years.

Chaos was in part alleviated through a diagnosis of CFS/ME but where no definitive treatment can be offered, this did not instantly put people onto an illness trajectory that they could relate to, of diagnosis, treatment and recovery.

Receiving a diagnosis was important in reducing the turmoil experienced and also opened up new challenges where CFS/ME is a contested diagnosis, no definitive treatment is available and are often unsure as to how to manage people once a diagnosis has been made.

Once a diagnosis had been made the search for treatments began, the third stage of the restitution narrative. The use of alternative therapies by people with CFS/ME in this study was widespread. Everyone in the group had tried a form of complementary/alternative medicine, many several therapies. The breadth and combination of treatments experienced are illustrated below:

I've had the meat-free diet, what else? I've had the diet, all the diets, I've had the acupuncture, and I've seen one of those people that relax you and talk to you. I've tried numerous things, but nothing's worked. Kevin.

Diets were the most common form of alternative treatment, eight people having followed a diet, such as wheat free, sugar free, no meat, no dairy products and a high potassium diet. The high use of alternative therapies is not surprising where evidence-based support for treatments such as exercise therapy and CBT is variable and access to specialist care not always available. The restitution narrative is evidenced through seeking recovery and the socially orientated desire to be seen to be working towards this.

The quest narrative was evident in 15 narratives. The illness experience had altered perspectives on life, mainly the ability to prioritise issues, putting health and happiness first, to recognise limitations, and make time and space for oneself. One participant stated:

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

Richard stresses that CFS/ME has *made* him stop and evaluate his life. He like other sufferers emphasised the external and uninvited nature of CFS/ME. The experience was described as being a double-edged sword, people both thankful for, but regretful of the experience:

I'm glad I've had it, I'm glad it's going and I wouldn't have wanted it. Linda.

Those who had gained an insight into the meaning and course of their life talked about changing jobs, moderating career aspirations, and cutting down on the amount of physical and emotional work, such as voluntary work and supporting wider family members. This was seen as a move to change a pre-illness pattern in their lives they felt had been detrimental to their health.

Contemplating such changes illustrates the thought process behind the life changes made:

I'm more inclined to want to start to make changes, to review the work I do and perhaps consider taking a less stressful job, finding fulfilment through other ways than just work. I'm not too sure if before I was getting satisfaction, every thing was rush rush rush, busy busy busy, I'm not too sure what satisfaction I was getting out of it really. The illness has made me stop, pause, think, review. So what I'm trying to say is I've made some life style changes, they're really personal changes about how I react to everyday life and I'm just not getting so bothered about it as I used to. Dominic.

A smaller group believed that the experience of CFS/ME had served to influence their personality making them stronger people, more confident and assertive:

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.

This group felt they could redefine their relationships with others, learn to say 'no' to requests and put their health first. Often restricting and scheduling the amount of activity they would take on. They no longer saw their ability to take on others needs for physical and emotional support as inexhaustible. The sufferers in this group express a clear message that many people have learnt from and feel empowered by their experience of CFS/ME. This does not demonstrate elements of fate or destiny, nor activism. The narratives reflect the memoir strand of quest narrative.

All but two people presented a quest narrative at the end of their illness narratives. People who presented a quest narrative had not necessarily fully recovered. All but two people were still experiencing symptoms and all but one highly mindful and expectant of relapses in the future. Nor was a quest narrative wholly related to a positive outlook on recovery. Some individuals with a negative outlook felt that they had gained positive elements from the experience of living with CFS/ME. What these people had achieved was a balance between living with and accepting the long-term implications of CFS/ME and living their lives, no longer consumed by searches for explanations of aetiology or treatment and reflective of the positive things they had gained through the experience. Length of time since

the onset of illness was not related to whether an individual ended with a quest style of narrative, although progression through a restitution narrative, followed by chaos and then restitution again did emerge as the prevalent pattern.

Discussion

The analysis reveals that for the majority of participants, restitution, chaos and quest narratives all surface as dominant narratives in the experience of living with CFS/ME. Two narratives revealed restitution and chaos narratives only. All narratives began with participants describing the onset of acute symptoms. These were contrasted against a picture of good health preceding the onset. The symptoms were normalised as flu and people attempted to continue with everyday routines. They sought, and expected to get better. This reflects the restitution narrative, yesterday I was well, today I am not and tomorrow I expect to get better. In hindsight, restitution was not possible offering an explanation for the focus on the causal act which would not be acknowledged so prominently throughout the narratives if recovery had been achievable in the acute phase (Frank, 1995).

Chaos was depicted by expressions of anger, depression and isolation. People described social detachment, an empty present and desolate future contrasted with a past that had promised much until illness destroyed this. Frustrations included the loss of career or plans for this, the loss of income and social contacts. Narratives are continuously made and remade as episodes happen. If a relapse was experienced the narrative reflected elements of a chaos narrative.

The illness experience brought with it positive changes in identity for the majority of the group, linked to new insights into their previous lifestyle. Ware and Kleinman (1992) and Schaefer (1995a) have described positive aspects in the illness experience amongst people with CFS and fibromyalgia, also noted in studies on the experience of living with other chronic illnesses (Lindsey, 1996; Morse, 1997; Royer, 1995; Schaefer, 1995b). For people with CFS/ME losing the identity of one's earlier self appears to be as advanced as that proposed for those living with other forms of chronic illness (Crouser, 1997; Ezzy, 2000; Thomas-Maclean, 2004). It remains unclear as to why the majority adopted the quest narrative, but does reflect earlier work (Clarke & James, 2003). Clarke and James (2003) proposed that the complete absence

of former patterns and meanings of everyday life led to this as evidenced by the failure of many friendships and alienation from much of the medical community. This study did not mirror the high level of resentment that appeared to drive the participants in creating a new identity in the former study. Rather than wanting to achieve a former self, people with CFS/ME did reject the values of the former self in the creation of a new self but this was borne more from a realistic evaluation of what was and could be attainable undertaken at an individual level and lacked the sense of a collectively driven agenda as described by [Clarke and James \(2003\)](#). Not everyone had reached this level of self-identity and reasons as to why some people were able to create a positive outcome and others not remain largely unknown.

Comparisons, and also differences, can be drawn between the narratives of people with CFS/ME in this study and those of people living with other chronic illness. The diagnosis of HIV and breast cancer signified the start of a period of chaos ([Ezzy, 2000](#); [Thomas-Maclean, 2004](#)) whereas this was seen as a positive step by people with CFS/ME who had narrated an often lengthy chaotic narrative prior to diagnosis. At diagnosis people with HIV and breast cancer were largely asymptomatic, this allowed people to distance themselves from the illness to a certain extent. Some people with breast cancer described being able to forget their body ([Thomas-Maclean, 2004](#)). Following diagnosis and treatment, people with CFS/ME cannot, symptoms remind people on a daily basis. Projections of prognosis were available following diagnosis for people with HIV and breast cancer, and people used their prognosis to shape how they dealt with the illness. Prognosis was not available for people with CFS/ME and although positive did not instantly take them out of a chaotic narrative, as treatment was not available.

Over one-third of [Ezzy's \(2000\)](#) sample described making plans for the future yet it was striking that people with CFS/ME did not. No one described making long-term plans, taking everything day by day. In CFS/ME with not only an uncertain prognosis, in common with other illnesses but also without any markers as to the prognosis and no reliable treatment, people did not believe that they would be 'cured', whereas some people diagnosed as HIV positive and with breast cancer did. A positive prognosis, central to the restitution narrative, did not seem to be as plausible an option for people with CFS/ME compared to those with HIV and breast cancer. [Ezzy](#) and [Thomas-Maclean](#) both state

that restitution narratives are unstable due to the possibility of relapse or progression of illness. People with CFS/ME do not embrace a restitution narrative as actively and it may be further suggested that this is related to the constant reminder of the illness that they live with; the body is never symptom free. People with HIV had yet to experience severe illness and people with breast cancer in [Thomas-Maclean's \(2004\)](#) study had experienced one episode of illness and surgery.

The narratives noted a pattern of movement, starting with a restitution narrative, moving to chaos, returning to restitution and onto quest. The two participants that did not move into a quest narrative had both experienced a prolonged period of time in chaos between the onset of symptoms and diagnosis (5 and 21 years) and this may be seen as an indicator. Yet this has to be contrasted to three others who also experienced a delay between the onset of symptoms and diagnosis (8, 30 and 32 years) who expressed quest narrative. Of note was that for all three, the quest narrative entered the overall narrative around 2 years before the onset of the study. As such it seems reasonable to hypothesise that a prolonged period of chaos sustained by uncertainty around diagnosis and prognosis inhibits the ability to 'move on' and some people may be unable to do so once a diagnosis had been made.

The illness narratives identified are in progress and unfinished because they describe lived time which is ongoing. Reflection on the timing of the interviews is necessary where it is possible that interviews conducted earlier, or later, in the illness experience could paint a different picture and highlights the importance of considering this in analysis, an area often neglected.

Limitations of the study

In the area in which the study was conducted, a CFS/ME clinic was available. The resonance of these findings to a wider population of people living with CFS/ME will be tempered by the access most people in the study had to a CFS/ME clinic. One-quarter of the people interviewed in this study had been referred to the CFS/ME and the pathway to a diagnosis of CFS/ME for people who do not have access to a CFS/ME clinic is unlikely to include such a referral.

The study has identified a possible trajectory in illness narratives for people with CFS/ME and compared these with those of people living with

other chronic illnesses. Further research to explore the resonance of these findings with a larger group of people with CFS/ME and other illness is needed to develop these preliminary findings.

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