

Art-making and identity work: a qualitative study of women living with chronic fatigue syndrome/ myalgic encephalomyelitis (CFS/ME)

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Abstract

Aims: Identity is at risk in chronic fatigue conditions because of physical dysfunction, role loss, and stigmatisation. This qualitative study explored the meanings of leisure-based art-making for women living with CFS/ME, in relation to preserving and promoting positive identities.

Method: Thirteen women with CFS/ME participated. They offered reflective accounts about their engagement in art-making in interviews or in writing, which were then thematically analysed.

Findings: All described identity loss since becoming ill, and described art-making as offering restorative experiences. Some contrasting themes emerged. About half of the sample portrayed their art projects as constrained by ill-health, and as demonstrating the reality of CFS/ME to others. This sub-group struggled with limited aspirations, tended to create art alone, and did not identify themselves as being artists. They were interpreted as 'salvaging' identity through their art-making. Art-making appeared to offer others more substantial identity reconstruction, despite continuing ill-health. Participants in this sub-group described more positive aspirations, fellowship with other art-makers, and typically perceived themselves as having become artists since the onset of illness.

Conclusion: The study contributes new understandings of the contribution of art-making to salvaging and reconstructing identity in CFS/ME.

Key words: chronic fatigue; art; leisure; identity

Introduction

Artistic activities may have particular potency for promoting positive identity in chronic illness. Carlson (1997), for example, argues that art-making may help some people to construct enriched identities and claim a new preferred life-story. Camic (1999) has argued that art can help people living with chronic symptoms to live more fully in the present. Such experiences may help to challenge the perception of being shackled and rendered powerless by illness. This qualitative study explored the contribution of leisure-based art-making to preserving or transforming the identities of women who were living with chronic fatigue syndrome/ myalgic encephalomyelitis (CFS/ME).

Chronic fatigue syndrome and myalgic encephalomyelitis (CFS/ME) are regarded as interchangeable terms (Munson, 2000). People affected by these conditions report not only chronic fatigue but also cognitive problems and muscle pain. Few people with CFS/ME recover complete health (Andersen, Permin & Albrecht, 2004), and, in addition to the discomfiting physical symptoms, they may find themselves subject to the burdens of disbelief and stigma (Åsbring, 2001; Åsbring & Närvänen, 2002; Clarke & James, 2003; Dickson, Knussen & Flowers, 2007; Edwards, Thompson & Blair, 2007). Prevailing social representations of CFS/ME present affected people as malingering, or as somatising psychological distress. In response, affected people may try to resist moral blame by emphasising how ME interrupted a previously active, socially 'valid' lifestyle (Horton-Salway, 2001), or by using discursive strategies that claim a legitimate organic basis for the illness (Tucker, 2004). Familiar, valued identities are critically challenged by this illness (Dickson, Knussen & Flowers, 2008). Some people affected by

CFS/ME manage to reconstruct a positive identity, but many do not (Åsbring, 2001; Clarke & James, 2003; Whitehead, 2006a; Whitehead, 2006b).

The discovery of new activities and sources of fulfilment may create significant turning points in identity reconstruction for people living with CFS/ME (Åsbring, 2001; Travers & Lawler, 2008; Whitehead, 2006a, 2006b).

The role of artistic leisure activities has been rather neglected in research to date, yet many types of arts and crafts are manageable by people living with the limited energy and other symptoms of CFS/ME, suggesting that their meanings should be explored. Both the content of artwork and the accounts that people offer about their art-making may reveal the losses and gains encountered during the journey through illness. Even small-scale arts projects leave a visible record of agency and achievement, helping to create a positive identity. Malchiodi (1999; p.20) asserts that in serious illness 'many people use the art process to author a new story for their lives...as a result, creating a new sense of who they are'.

Although used widely in research into the experience of chronic illness, identity is a problematic concept. Personal identity has been framed as having 'unity, coherence and consistency across time' (Crossly, 2000, p.20). The personal or 'felt' identity may be largely tacit until disrupted by illness or injury, or other life events (Goffman, 1973). Identity work in chronic illness may involve recapturing the subjective sense of coherence, as well as regaining a view of self as worthy and capable of meaningful further development (Corbin & Strauss, 1987). On the other hand, multiple social identities may be derived through interacting in many roles and social situations, suggesting fluidity

rather than consistency. In the context of understanding the identities of craft-artists through narrative analysis, Mishler (1999) cautioned against assuming that people 'have' single identities. Rather he described his participants as presenting 'a plurality of sub-identities', arguing that, 'Metaphorically , we speak - or sing - our selves as a chorus of voices" (p. 8). This study focuses primarily on whether and how women living with CFS/ME regard their art-making as contributing to the reconstruction of a coherent, positive personal identity.

Research aims:

The aim of this study was to examine how women living with CFS/ME who engaged in art-making described the influence of their artistic activities on their personal identities, including their feelings about themselves, their competence, their place in a wider social network, and their future personal development.

Method

Ethics: All the materials and procedures received School Ethics Committee approval from the host university.

Sample: Invitations to participate in the study were placed in two national UK arts magazines, and further information was provided to a local support group for people with CFS/ME. Those expressing interest were given full information, and the main interview questions prior to giving consent. All participants self-reported a medical diagnosis of CFS/ME; this was not independently confirmed. Only women volunteered for this study (12 from the magazine request, one from the local support group). Ten agreed to be

interviewed. The other three women preferred to prepare lengthy written answers to the main interview questions, as this method enabled them to pace their involvement to suit their energy levels. Such adaptability in data collection methods to suit participants' needs has been advocated in a previous study of people with chronic fatigue (Clarke & James 2003). Participants were aged 34-62 years, with most (nine) in their 50s. Nine of the sample had partners and four were single/ divorced. This was a well educated sample, with most having been employed in a professional job prior to their illness. All had taken early retirement from full-time work for reasons of poor health. Participants had all lived with CFS/ME for 5 years or more, and had taken up art or substantially intensified their involvement in art since becoming ill (rather than being life-long artists). Pseudonyms have been used to assure participants' confidentiality.

Data Collection: The first author conducted one-to-one in-depth interviews with 10 participants. The main interview questions were provided to participants prior to interview, along with the information sheet and consent form. This enabled those who chose to submit written answers to do so, and enabled participants in the interviews both to provide properly informed consent and also to reflect on the topics ahead of the interview. The opening 'grand tour' question invited participants to reflect on the ways in which their daily lives and sense of self had been affected by CFS/ME. The interview also explored how participants' interest in art-making had begun, what they found satisfying about creative activity, and any hopes they had for the future. The relatively few questions on the topic guide helped to encourage participants to follow their own, rather than the researchers', agenda. For those who were interviewed, other questions were asked, as appropriate, to encourage a free-

flowing conversational interview. Clearly the written narratives were fixed, although later e-mail contacts enabled the authors to clarify certain portions of text in a limited way.

Data analysis: The interviews were transcribed fully and thematically analysed, first idiographically and then comparatively. Analysis involved initially reading and re-reading transcripts in order to become familiar with their structure and content. The authors carried out independent analyses and then met to agree upon the specific and recurring themes. The initial descriptive phase focused on identifying themes in participants' accounts of art-making which related to self/identity, including their use of metaphors and other aspects of language. When the recurring themes had emerged, interpretation was made regarding broader, superordinate categories to achieve further understanding of the different ways in which participants were representing the contribution of art-making to the preservation or reconstruction of identity.

In all subsequent quotations, the use of '...' indicates omission of material for the purpose of brevity. Occasional words have been added (indicated by use of []) to make the participants' intended meanings more explicit.

Findings

As found in previous studies (reviewed earlier), all participants had experienced CFS/ME as profoundly undermining their identities, and had struggled to reclaim feelings of competence, and inclusion in social life. Many made contrasts in their accounts between their former and current selves:

'I'm a very active person, I used to do a lot of gardening, I used to do a lot of walking. Can't do any of that any more. And playing the piano. I can do about quarter of an hour perhaps before my arms get the pain in them' (Jill, 59, lived with ME for 8 years).

Some reflected explicitly on their loss of self or identity, and the struggle to reclaim it:

'I felt for a while that I had no identity apart from just being a sick, non-person and I'd lost all my former roles... I particularly lost my identity as a woman in some ways, a grown-up. I think I've managed to get that back again, but I had to work hard at it' (Georgia, aged 51, former administrator, severe ME for 17 years).

Art-making seemed to offer each participant a means of restoring or transforming identity, but the close analysis of their accounts revealed that for some, participation in art was not regarded in wholly positive ways. Instead, two broadly contrasting sets of themes were inferred (as shown in Table 1). One sub-group of participants presented accounts in which their participation in art-making, although satisfying and psychologically helpful, was highly constrained by their illness. They emphasised the ongoing power of illness to control and define them. They chose artistic media that accommodated to their illness, working on smaller-scale (or shorter) projects than they would have preferred had their health been better. Some perceived their small creative products as communicating both to self and to others the reality of the illness, helping to gain social acceptance for their condition. Art-making for

this sub-group remained quite an isolated activity, carried out in the home, usually for short periods of time. It rarely brought the person into contact with others who shared this interest outside the immediate family. Participants celebrated their artistic achievements, and many agreed that they had recovered creative or artistic aspects of self. However, they emphasised their limitations, had modest aspirations for future projects, and did not identify themselves as being 'artists'. They continued to experience CFS/ME as exerting powerful constraints over lifestyle and identity. This somewhat restricted engagement in art-making did not seem to reflect the severity of their illness in any simple way, as will be explored in a later section.

The other sub-group offered contrasting emphases in their accounts, suggesting that they had managed to engage much more fully in the process of art-making, despite the ongoing restrictions of CFS/ME. The implications of these differing accounts for identity preservation and reconstruction will be discussed subsequently.

1. *Art-making supports identity within the restrictions of CFS/ME*

Art-making has to accommodate to illness

Although art-making provided a welcome source of pleasure and achievement, the participants in this sub-group all emphasised that they had to act within the tight constraints of their illness. Participants described having to reconcile their creative endeavour with their limited health resources. Most argued that they had reluctantly accepted such limitations:

'Instead of pushing the boundaries I now say, no, time to go and rest or I can't do it anymore and I just accept that's the way things are' (Julia, aged 62, former clerk, lived with CFS for 16 years).

'The simpler things give more pleasure and are really better, because if you over-achieve, you're only setting a huge situation for disappointment. Because in the ten years... that I was actually trying to do a lot of craft work ...I would set my sights too high and then come down with disappointment when I couldn't keep it up' (Barbara, aged 56, lived with ME for 25 years but with worsening symptoms in the last 5 years).

Participants in this sub-group differed, with some expressing some acceptance of their physical limitations, and others offering more conflictual accounts. Some, like Barbara, portrayed a lengthy process of wrestling with their illness, describing an alternating succession of triumphs and defeats.

Small projects are perceived as inevitable

As a further indication of accommodating their art-making to illness, these participants repeatedly used the word "small" or related words such as "miniature", "neat" or "little," when describing their need to choose projects that were feasible within the stringent constraints of their energy and physical strength.

'Small [patchwork] squares, sewing one little seam together and that just made me feel marvellous' (Barbara).

For those who engaged occasionally in art prior to becoming ill with CFS/ME, several commented on how their preferred subject matter or media had changed, moving to smaller or lighter pieces and projects that could be better managed in the context of fatigue and confinement to home:

'I do little collages... Since ME, I've been taking close-up photos and small scenes, 99% nature as I have very little energy for people interaction and I'm mostly housebound' (Karen, aged 53, lived with ME for 11 years).

Although limited in scope, and clearly accommodating to illness, small-scale artwork was nonetheless absorbing. It provided a visible record of achievement and helped participants to feel that they were not totally defined by their illness.

Demonstrating the reality of CFS/ME to self and others

Several (but not all) participants in this sub-group referred to their small-scale or slow pace of art-making as validating their condition to others. Validation can be understood as an important achievement given the socially contested nature of this condition. For example, one participant made cards for friends and family with cross-stitch decoration. She thought that recipients understood the effort and energy that each card required:

'It gives you an incredible sense of satisfaction and of course people treasure it, because they know that you've not only done it just for them, but what it's cost to do' (Barbara).

Such small projects, experienced as so consuming of energy and effort, were regarded challenging others' potential disbelief about their illness.

Art-making is a solitary activity

Participants in this sub-group mostly made little reference to enjoying support or camaraderie in the context of art-making. Participants generally represented themselves as lone figures struggling both to cope with their illness and to accomplish their arts and crafts, as this interaction between the interviewer and Sharon shows (this participant was aged 60, and had lived with ME for 18 years).

Int: 'Some people meet people through doing creative things, have you?'

S: 'I'm more solitary. I've lost touch with a lot of people, as you do, because you don't have the energy, you know. I've tried all sorts of things like reading circles and things and you just have to give up, so I just had to give up, so that's another thing. So no, I wouldn't say that I've met people or probably ever will, I don't know.'

Int: 'So for you it's more of a solitary hobby or activity?'

S: 'Yes, I think so, absolutely, yes, it's certainly not a communal thing...'

Limited aspirations for future artistic projects

The sub-group of participants who revealed all or most of the above themes in their accounts also expressed very modest aspirations for their future artwork, even though they drew great meaning from this leisure occupation, and believed that it had contributed to their quality of life. Participants appeared doubtful that both their physical health and their artistic skills would improve substantially. For example, in response to a question about her plans for

future artistic projects, one participant who engaged in collage, miniature painting and creative photography emphasised how her ME was always likely to limit her artwork:

'[In the future] maybe get brave enough to buy a better camera. Maybe find a tutor who'd go slowly enough that I can learn, with holes in my brain. Not big aspirations in traditional terms, but big in ME terms'

(Karen).

Others were cautious about the disappointment with self that might arise if they were too ambitious in their art-making:

'If you didn't achieve what you wanted to achieve, you could end up being even more frustrated than you were before you started' (Julia).

Identity - Not yet an artist

One interview question asked whether participants now regarded themselves as artists. Whilst most recognized that they had acquired artistic skills and aptitudes, and all enjoyed their creative hobbies, none of the participants who included the above themes in their accounts considered themselves to be artists.

'I just can't get down on paper what I have in my head. So, no, I don't think of myself as artistic, not in the sense that I think everybody would think of artistic' (Julia).

The ever-present influence of CFS/ME was often used to justify answers to this question:

'I just love nature and creation and everything and while I'm a lot better [health-wise], well, not a lot better, but significantly better, I wish more

and more that I was good as an artist ... but I don't quite think of myself as an artist, no' (Grace).

2. Art-making contributes to positive identity reconstruction despite CFS/ME

The other seven participants (that is, about half of the sample) described their art-making since the onset of CFS/ME in terms that suggested the experience of greater choice and power. As will be discussed subsequently, these themes may be interpreted as revealing a more complete and positive identity reconstruction, although somewhat fragile and liable to break down on 'bad days'. This sub-group of participants tended to include the more positive themes of Table 1 in their accounts. They perceived themselves as gaining valued and new aspects of self through art-making, used their art to claim personhood rather than illness, were exploring larger or more complicated projects, and described having more ambitious plans for future artwork. Some (though not all) enjoyed the camaraderie of fellow art-makers (through at least occasional personal contact or via the internet). Several (but not all in this sub-group) identified themselves as having become artists (or 'craftspeople') since the onset of illness. As a sub-group, these participants did not appear to be simply 'less ill'. Why they might have been able to use art in this transformative way will be examined in a later section.

Art expresses valued and developing aspects of self

Some participants traced significant developments in their arts and crafts skills since the onset of their illness and took great pride in the achievements

they had made in the face of considerable adversity. They believed that this growth in their artistic skills had helped them to recover self-confidence, and had challenged the power of CFS/ME to restrict them physically and define them socially:

'I mean to start with, it [art] was just something to do. You know, and as I got a bit more sort of confident and thought, "Well, if I can do that, then I can perhaps do this", and I'm sort of designing my own things, and yes, I'm really enjoying it...I'm definitely getting a lot more confident in developing my own skills' (Elizabeth, aged 34, had lived with ME for 11 years, worsening in the last 2 years).

All participants regarded their illness as continuing to limit their engagement in art. Yet this group appeared determined to make less accommodation to illness. One participant who had recently enrolled on an arts course, despite ongoing problems with her fatigue and eyesight, highlighted her dilemma of whether to accommodate to illness (by focusing on small projects) or to express herself more fully in more ambitious artwork:

'Do you start painting in acrylic, or small miniatures that you can carry [on the train] in the rush hour? [Instead] I thought that printmaking might free me up to work in a totally different way and I'd be actually freer...it would be good for me' (Jocelyn, former arts administrator, lived with ME for 20 years, but worse in the last 10 years).

Others described using their art to move beyond their physical and psychological 'comfort zone', to experience a level of challenge that they used to enjoy (for example, at work) before the onset of illness:

'Perhaps I am starting to think in a more creative way and it has pushed me on into looking at card making and textiles, which is ...a lot more loosely defined than I would have been comfortable with. ...I'm starting to explore that a bit more' (Gwen, former IT specialist).

Larger projects are perceived as possible despite CFS/ME

In some contrast to participants who perceived their artwork as necessarily "small" and limited in scope, this sub-group mostly described their artwork as increasing in size/scale, quantity and quality over time, and some quotations above have already illustrated this experience. Many in this sub-group described themselves as gaining confidence in recent months or years to work on larger and/or more challenging pieces, in the process feeling less aware of their illness and less disempowered by it:

'I've wanted to do something for the church for two or years now, altar backdrops or just hangings ...And I like working big, big pieces... I'm finding I can express more ...So I feel that I'm achieving what I want, and I'm managing it ...producing some exciting work now. [I say] keep going, don't give up, push it, don't do things because they're quick or easy, do the difficult things. And that's good because it gives you a bit more challenge and again stops you worrying about things like dwelling on where you hurt' (Lydia, former health professional who took early retirement through ill-health, aged 35, lived with ME for 8 years).

Art confirms the person rather than the illness

As noted in the theme above, some participants were able to engage in bigger projects that helped to resist definition by CFS/ME. In so doing, they might be

interpreted as finding new facets to their personal identities, regarding themselves as people who still had to negotiate with CFS/ME in their everyday lives, but who were no longer intimidated by it:

'I feel like a different person, I've always been a shy person ... But now my confidence...[has] finally emerged, it's a different side of me',
(Lydia).

Some portrayed their art-making in quite adversarial terms, as a tool that helped them to resist the overpowering force of their illness.

'If you can produce [creative] things and think, well all right, I might be confined to an armchair a couple of afternoons a week or I might be in bed a couple of mornings, but I can jolly well do things, you know. And I can do them better than you – this sort of attitude. I'll show you' (Jill).

Art-making is associated with allies and social support

Some of the participants in this sub-group described learning about artistic techniques and media from friends and adult education classes, or from contacts met on relevant internet sites. No-one had managed to sustain their art-making sufficiently to join an arts or crafts guild, or take a lengthy City & Guilds course, and most described their leisure activity as largely conducted at home. Nonetheless, participants presented their art-making as a less solitary activity than those in the previously defined sub-group.

Jill: 'It was a friend I met via the steam [engine] shows who showed me that [patchwork technique] and she said that she'd learnt it at a class...'

Int: 'So essentially that was a technique you learnt from seeing a friend?'

Jill: 'Yes ...and, as I say, I did try going to a class. When we first moved down to this part of the world [southern England] I thought, well, if I'm going to do this, I ought to do it properly and I went to a class' (Jill, 59, ME for 8 years, former biomedical scientist)

Future aspirations for art-making are increasingly bold

Although these participants did not hold strong hopes for making a physical recovery from their illness, some expressed confidence in developing a more positive and productive future self. They prioritized their time and limited energy to enable regular participation in their art-making. No-one anticipated that these projects would have any therapeutic effect on their physical health. Instead, they were valued for increasing life satisfaction and helping to create a more positive identity as a person who – whilst hampered by CFS/ME – was not totally dominated by it:

'In my mind I have so many projects turning over, that I begin to wonder if I will have time for them all...I have always loved to travel and see new things, and though I can't get around as much as I would like, the act of trying to draw some aspect of wherever I may be seems to satisfy my spirit, instead of my feeling intense frustration, as formerly' (Ann, aged 59, former nurse, written account).

'I have a bit too many [projects]... my creativity is sort of almost exploding...But a lot of it [the problem] is, there's almost not enough time in my day to do it. I rest every afternoon, very rarely do I manage

to get through a day without an hour's real sleep...My day is quite short, even though I don't go out to work' (Susan).

As shown in the two quotations above, participants did not find it easy to engage in art-making, and had not recovered physically. Their physical health continued to demand long periods of rest if they were to have sufficient energy and concentration for artwork, and other activities. But they expressed optimism about what could be achieved within such constraints.

View of self: becoming an artist

Many (but not all) of this sub-group were willing to describe themselves as having become artists (or craftspeople) since the onset of the illness.

Everyone who had been employed had been obliged to take early retirement through ill-health, and some had found their marriages and family roles to be seriously compromised by their illness. So the positive impact of this new identity as an artist, usually after many years of struggling to live with CFS/ME, cannot be underestimated:

'More and more I do [regard myself as an artist] partly because I now produce work which other people value and partly because I feel I know myself better ... it's given me more confidence to know that this really is me being able to be an artist. It's not something I've tried to be that isn't me' (Susan).

*'I consider myself a craft worker. I think having something to do that I **could** do and something that gave rise to a very pleasing end product, something I could say I did' (Gwen).*

Do the identified themes simply reflect participants' levels of health or other factors?

Two rather distinctive lifeworlds emerged from this analysis. In one, the women's accounts continued to be dominated by the constraints of CFS/ME. For this sub-group, art-making offered a satisfying leisure activity, but one that they regarded as very limited by fatigue/ other symptoms, and unlikely to develop much further in scale or skill. Former roles, accomplishments and pastimes continued to be mourned, and there was ambivalence about current achievements. In contrast, another sub-group of participants pursued artistic endeavours despite their ill-health, valuing opportunities for self-expression and development. They coped with ill-health in ways that resisted its potential to define and degrade personal identity. To explain these differences, it might be thought that the second group was simply 'less ill', but this is not supported by the data. Neither sub-group regarded their art-making as capable of healing them physically:

'So I began to illustrate a story going through my head. It was a simple poetic journey from one place to another. Later I had the feeling that if I could somehow make external the pain and struggle of my illness I would recover. Nice idea. Didn't quite work but important to try' (Gillian, 50, lived with CFS for 8 years; former garden designer; written narrative).

Without quantitative measures, it is not possible to exclude the influence of illness symptomatology, or to assess the role of other potentially relevant protective factors such as social support. Not surprisingly, one participant who

described very severe CFS/ME symptoms emphasized the limitations that the illness imposed on her artwork. Yet two participants who reported worsening symptoms over recent years, and also profound functional restrictions, offered *all* of the more positive themes in their accounts. Time since diagnosis did not predict the type of account told about art-making, and participants in *both* sub-groups reported ongoing problems with fatigue, muscle pain and other CFS/ME symptoms, usually fluctuating in severity. For example, a participant who offered most of the positive themes that have been identified said:

'I used to love learning, I do like learning, I like learning in a practical way, but I'm finding it difficult to assimilate information and stuff. At the moment it's really bad, I'm spending one or two days a week in bed... I'm not sure I'm rescued ... There are times when the illness just takes over and I can't do anything and then it's well, to hell with the world, and I'll probably just sit in front of the television not caring what I'm watching' (Jill).

Such accounts convey the experience of fragility of self in CFS/ME, as noted by Whitehead (2006b). Attitudes and values, not only physical symptoms, seemed to influence participants' experiences of self. For example, a participant who seemed to have achieved positive identity reconstruction through her art-making recounted a strategy of benefit-finding within the context of worsening health:

'These last two years, it's probably the worst that it's ever been. So, I had to leave my job then and to start with, it was very difficult. But I've really got used to having time to myself and I can do whatever I want to do, which is fantastic, and I'm developing in other areas, rather than

career-wise. There's this sort of creative side of things, it's very important to me...I've learnt more about myself in the last couple of years, than I ever had, I think, because I've needed to' (Elizabeth).

Another also chose to value her new accomplishments rather than mourn her lost roles:

'It's a different side of me [that's emerged]. ...The one that was very dormant, that's become the strong side now. That's interesting' (Lydia).

Discussion

The accounts provided by the participants supported previous studies which have shown that CFS/ME undermines identity (e.g. Åsbring, 2001; Dickson et al, 2008; Whitehead, 2006b). This study specifically, and uniquely, explored the contribution of artistic leisure occupations to protecting and reformulating identity, and two broadly distinctive patterns emerged.

Åsbring (2001) argued that people with CFS/ME address the various challenges to their identity by engaging in 'the biographical work of identifying activities which could be kept up and those which must be given up or carried out in a different way' (p.316). This study further examined this process in relation to art-making, taken up or intensified as a leisure occupation after the onset of CFS/ME. The themes inferred from the qualitative accounts can be interpreted together as revealing different levels of identity reconstruction. One sub-group of participants seemed to be modestly salvaging aspects of identity through their creative endeavours, whilst another sub-group was engaging in a more thorough and positive identity reconstruction. 'Salvaging'

is a process of saving from ruin or destruction. Despite the satisfactions of art-making, for this sub-group, the rescued identity had value but remained imperilled and constrained by ill-health. The other sub-group, despite evident functional limitations, expressed a deeper engagement in their art-making. Essential differences in participants' lifeworlds have been noted in other qualitative studies of contested illness (Råheim & Håland, 2006).

Participants who were interpreted as salvaging aspects of their former identities emphasised how their art-making had to accommodate to the constraints of illness (for example, that projects had to be small in scale), that artwork communicated to both self and others the reality of the illness (helping to resist stigmatisation), and that only moderate creative aspirations were possible. Managing illness and creating artwork was quite a solitary process. Whilst all enjoyed art-making, no-one in this sub-group regarded themselves as artists. In contrast, some participants offered different emphases in their accounts which could be interpreted as conveying a process of more positive identity reconstruction. For this sub-group, illness continued to pose limitations on energy, mobility and other aspects of daily life, yet both familiar and new aspects of self were encountered through art-making. Participants' projects were increasing in size and challenge, and many were beginning to have bolder plans for their artwork. Art was not used to validate their ill-health but rather their personhood. Some sought contact with fellow art-makers, and some (but not all) described themselves as having become artists or craftspeople during the course of their illness.

It remains possible that those who presented themselves as engaged in identity salvaging might go on to more positive identity reconstruction at a later stage, perhaps if their symptoms abated, or if they came to terms with the losses wrought by CFS/ME. Whitehead (2006b) noted a positive shift in narratives about identity in the middle and longer term among people living with this illness. In Frank's (1995) typology of self-transformational 'quest' narratives offered by people with chronic illness, there is an early stage which he refers to as 'the road of trials', which might also describe the accounts of people whose engagement in art-making was more effortful and constrained. In the present study, it is not possible to predict whether the themes suggesting identity salvaging through art-making might give way eventually to positive identity transformation. Time elapsed since the onset of illness (or time since recourse to art-making) did not appear to be relevant, although a larger quantitative study would be needed to address this issue. However, the findings confirmed previous evidence that the sense of self in CFS/ME is fragile, and liable to break down when symptoms intensify or when stigma is more perceptible (Whitehead, 2006b). No-one rejected their former selves, unlike the participants described by Clarke and James (2003) but in agreement with the findings of Whitehead (2006b). Art-making offered experiences that both reminded participants of their pre-illness capabilities and that also offered a possibility of personal growth albeit within highly constraining physical and social circumstances. There was little reference to using imagery cathartically to express feelings about illness or loss of self, although this process is widely accepted in the art therapy literature (e.g. Malchiodi 2005).

Previous qualitative research has uncovered many ways in which leisure-based art-making promotes subjective well-being in chronic illness (Reynolds and Prior, 2003). There has been a widespread view that 'art is good for people' (Stickley, Hui, Morgan & Bertram (2007; p. 783). This study has offered a finer-grained analysis of identity-related themes and suggests that, for some people affected by CFS/ME, art-making can be helpful yet does *not* necessarily offer a powerful means of identity reformulation. Its somewhat limited influence (for some participants) may be linked to the multiple burdens of sudden and profound physical disability, uncertainty, lack of treatment and social stigma which are all so limiting of choice, hopeful attitudes and normal activity. It may be argued that meaningful leisure pursuits other than art-making might also strengthen or redefine identity, particularly if they meet the various indicators of 'serious leisure' such as commitment, fulfilment, progression of skills, and social recognition (Stebbins, 2006). However, CFS/ME is an illness that imposes marked constraints upon activity, limiting choice. Art-making may have potency as a self-expressive activity that is manageable within constraints such as fatigue, low mood, and confinement to home, even by people with quite limited skills. Visible and lasting products may also help to support an identity that is not defined by illness. Art-making offers a respite from CFS/ME concerns whereas certain other coping responses such as pacing and self-help health promotion strategies may serve to maintain a focus on illness.

Future research might combine qualitative enquiry with more quantitative assessments of physical symptoms, depression and social support. Then it might be possible to determine to what extent the accounts which have been

interpreted as revealing positive identity reconstruction are related to such factors (to understand, for example, whether those who engaged in 'identity salvaging' are measurably more depressed or more physically disabled). Whilst many qualitative studies rely solely on interview data, some have also included standardized, quantitative measures of well-being for comparative purposes (e.g. Hugel, Grundy, Rigby, & Young, 2006; Nicholls, Glover & Pistrang, 2004). Further qualitative enquiry should also seek to understand in more depth the influence of the wider social context, focusing for example on whether participants who experience affirmative relationships are more able to commit themselves to creative activities which support positive identity reconstruction in CFS/ME.

The study has the usual limitations which are present in most qualitative research relating to small sample size and self-selected participants, with the consequence that the findings cannot be generalised in any simple way. Most participants were in their 50s, and it is unclear whether younger people regard art- and craft-making as such a potential source of identity. Another limitation is that a single retrospective interview was used, whereas richer, possibly contradictory, identity narratives might have been gathered if each person had been interviewed on several occasions (Flowers, 2008). All participants had lived with CFS/ME for many years, were drawn from community sources rather than specialist clinics and were not seeking medical help at that time, and all had strong educational and professional backgrounds. They therefore comprised a more homogenous sample than certain other qualitative studies of CFS/ME (e.g. Whitehead, 2006a). This has some advantages, enabling deeper exploration of common experiences. Yet a wider sample may reveal

more facets of the experience of chronic fatigue and art-making. Interviews are inevitably co-constructed by both interviewer and interviewee and the nature of the questions to some extent influences the scope of the responses. So for example, in asking whether or not participants thought of themselves as artists, this aspect of identity was highlighted. Yet the authors experienced data saturation in relation to the themes highlighted, with many recurring illustrations of each theme within the transcripts. The different professional backgrounds of the researchers also assisted the depth of the analysis, and enhanced the confirmability of the themes. Whether the meanings of art-making might change over time, with participants gradually moving from salvaging aspects of identity to more positive identity reconstruction through their art-making, is a question that remains unanswered, and needs a more longitudinal research design.

In conclusion, this study has addressed a neglected topic, namely whether and how art-making as a leisure activity may protect identity from the challenges of CFS/ME, and promote positive identity reconstruction. Creative art-making was interpreted as helping to salvage the identity of some participants, whereas for others, it promoted much more profound and positive identity reconstruction. This was not an intervention study so cause and effect cannot be assumed. There are implications for health professionals, counsellors and artists who work with people affected by CFS/ME, for example in recognising the struggle that people can experience in realising their artistic aspirations and recovering a positive sense of self in the face of chronic fatigue, and the relatively simple adaptations (e.g. in

choice of artistic media, and in gaining the support of fellow art-makers) that may facilitate further artistic development and positive identity transformation.

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