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13 Stitching Together Past and Present: Narratives of Biographical Reconstruction During Chronic Illness

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Many studies have noted that a strong sense of biographical disruption can follow the onset of chronic illness. There has been limited research into people's ways of managing this disruption in the longer term. This study elicited life narratives from four women, who had experienced serious chronic illness (such as cancer) for at least four years. The women joined the study because they had identified themselves as discovering creative occupations (such as textile arts) in the aftermath of diagnosis. Their narratives revealed how creativity had become central to their subjective well-being, and physical resilience. Their accounts document how immersion in creative occupations permitted strong connections to be forged between former and current identities, repairing the initial disruption that had been experienced, and facilitating a strong sense of ability rather than impairment. The narratives in which discovery of the creative occupation are described are often marked by humour. This paper explores the multiple meanings that humour may serve in the women's responses to the interview, and the choices that may be made during narrative analysis. The participants appear, on the surface, to be living very different lives from those that they had enjoyed when healthy, but their accounts make strong connections between present and past roles, abilities and interests, demonstrating a sense of biographical continuity.

Introduction

Chronic illness is understood to present many psychological challenges for individuals and their families (Charmaz 1991). Fearful thoughts about the meanings of current symptoms and future prognosis may dominate the person's daily life. Some chronic conditions such as arthritis are associated with ever-present pain, and other physical difficulties such as fatigue and sleep disturbance. Uncontrollable symptoms, not surprisingly, may lead to a sense of powerlessness, and for some, depression. Chronic illness may also carry radical implications for the self-image, to the extent that self-defining activities, roles

and relationships are affected. For example, the majority of people with multiple sclerosis become unemployed within a few years of diagnosis (Jackson and Quaal 1991). With premature retirement comes the challenge of how to use leisure time productively. Indeed, difficulties in managing leisure and personal care may have a more detrimental effect on quality of life than physical symptoms *per se* (Lundmark and Branholm 1996). Self-esteem may become progressively eroded if the person becomes increasingly confined to activities within the home and family environment.

Jensen and Allen (1994; p.353) summarise these issues by arguing that illness can prompt ... "the recognition and redefinition of one's self, roles and goals. Considerable energy is expended in re-framing one's place in the world, ... in learning to live again with a 'new me'".

Whether and how chronically ill people rebuild a satisfactory identity in the face of physical losses and limitations has received relatively little research attention. Evidence, mostly based on studies of people who are maintaining high levels of psychological well-being in their later years, suggests that three key factors are particularly helpful in supporting the adaptive process. Firstly, instrumental and emotional social support increase the person's resources for coping with the stresses involved with illness and ageing (eg. Day, 1991). Secondly, satisfactory financial resources are likely to increase the possibility of satisfactory levels of choice, for example, over care arrangements, and access to transport (Adams-Price, 1998; Day, 1991). Thirdly, meaningful occupations enable self-expression, social contact and the productive use of time (eg. Fisher and Specht, 1999). As there is relatively little information about the role of meaningful occupations for people coping with chronic illness, the author's research explores this issue.

The author's research has invited narratives from women who regard their involvement in textile arts as central to their experience of living positively with chronic illness. The study has explored participants' views about the therapeutic value of textile arts, the process of discovery of creative occupations, and the influence of earlier interests, friends and family.

The study focused on textile arts (eg. quilting, tapestry, embroidery and patchwork) in order to provide a common focus for participants and to facilitate discovery of common themes. No *unique* therapeutic function is suggested. Textile arts, in common with the other visual arts, enable self-expression, and they provide a visible record of achievement, building self-esteem. They provide, as do other types of visual art, the means for chronically ill people to 'make their mark' on a world that too often overlooks their abilities (Szepanski, 1988). Warren (1993, p.4) argues 'Each creative mark reaffirms the self. It says "I am here", "I have something to express".' Such creative experiences may also enhance the person's sense of control over events particularly when the body is experienced as 'out of control' by virtue of the disease process (Szepanski, 1988).

Reynolds (1997) reported that needlework practitioners coping with chronic illness often described their artwork as a potent means of preserving or re-gaining a satisfactory sense of self. Artwork helped participants to define an 'able' identity, regardless of mobility limitations, pain or fatigue. This identity-enhancing function was particularly valued by women whose illness had enforced a dependent role within the family or early retirement from work. Involvement in this leisure interest had the additional benefit of stimulating social contacts outside of the family, based on mutual interests rather than 'caring' and 'illness'. Almost all participants regarded creative pursuits as escape, distraction or relaxation, all of which could help reduce feelings of depression or anxiety about the illness. Some of those who were facing a terminal illness saw their creative work as providing a legacy to others.

Despite the role that textile art had come to occupy in the women's lives, most had discovered its significance *after* diagnosis. Only 6 out of 32 participants reported lifelong interest in such creative activity. The majority of the sample had taken up this interest as a way of coping with hospitalisation and recuperation, usually as a result of an apparently serendipitous event such as the gift of an embroidery book or kit. The process of discovering the therapeutic significance of artwork is explored in this subsequent narrative study.

Why was a narrative methodology selected for the current research? Women's experiences of discovering that creative artwork enhanced their coping with illness was clearly intriguing but it could not be probed deeply in the previous research, as the participants provided written accounts. In a relatively new field of enquiry, minimally structured interviews are more likely to permit the discovery of the unexpected. A narrative approach enables the researcher to explore whether and how chronically ill women 'connect' with their pre-illness selves, and whether such connections foster a sense of coherence. However, a central dilemma is often encountered in the analysis of narratives, namely whether to take a 'realist' perspective and regard the participants' accounts as transparent 'windows' on their enduring experiences, strategies and values, or whether to understand the structure and content of the discourse as negotiated at the moment of the encounter with the interviewer (Crossley, 2000).

A 'realist perspective' on the narratives is supported to some extent in the present study because the participants' displays of artwork and demonstrations of technique testify to certain enduring strategies and values that inform their ways of living with illness. However, an exclusive reliance on a realist perspective is not advocated. Each participant must inevitably make many 'editorial' decisions during a 1-2 hour interview regarding what to describe from their whole life experience. Their perceptions of the interview agenda, context and interviewer are likely to have a bearing on both the form and content of their narratives (Charmaz, 1999).

This paper examines these analytical dilemmas in the specific context of participants' use of humour when describing their discovery that textile arts offered a meaningful way of living with illness and reconnecting with a positive identity.

Method

Who Participated in this Study?

Thirty two women have been interviewed, but for clarity this paper focuses on four narratives:

Lydia: 32: fibromyalgia and ME; former therapist
Sue: 48: multiple sclerosis; former social worker
Geraldine: 49: post-viral neurological illness; formerly a garden designer
Jane: 55: years old: rheumatoid arthritis, hip replacements, breast cancer; former teacher/head of department

All four women had retired from professional work because of ill-health. All except Geraldine were currently married, and all except Lydia had children. (NB. all names are pseudonyms.)

How Were Participants Recruited?

Some participants responded to an invitation placed in textile arts magazines, and others were recruited through snowballing methods. All received full information about the study including the interview guide, and gave informed consent. They were interviewed in their own homes, for between 1-2 hours, and the audiotapes were fully transcribed.

What Questions Were Asked?

These included:

1. Could you start by telling me about yourself?
2. When did the problems with your health first become noticeable?
3. How did your needlecraft interests begin? Were there any significant events or people encouraging you to take up textile arts? Results:

This section focuses on aspects of their answers to *question 3* above.

Findings and Discussion

The Origins of Participants' Interests in Textile Arts

All of the women had experienced some tuition in textile arts at school, but none had really enjoyed this or shown particular talent at that time.

Int: You are saying that before your diagnosis you didn't do any of this {embroidery}?

Sue: No

Int: Not even as a child?

Sue: No, only the usual childhood things, perhaps a little bit of cross-stitch, like you do, those little needlework cases, there was no (pause) and what amazed me was - I was never any good either. At the Senior School we used to do needlework, the tutor was very nice actually, Mrs Moore, I'll never forget her, and I never finished anything, I was never that fully interested, I would be happily out doing something else, but she must have liked me because I've never forgotten on one of my reports it said 'Susan has done a creditable piece of work' (laughs). A creditable piece of work (laughs) - what is that? I'd done nothing, a half-finished skirt, cut up one side, and that was it. I thought she must have liked me (laughs).

Lydia: I was sewing when I was five, only basic things and my mum's sister never married, and she was always very creative, always sewing, embroidering, very traditional things, and I was always surrounded by that. I was put off art at school by not being very good at it, being told I wasn't any good at it.

Only Lydia had regularly enjoyed sewing (cross-stitch) in adulthood prior to the onset of her illness. None of the women had developed high level skills, or attended embroidery/textile classes until after their retirement from work on health grounds. In that sense, their involvement in creative artwork was facilitated by the restructuring of their lifestyle following illness, in particular retirement from work.

Use of Self-Deprecating Humour/Irony

In the narratives of all four participants, the discovery of textile arts in the aftermath of diagnosis or hospitalisation represented a marked turning point - the point at which their despair diminished and the process of biographical reconstruction began. It is intriguing that each woman's narrative about this event was marked by some humour, or self-deprecating irony.

Jane: I started to go to exhibitions in London, impressionists and that sort of thing, absolutely wow, and you go home and you think I could do

that, it's only brush strokes, and you go home and it looks like the dog's dinner (laughs) but it's brilliant just to try that.

Lydia: {The first project} ... that was the turning point (pause) that made me think that there was something in this and I needn't just be a 'happy little wife' sitting at home doing her table-cloths, I could do some exciting stuff (laughs).
{Note that 'happy little wife' is pronounced in a tone of voice that signified sarcasm}

Geraldine: I saw an advert in the Post Office for a community textile project ... and I spent the first two weeks terrified someone would discover that I couldn't embroider!

Sue: I worked with Social Services, and then I retired on medical grounds, because the illness kept re-occurring. I'd never sewn, never stitched before, I was an outdoor person, horse-riding, dogs, bringing the children up (um) and then all of a sudden it stopped (um) retirement on medical grounds as I stated. Then my daughters grew up, my job stopped and I was suddenly left with this huge void, and er what do you do? And I've always loved craftwork, always loved to see it, always loved to go to galleries ... and (laughs) I found a craft-book and I tried to do patchwork (laughs). Absolute disaster! (laughs) ... I thought this is bloodystupid!!

These brief extracts return us to the dilemma noted earlier. In narrative analysis, it is rarely clear whether the words that participants use permit the audience genuine glimpses of their original experiences, or whether the text represents the outcome of a context-dependent negotiation between interviewee and interviewer, in the service of presenting a particular image. Both possibilities permit some interpretation of the meaning of the humour that the women use.

Does the Humour in Some Way Reflect the Original Experience?

If the researcher adopts a 'realist' perspective, the humour may be understood as present in the original experience, and revived during the evoking of the memory of those events. In that case, perhaps the narrative conveyed the tension relief that indeed occurred as the woman discovered a means of living more positively with her health condition. The serendipitous nature of the turning point may have been received with some joy and gratitude. The humour, if originally present, may have signified the emotional distancing that had emerged at that moment. Such distancing would have facilitated reflection, new choices, and positive movement within the grief process. Some authors

have indeed argued that such distancing and humour are vital resources for living positively with difficult life circumstances and transitions (Day, 1991; Lefcourt and Davidson-Katz 1991; McGuire and Boyd 1993; Young and McNicoll 1998).

On the other hand, if a discourse analysis perspective is adopted, the humour may be regarded more as a conversational strategy adopted during the interview for the sake of image-management in front of the real (or imagined) audience. Supporting this perspective, one of the participants showed that she was very aware of the researcher-as-audience at the outset of her account:

Geraldine: I'm a curved line person, love water and stone and need air and space. That's the real information but now here is the fodder for your computer!

Humour is a common conversational strategy in everyday encounters, indicating for example, that the speaker is aware of social conventions that discourage 'boasting' about personal achievements. Alternatively, the speaker might be signalling her awareness that a 'collision' is about to occur in her account between a biomedical discourse and a creative arts discourse (eg. that she places trust - that some might consider paradoxical - in both chemotherapy *and* creative work for surviving breast cancer). Alternatively, perhaps the self who discovered textile artwork now appears somewhat incongruous with the present creative self, so the speaker injects some humourous distance or irony into the story. Humour could also be a conversational device for protecting the listener, or indeed the speaker herself, from distress, by masking the depth of previous (and possibly current) negative emotion (Charmaz 1999; Young and McNicoll 1998). There is less evidence in the narratives for this last interpretation as all the women testified to very painful experiences at other points in the interview:

Lydia: ... it's only two years ago it really hit me, I admitted I'd got chronic fatigue syndrome, I was fighting it, I wouldn't give in to tiredness, I wouldn't give in to the aches, and I wouldn't let it stop me because I've always been an active person and that was incredibly hard, but then I had to give in, I was so depressed, I was terrified of going out, of being on my own, and that was the big change.

The women's use of humour may have multiple parallel meanings, reflecting the myriad of choices that the speaker makes with varying degrees of conscious awareness. The very limited analysis offered here confirms the richness of narrative material for exploring the life worlds of people living with chronic illness, and the complex process of biographical reconstruction through creative occupation.

Conclusions

- Participants' accounts of coping with serious illness demonstrated considerable personal resourcefulness
- Participants revealed high levels of self-awareness of the restorative value of their creative work - and the importance of reconstructing a meaningful life and identity in order to cope with chronic illness
- The 'discovery' of a creative arts occupation was represented by the participants as a significant turning point in grieving for lost functioning/self and moving on
- The participants' narratives were punctuated with humour and laughter, and these conversational strategies warrant further examination

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