

Reynolds, F. (1997) Coping with chronic illness and disability through creative needlecraft. *British Journal of Occupational Therapy*, 60 (8), 352-356.

Abstract:

Chronic illness and impairment commonly restrict the individual's access to work and leisure activities. Furthermore, if increasingly dependent upon family care, the individual may experience loss of valued roles and self-esteem. A qualitative study was carried out on the written narratives of 35 women, aged 18 to 87 years. All had acquired a disability or chronic illness in adulthood, and although facing different health problems, they shared needlecraft as a common leisure pursuit. The narratives explored the circumstances in which needlecraft had been adopted as a leisure pursuit, and the personal benefits experienced. Most of the women had taken up this activity in adulthood to cope with the crisis of illness. Needlework activities were commonly viewed as providing a means of managing pain, unstructured time, self-image and reciprocal social roles. The women's accounts confirm the value of creative activity for patients learning to cope with chronic conditions.

INTRODUCTION

Chronic illness and impairment may present the individual with several coping challenges. Although each illness may pose specific problems, Moos and Schaefer (1984) argue that the chronically ill face four common adaptive tasks, namely:

- i) To preserve a satisfactory self-image and sense of achievement or competence

- ii) To retain a psychological equilibrium (eg maintaining hope and humour; controlling anxiety , anger and other negative feelings)
- iii) To maintain positive relationships with family and friends
- iv) To prepare for an uncertain future.

Other researchers have identified similar needs. "When we are ill, we experience a fundamental doubt about the viability of the future self that we have envisioned for our life story " (Brock & Kleiber (1994; p.413). Swanson & Chenitz (1993) found that individuals with a chronic condition commonly described themselves as having to preserve or regain a valued sense of self. Robinson's study (1990) of people with multiple sclerosis came to a similar conclusion in proposing that the illness and its progressive effects need to be integrated into the self-image, with positive meaning extracted from the experience. Jensen & Allen (1994; p.353) sum up: "Health-disease thus involves 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'."

Psychological adaptation is typically made far more difficult for the individual by the disabilities imposed by the physical and social environment. Disability has been defined as "the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal basis with others due to physical and social barriers" (Finkelstein and French 1993, p.28). Such barriers commonly restrict access to work and leisure pursuits, increasing the likelihood of depression, loss of social roles and poor self-esteem (Angeleri et al 1993).

This research study has focused on the perceived value of a creative leisure pursuit in

enhancing well-being among women reporting chronic illness and impairment.

Previous studies of patients and carers (eg Greveson & James 1991) have confirmed that constructive use of leisure time may improve the quality of life, for example after stroke. Yet "there appears to be a growing opinion that not enough is done to enable patients ...to resume former interests or to acquire new ones" (Drummond & Walker 1995).

Creative leisure activities provide a particular means for disabled or chronically ill people to 'make their mark' on a world that too often overlooks their abilities, promoting feelings of self-worth and enhancing the sense of control, particularly if the body is experienced as 'out of control' (Szepanski 1988). The experience of disability is also moderated where leisure (and work) activities can be shared on an equal basis with able-bodied friends and colleagues.

It is a foundational principle of occupational therapy that purposeful activity is a catalyst for motivation, satisfaction, and a sense of mastery (Randomski 1995). Activities empower to the extent that they enable choice and fulfilment of personally relevant roles. Conversely, if valued activities are lost as a result of illness or acquired impairment, the individual may experience depression through loss of perceived independence, mastery and control. Although occupational therapy traditionally introduced patients to new leisure pursuits, there has been a move away from the therapeutic use of art and crafts in recent years, particularly in physical settings (Taylor & Manguno 1991). There is continuing professional debate about the adaptive value of art and craft-work in rehabilitation.

This study focuses on the adaptive potential of needle-craft through the reported experiences of disabled practitioners. Whilst a qualitative exploration needs to listen

carefully to the 'unexpected', the study had two broad aims:

1. To examine the inception of needlework as a leisure pursuit, examining (for example) whether participants had 'simply' adapted a life-long activity to their acquired disabilities, or whether the crisis of illness had provoked a search for a meaningful new activity.
2. To examine the therapeutic benefits of needlework, in contributing to adaptation and well-being. Specifically, the narratives were examined for their inclusion of the adaptive tasks identified by Moos & Schaefer (1984), together with any additional themes.

METHOD:

Design:

The study sought personal accounts from disabled and chronically ill individuals about the role of needlecraft in their lives. The study was descriptive and exploratory in nature.

Procedure:

A method needed to be devised of contacting disabled individuals pursuing needlecraft as a favoured leisure pursuit. Contact via sewing guilds or adult education classes was considered, but rejected as likely to skew the sample towards the more mobile and socially oriented.

An alternative means of contact was chosen, via a needlecraft magazine.

Respondents were recruited through a request printed on the readers' page. The author's choice of magazine was influenced by its level of circulation and its previous articles about disabled embroiderers, which prompted enquiry into the role that needlework may have in the lives of people living with chronic illness and impairment.

Respondents with disabilities/ chronic illness were asked to write about their reasons for taking up and currently enjoying needlework. They were asked to include details of age, marital status, occupation (paid or otherwise), and age at which this leisure pursuit was taken up. Apart from answering these questions, respondents structured their remaining accounts as they wished. The author was identified as a lecturer within a School of Occupational Therapy.

The sample was obviously self-selected rather than random, but was elicited by a method that has been used by other qualitative researchers in attempting to locate a 'hidden' sample (eg Wilbur et al 1990).

Whilst interviewing is the most common method of eliciting narratives, the qualitative study of written documents is also recognised (Mason 1996). All methods of eliciting narratives have an impact on the structure and content of the material gathered, as all stories are told in a social context, with an audience in mind. "In the research interview, the interviewee does not tell a standard story but a particular story which is designed to present a particular image to the interviewer" (Murray 1997; p.13). Both oral and written narratives can be viewed as a selective but nonetheless authentic personal portrayal of experience.

On receipt of the written accounts, respondents were sent a letter of thanks, confirming

the confidentiality and security of all materials received. If photographs of needlework had been enclosed, these were examined and returned.

Content analysis

The accounts were read and re-read several times to ensure familiarity prior to a qualitative content analysis (Crabtree & Miller 1992). In qualitative analysis, the researcher inevitably faces the task of differentiating key meanings in the mass of text collected.

A provisional 'start-list' of coded categories (reasons for valuing needlework) was adopted at the outset, as recommended by Miles & Huberman (1994). The 'start-list' was based on the common adaptive tasks described by Moos and Schaefer (1984), and outlined in the introduction to this paper. When respondents described purposes/benefits that did not clearly fit Moos' and Schaefer's categories, the list of coded themes was extended. Some of the original categories, on further immersion in the data, warranted further differentiation in order to capture individuals' meanings more precisely. The accounts were also read "with an eye to surprising or counterintuitive material" (Miles & Huberman 1994, p.58), and for regularly occurring phrases. The ultimate aim was for the categorisation scheme to account well for respondents' reported experiences. The proportion of the sample referring to each theme is indicated to enable the reader to appreciate the patterns in respondents' narratives (Morgan 1993).

In order to establish reliability of thematic coding, a second coder (psychologist) read a proportion of the narratives and independently applied the categories that had been

identified. Discussions between author and second coder further refined the conceptualisation and categorisations of the data.

RESULTS:

Research Participants:

Thirty five women provided written narratives for this study. Their ages ranged from 18 to 87 years, with an average age of 49.3 years. Without exception, they had acquired a disability/ chronic illness after childhood. Rheumatoid arthritis was the most commonly reported condition (8). In all, 20 reported joint/mobility problems. The sample also included women with cancer, muscular dystrophy, chronic respiratory conditions, polio, stroke and M.E. The women in this study were all living in the community. Regarding paid occupation, 4 were in full-time employment; 7 were part-time. 24 did not work outside the home. Of the 30 who disclosed marital status, 27 were married.

Aim 1: When and how did respondents discover the therapeutic value of needlework?

Three respondents omitted to describe when and how they had discovered their interests in needlework, so the remaining figures in this section are based on the data from 32 women.

Although 20 recalled being introduced to needlework in childhood (at home or at school), only 6 had maintained constant interest in this hobby, with some adapting their preferred forms of needlework to their physical condition. Women coping with painful

joints had commonly discovered that cross-stitch and tapestry work which require a 'stabbing' action were more easily accomplished than other forms of needlework. Of the 20 with some early experience of needlework, 14 had only re-discovered this pursuit in their adult life, following illness, commonly as a means of coping with hospitalisation or convalescence.

The remaining twelve women in the sample described taking up needlework in their adult years with no previous experience in childhood. Most had been intrigued by seeing the creative items made by friends or colleagues. Accounts often suggested that the discovery of needlework had been serendipitous - with a chance encounter leading to the discovery of a highly meaningful activity and renewed identity and optimism.

None of the sample reported being introduced to needlework via occupational therapy although two argued that it would have been the most effective 'prescription' that the National Health Service could have made.

Aim 2: In respondents' experiences, how does needlecraft activity contribute to coping with disability?

As described earlier, the narratives were initially examined to establish whether reference was made to any of the general adaptive tasks identified by Moos & Schaefer (1984) as enabling successful coping with chronic illness. In addition, the list was extended to include three further themes within the narratives that were related to well-being, namely coping with pain and restricted mobility; coping with unstructured time and achieving paid employment. These four original and three additional themes

are described in more detail below, with illustrative quotations.

1. Preserving or re-gaining a satisfactory self-image and sense of achievement or competence

About half of the sample (17) portrayed their needlework as enabling a sense of achievement. It was notable that even those respondents in full- or part-time work experienced their sense of personal worth as enhanced through their creativity. **All** of those who reported having to retire from ill-health focused in their narratives on building self-worth through their needlework.

Some described gaining a personal sense of achievement and mastery from completing craft projects:

"It is relaxing and makes me feel that I am not done for at 26. I can create beautiful things and that is surely worthwhile!"

"There is such a sense of achievement when you finish something. You can say "I did that!" I'm still of use to this world - O.K. so walking's restricted, someone else does the housework and often the cooking too but I can still DO SOMETHING".

"It gives a sense of control that is often lacking in a disabled/ ill person".

Some respondents appeared to gain self-esteem from the praise and recognition given to their products by others.

"Needlecraft helps one relax and when others appreciate it, it helps to restore

one's self-esteem"

2. Maintaining psychological equilibrium: coping with anxiety, depression and facilitating positive enjoyment

Of all the 'adaptive tasks' identified by Moos and Schaefer (1984), the maintenance of emotional equilibrium was most commonly referred to by respondents. Of all therapeutic benefits attributed to needlework, relief from anxiety and depression was most frequently described (by 26 respondents).

"Needlework has most definitely given me a reason to get up each morning. When I don't have a project under way I find I start to dwell on my illness and ..the frustrations I feel at not being able to do all the things I used to"

"I found I had to keep myself busy to avoid depression, loneliness and a sense of loss following giving up my career of 29 years".

Thirteen described the activity as relaxing, calming, or reducing worry.

"It would be horrendous if I hadn't my stitching to escape into -something to keep my mind away from worrying about what could happen" (respondent aged 37 years, diagnosed as having cancer).

Many facets of the activity contributed to relaxation. Some found that the rhythmic activity itself was soothing or banished anxiety-provoking thoughts. Others mentioned that the planning of designs and monitoring of the sewing (watching the growth of

texture, colour and pattern) offered welcome distraction from negative feelings. Some also described the positive pleasures derived from creativity.

"It is very interesting and absorbing and very therapeutic creating something".

3. Maintaining/ enhancing positive social relationships

Although Moos and Schaefer referred to the general need for preserving relationships, respondents in the present study made finer distinctions about their social needs.

Some respondents described maintaining social contacts, and reducing isolation through their needlework activities. Others portrayed themselves not only as having an active social network but also as being a useful member of that network.

For many in the sample, needlework was not regarded simply as an individual 'creative' activity. Fourteen described developing social contacts through their needlework, from joining classes, guilds, sewing groups and (in four cases) going on to teach their skills to others (usually the elderly or people with learning difficulties). Three women confined to the home had met pen-friends through needlework magazines. These social contacts were seen as valuable in offering support, and sharing of skills.

"Craft-minded people are so willing to share ideas and knowledge and cheer each other up".

Many respondents had found that their needlework provided them with an expanded social role, and a means of making a 'useful' contribution (in their own eyes) to their families or wider community. There was a commonly expressed need to feel less dependent and to be able to offer something in return for the care received from others. Almost half of the sample (17) described their enjoyment in making gifts and cards for family and friends. Eleven made items for charity or their Church, sometimes in the company of others. To give and to feel useful was experienced as a common benefit of needlework. This aspect could be understood both as facilitating healthier reciprocal relationships and as preserving/re-newing self-esteem.

"My children give me requests for their children's clothes so I feel a useful member of my family" (respondent is 51 years with muscular dystrophy).

"It gives me a lift to make presents for people I care about".

The social contacts and reciprocal giving appeared to offer validation of the self as an embroiderer, cross-stitcher, quilter and so on, rather than as a 'disabled' person. Through this activity, the self could be preserved from domination by the physical impairment.

4. Coping with an Uncertain Future

This 'adaptive task' of Moos and Schaefer was the least in evidence in respondents' accounts. In most narratives, needlework played its part in enhancing current life rather than as a means of coping with the future. Perhaps this was because most of

the sample had lived with their condition for many years and had achieved some acceptance. However, five respondents with progressive conditions saw the products of their needlework as a legacy - that would remind grandchildren (or others) of their lives. Some poignantly wrote that they regarded their longterm needlework projects as helping to 'guarantee' their future. Four out of this five were facing life-threatening illness. This group was in mid-life rather than later life, and understandably may have had greater concerns about premature death. For example, a woman with cancer wrote:

"Since when really depressed I can usually convince myself that it would be a waste to leave some project unfinished, I am very careful always to have several on the go at once and never ever get them all finished".

5.Coping with pain and restricted mobility

Additional to the four adaptive tasks above, respondents attributed other benefits from their needlecraft activities. These included relief from pain and restricted mobility.

Half of the women (10/20) with joint problems reported that needlework helped them to cope with pain, either by easing stiff joints or by distracting their attention away from pain. Narratives from a further 5 women (with cancer, asthma, dyspraxia, ear pain and polio) echoed these themes. For example, one woman coping with constant pain and limited mobility from a back injury wrote:

"The needlework is my 'escape' and I can absorb myself in my work and let my imagination fly..."

Another confined to home by a progressive illness wrote :

"I cannot just sit in a chair all day and stay sane. I can forget about the pain while I am sewing, for a while at least, and the rhythmic movement actually eases my joints".

6. Structuring time

A need to structure the day and fill time productively was described by 8 respondents although this seems to be an adaptation to chronic illness not explicitly included in Moos' and Schaefer's categorisation. Seven of this group were not working, and the eighth had reduced her hours of work in response to her illness. The group who expressed a need for structure to the day were also younger. Their narratives described needlework as offering a means of filling time in the day creatively.

"I can no longer manage full-time work and need something to do while I am sitting".

"If you can occupy the hands, you can reduce stress and pain levels and fill an otherwise useless day".

Some with varying symptoms also saw that their needlework provided a record of their 'good days', eliciting a more hopeful outlook.

"When my disability is bad I have something to remind me that I do have good days as well".

7. Providing paid employment

A few respondents (5) identified their needlework as a minor source of income. Income was derived from making goods to order, making up kits for shops, and selling items personally at craft fairs. One respondent had set up her own mail order business selling sewing materials and kits. All regarded income earned in this way as helpful - both financially and in boosting feelings of independence and self-worth, but two commented on the exploitation they had experienced as 'home-workers'.

DISCUSSION:

The respondents in this study viewed needlecraft activities as vital means of coping with their illness/disability and maintaining a satisfactory self-image. The content analysis of accounts suggested that this form of activity could contribute to the achievement of each of the adaptive tasks, described by Moos and Schaefer (1984). Contrary to expectation, the narratives indicated that most respondents had not simply adapted a long-cherished leisure pursuit to their changing physical state, but had discovered (or re-discovered) needlework in their adult years, commonly following illness. The activity had then become central to their coping - with hospitalisations, pain, limited mobility, unstructured time, and lack of paid occupation.

The written accounts made many references to identity and self-esteem issues. For some, the creative self-expression inherent in the activity provided one route to self-esteem. The narratives also conveyed how (for many) skilful embroidery (and other craft forms) provided evidence of an 'able' self, allowing the woman to resist mastery by her illness (Charmaz 1991). Needlework was described not only as enriching solitary leisure time, but also as providing opportunities for greater community

participation. Through classes and sewing guilds/groups, some disabled women enjoyed a means of mutual interaction with others where her abilities (rather than disabilities) gave her common interests and social recognition. In using her talents to raise money for charity or to refurbish her church, she could 'make her mark' on the world, even from the confines of home. Within the family, the woman dependent on care sometimes regarded herself as establishing a more equitable relationship by giving items that others needed or simply admired. "Identity defines a person as a social object locked into group memberships and social relationships" (Kelly 1992, cited in Kelly & Field 1996). Accounts often emphasised that this form of activity provided access to a 'healthy' participatory identity, which helped to counteract experiences of social exclusion through illness. In short, many described this activity as 'normalising' (Robinson 1993).

Whilst the analysis has focused on the themes within the accounts, some attention may be given to the rhetorical features of the stories presented. As also noted by Radley & Billig (1996), respondents commonly appeared to be bringing order and meaning to their personal health crises through the story that they constructed. Some were arguably presenting a rather 'tragic' view of disability, for example, in referring to their efforts to triumph over feelings of 'uselessness'. Perhaps some women with acquired disability had indeed internalised negative cultural attitudes - or perhaps these were views that she had encountered in others and was vehemently resisting. As Radley & Billig (1996) point out, efforts at 'legitimation' are often embedded within 'illness talk'.

Reflection may be offered on respondents' motives for writing their stories. Confirming Robinson's finding (1990), the narratives commonly presented a view of self as strong, able, creative and worthwhile, and the writing of such accounts may have had some

therapeutic impact. Perhaps some respondents wrote about their lives to offer hope to others in similar positions (as noted in other studies by Murray 1997). Perhaps the motive of some (explicit in some accounts) was to give 'witness' to the value of occupational therapy, as there were common perceptions both that the profession values creative activity and also that this form of treatment needs to be more available.

All methods require critical scrutiny (Mason 1996). Written life stories may be as authentic as those told in face-to-face encounters, and are also as subject to social conventions about story structures (Murray 1997). Arguably, written accounts are less open to influence by the researcher's agenda and relationship to the respondent. For the researcher, they have the advantage of permitting access to a wider range of individual experience within a given time frame. However, the study of written accounts is limited in that they cannot be probed. It is quite possible that respondents experienced a wider range of therapeutic benefits than they selected for discussion. Hence the number of respondents including a given theme in their stories (such as distraction from pain) needs to be treated as a minimum estimate. The sample was 'volunteer' and self-selected through having an interest in craftwork. Noone wrote about the limitations of this approach to recovering selfhood. Nevertheless, the respondents' accounts provided insights into under-researched aspects of experience and helped to establish key ways in which creative leisure activity may enhance quality of life.

When evaluating qualitative methodology, attention also needs to be given to the role of the researcher in the research process (Mason 1996). The author has a personal interest in needlecraft and the impact of creative activity on well-being which perhaps increases sensitivity to meanings within the accounts submitted. However, the author acknowledges that by disclosing that she lectured to occupational therapy students, the respondents may have partially shaped their accounts to 'legitimise' her interests

and role.

Regarding recommended further work, interviews would allow more detailed enquiry into these women's life histories, particularly to explore their initial motivation to try craft activity following illness/diagnosis, as this could be of value to occupational therapists conceptualising treatment options.

Many studies have examined how individuals with a common illness (such as multiple sclerosis) cope. This study has instead taken a shared coping activity and examined its role in the life of individuals with a variety of chronic conditions. Although comprising many adaptable and varied elements, some common benefits emerge, particularly restoring self-esteem and relief from negative emotions. The activity seems potent on several psychological levels.

Many of the respondents described discovering (or re-discovering) needlework in their adult years, which suggests that adults can be open to innovations in their leisure pursuits. This may provide occupational therapists with further confidence that craft-work introduced to clients may have long-term therapeutic value. These accounts also indicate that the potential of leisure counselling to help those newly diagnosed with a chronic illness should be further investigated.

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