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Symbolic aspects of coping with chronic illness through textile arts¹.

Frances Reynolds, Ph.D., Dip. Psych. Couns.^{*,**}

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^{*} Frances Reynolds is Senior Lecturer in Psychology, Dept of Health & Social Care, Brunel University, West London, TW7 5DU, UK.

^{**}E mail: Frances.reynolds@brunel.ac.uk

The relevance of art for people living with chronic physical illness is gradually being recognized (Kaye & Blee, 1997; Malchiodi, 1999). Chronic physical illness poses more than physical and functional problems. The person is also likely to face a range of negative emotions, including anxiety, anger and depression. Illness threatens taken-for-granted assumptions about the self and the future. The person's core identity and self-esteem may be challenged, particularly where the illness leads to loss of roles, abandonment of valued activities and changes in social relationships (Charmaz, 1992; 1999).

What is the therapeutic value of art for people coping with long-term physical health problems? It clearly provides a vehicle for self expression (Baer, 1985; Malchiodi, 1999). Some people find it difficult verbally to express their feelings about the losses involved in chronic illness. They may lack a confidante, or may find that words do not really express the turmoil and distress involved. They may feel safer containing these 'unspeakable' feelings within artwork and expressing them symbolically or 'obliquely' (Schaverian, 1989). Art has been represented as strengthening the sense of self, offering a testament to its durability and continuity. Aldridge (1996) argues that creative activities not only facilitate self-expression, but also help to integrate different aspects of the self, enhancing a sense of coherence. This can be a much needed process following sudden changes in health, when the person attempts to integrate the familiar functioning and unfamiliar impaired aspects of self into a new acceptable self-image (Ellis-Hill et al, 2000). Warren (1993) argues that "each creative mark reaffirms the self. It says "I am here", "I have something to express" (p.4). Immersion in artwork may also enhance the experience of control. This may be highly therapeutic for a person whose body is experienced as out of control by virtue of the disease or impairment process (Szepanski, 1988).

Although some art therapists have researched and written about the outcomes of art therapy in medical settings, the personal meanings of art for people with chronic health problems have not been extensively explored. Many years ago, Hill (1951) analyzed how his artwork had enabled him to cope with tuberculosis. Fisher & Specht (1999) interviewed elderly people who were presenting work at an art exhibition about the role of art in their lives. Interviewees described their artistic endeavors as having many positive outcomes, including continued personal growth, increased autonomy, and extended social networks. An interview study of women aged 70 years and older, found that they often regarded arts and crafts as contributing to their health through maintaining cognitive functioning, enabling the reciprocation of care through hand-made gifts, and providing a productive structure to the day (Day, 1991).

Reynolds (1997) reported a qualitative study of needlework practitioners spanning a wide age range, who were all coping with chronic illness or disability. In written accounts, they reflected on the role of textile arts in their lives. Creative activity was often represented as a potent means of preserving or re-gaining a satisfactory sense of self. Artwork helped participants to define an 'able' identity, regardless of their mobility limitations, pain or fatigue. This identity-enhancing function was particularly valued by those whose illness had enforced a dependent role within the family or early retirement from work. Involvement in textile arts also improved quality of life through leading to social contacts outside of the family, based on mutual interests rather than 'caring' relationships. A large number of the participants regarded creative pursuits as escape, distraction or relaxation, all of which could help combat feelings of depression or anxiety about the illness. Some of those who were facing a terminal illness portrayed

their creative work as a legacy or reminder to others. The findings demonstrated that individuals could reflect in detail upon the meanings of creative activities and could offer from a personal perspective, a careful analysis of their therapeutic elements.

A further study of the role of needlecrafts in the lives of women experiencing chronic or episodic depression discovered some similar themes (Reynolds, 2000). Contrary to expectation, in both sets of narratives many respondents described discovering (or re-discovering) needlecrafts in their adult years, commonly *following* illness. Relatively few had shown more than a casual interest in the creative arts during childhood or had defined themselves as creative or artistic in their younger lives. Nevertheless, once discovered in adulthood, artwork had become central to maintaining an 'able' identity, allowing practitioners to feel that they were resisting mastery by their illness and positively promoting their own health.

Taken together, these studies suggest that artwork contributes to well-being in a number of ways. Many outcomes such as filling the day productively, distracting the mind away from illness and providing a sense of accomplishment require little interpretation. They clearly improve the quality of life in chronic illness. However, well-being may also influence, and be influenced by, the symbolic meanings of artwork, and this possibility has been little explored in previous research. It is uncertain to what extent 'lay' people engaged in artwork regard their choice of color, image and creative process to have additional, hidden, possibly abstract dimensions. Art therapists have developed a rich array of psychodynamic theory to interpret therapy processes (e.g. Schaverian, 1991, Read Johnson, 1998). This study specifically examines whether lay arts practitioners understand their artwork as having symbolic meaning, and if so, whether these meanings have a therapeutic part to play in coping with illness.

Methodology:

Qualitative interviews were carried out with 30 women, and a further five submitted extensive written answers to the interview questions. They ranged in age from 29 to 75 years, with most in their 50's and 60's. All described themselves as having long-term health problems, and regarded their involvement in textile arts as helpful to their coping with illness. Participants practiced a wide range of textile arts included embroidery, quilting, tapestry, applique, and multi-media. They were recruited through a range of community resources, including requests in needlecrafts magazines, and embroidery classes. The participants were coping with long-term illnesses such as multiple sclerosis, chronic fatigue syndrome, post-polio syndrome, arthritis and cancer, or had recently finished treatment for cancer. Almost all had retired from work on health grounds. The majority were married. Some had adult children living away from home. Only three had young children or teenagers living at home. The majority had a professional background, including teaching, social work, physical therapy, nursing, graphic design. The participants were given full information about the study and a copy of the interview guide in order that they could give informed consent. The women were assured of anonymity, and the secure keeping of tapes and transcripts. In most cases, the 1 to 2-hour in-depth, semi-structured interviews were carried out in participants' homes. The participants were not directly asked about symbolism in their work, because a wide range of therapeutic outcomes were of interest, and also in order to avoid influencing their accounts. The interview questions were formulated to guide a focused conversation about the role of textile arts in coping with long-term illness. The questions included:

1. What kinds of textile arts and needlecrafts give you most satisfaction? Can you describe what is satisfying about creative activity?
2. What influences your textile designs and artwork?
3. In what ways has your creative activity helped you to live with your long-term

health problems?

The tapes were transcribed verbatim. Analysis procedures for both interview transcripts and written accounts were based on the constant comparative approach suggested by Strauss and Corbin (1990). Major themes in participants' accounts were identified and compared. For this paper, the analysis focused on symbolic meanings – that is, extracts from the accounts in which participants interpreted their creative process or artwork as having a deeper or more abstract meaning than that which was superficially obvious. A second coder checked the validity of the themes identified in a sample of the transcripts.

Findings: Symbolic meanings in textile arts

Whilst artistic occupations were generally experienced as pleasurable on a number of levels, over half of the women in the sample (18/35) described their textile artwork as having symbolic meaning. That is, they interpreted their choice of color, image and style of work as expressing at times hidden or oblique values, motives or meanings. Seven major themes were identified, in which the artwork (process and product) symbolized the following:

1. Suffering (the art was not 'merely' decorative but symbolized some aspect of the illness experience)
2. Changing feelings about the experience of illness (including renewed hope and optimism)
3. Transformation of an 'empty present' into a meaningful fulfilled life
4. Mastery over the effects of illness /treatment (transformation from being dominated by illness or treatment to controlling its impact on life)
5. Religious/ spiritual values

6. Transcendence (moving beyond preoccupation with self to awareness of global and historical connectedness)
7. A new positive self (transformation from pre-illness self to a more reflective, creative, stronger person)

In line with the recommendations of Strauss and Corbin (1990) to locate a 'central' or core category, the seven categories above seemed to relate to the core category *Transforming the illness experience*. These themes will be discussed further below, and illustrated by quotes. All names are pseudonyms.

Artwork as a symbolic marker of suffering (art can be understood both as a 'superficial' decoration and as a symbolic marker of illness, pain and suffering)

Many of the women regarded some of their textile artwork as representing, in at least a veiled way, their pain and suffering. All of those describing the meaning of their work in these terms appeared to have moved through the most intense phase of grief about their lost health and functioning. In retrospective review, they saw at least a faint impression of their journey through grief located within the artwork that had been accomplished during that time.

Jane : (52 years old, with rheumatoid arthritis, survivor of cancer, former teacher);

Cross-stitch, simple in your head, simple for your hands, and it was something I could manage and was sure to get right... But it also stands for something in my life now, so I keep it somewhere now and I think 'that's a stage in my life that I went through'.

Lydia: (32, chronic fatigue syndrome, former health professional):

You get very attached, I haven't sold any work yet, and people keep saying why not, but they become part of you, and it's very hard, and I think more so, because it's helping me cope with my illness, it marks certain points, and I think yes I'd like to let them go but they're still too important. Only now I'm getting to the point where I can think yes I'm ready to let them go now, and it would be good to let them go (pause) But you do get really involved in them.

Geraldine: (52, former business woman, progressive neurological disorder) :

I had tentatively begun a few small projects of my own as presents but felt an undercurrent of desire to do something more personal and meaningful. 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 – it didn't quite work but it was important to try. People's reaction to this series is that it is difficult and uncomfortable and captures the harsh reality of pain and trauma during transition. I like that because traditionally needlework has been seen as 'pretty' 'useless' 'feminine' and other derogatory terms.

Transformation of feelings during the course of illness/ treatment

Some participants, in reviewing their array of textile artwork, saw that change had occurred in images, themes, colors, preferred media and styles during the course of

their illness. Earlier textile artwork often expressed deep, perhaps denied, feelings about illness, in particular those that surfaced following on from diagnosis or early treatment. In some cases, the images were so disturbing that friends or family had commented on their likely significance. Only then had the meanings expressed within the artwork become recognized by the woman herself. Some women observed that their choices of image and color had changed over time, associating this with an improvement in functioning, or with the process of coming to terms with the illness. These changes rarely demonstrated conscious choice about subject matter, but became interpretable in the later phases of the illness trajectory.

Joyce (56, treated for breast cancer and other health problems):

And at the time (of the breast cancer) I was still drawing and when I look back now I did the most gruesome scary drawings. They were all sort of, they were goblins and things like that, they were all sort of drowning, it was sort of gruesome, and I thought they were fine at the time. But when I look back now I think 'crikey', and my family say 'weren't they awful?'. And then when I started getting better, things perked up and I was doing cheery mermaids (laughs) but it was really worrying at the time.

Interviewer: And had you drawn like that before?

Joyce: Never, they were just really scary, obviously that was how I was feeling inside I presume, sort of drowning.

Lydia:

Autumn colors, there was always a bit of orange in everything I did, and I used to worry about that, I've stopped that because I think that's what I'm comfortable with. Every now and again I have a break and I think, no, I don't

like that color any more, but it's where I feel safest. Autumn is my favourite time of year, and then again Spring with the yellows but then again it's yellow and orange, it's like a new beginning.... I still don't think I can draw, but I can get an image down that other people can recognize and that gets over what I feel about something. And you can put you into it ... And I have noticed that I do like bright colors, I never used to, I used to like pastels but I was being drawn to bright colors, and I went on a dyeing course for a week with an American girl who loved color and I lost my fear of color. I'd been trying to use it but I wasn't quite brave enough (pause) and now thinking back I like bright sunny days and being surrounded by light and bright things. Pastel colors are just too pale, and insignificant, and don't lift the spirits somehow.

Geraldine:

Sometimes I'm driven by something inside that I have to explore. Conflict, my own and as a human catastrophe is what I'm researching at the moment. Nothing frightens me as a subject.....Ideas for future work stretch forever. That is what keeps me alive quite simply, after my children of course. The ideas keep inspiring me. I just crave more energy to give them life and make the image more powerful or memorable. Probably I'll go on to do more lyrical or humorous pieces.

Miriam (early 60's, breast cancer, former social worker and counsellor):

It calms me, I mean after the {mastectomy} operation in the summer... I didn't recover terribly well, but when I got home, I made a collage, and that was really terribly therapeutic. I'd get out of bed, you know, feeling really ghastly and sort of stick things on. ... It was very important for ... getting it out of me.

For some women, their textile artwork also helped expression of feelings about other distressing aspects of their lives as well as personal illness:

Pippa (50's, Cushing's syndrome, chronic fatigue):

As far as use of color is concerned that depends, I think, very much on the frame of mind you're in at the time. And you can actually see the change.... I can see it particularly in some pieces of work I did, I didn't see it at the time, I didn't realise it at the time but that was some of the things that I did for Part 2 City & Guilds that went on display. And what interested me about this, I made them shortly after a good friend of mine had died who was the same age as me and not particularly old at the time, and as I say you could see it in the work and in one piece in particular. And people looking at it saw it as well because ...they come round and discuss it and they found this piece quite - not exactly depressing but disturbing in a way, so I thought that was quite interesting...

Interviewer: Did you get any sense that you were conveying something about your friend?

Pippa: No, I didn't. I think you don't always see what's going into the work until afterwards, actually. When you've got a bit of distance from it.

Transformation of the 'empty present'

Chronic, particularly life threatening, illness casts some people psychologically and socially adrift in an 'empty present' (Crossley, 2000). The past, with its assumptions

about fairness and certainty, seems split off and difficult or painful to remember. The future seems unattainable. Without a sense of past or future, choices in the present lack purpose and significance. One therapeutic benefit of psychologically engrossing artwork is that it both enhances quality of life in the present and motivates the person to believe in the future (at least the short-term future). Many participants considered that their artwork took them out of a painful, dreary present and provided a rich sense of future possibilities.

Geraldine:

The isolation goes as I enter another world where the rules are mine and I can get lost as I journey with the work.

Lydia:

It's escapism also, I think, creating, because you can create a picture or a setting which is where you want to be, and when you've finished that it's like moving on to another chapter of your life.

Mastery over illness /treatment

Powerlessness is a common experience for chronically ill people (Charmaz, 1999, Hildebrand, 1999). If the illness is uncontrollable, the symptoms intrusive and the treatment options limited, the person may regard the illness as having a 'master status' in his or her life. For some women, their involvement in textile arts restored feelings of power and mastery over the impact that the illness was having on their lives.

Joyce:

I thought I just can't sit down and feel sick with this chemotherapy, and so I just used to shut myself in my room and do textiles just about all day obsessively. I was working for an exhibition and at the same time making cards and I was a bit manic about it, I thought I've got to do all these things, and it took my mind off the chemotherapy, and so it was a great help to me. Sitting down doing nothing and taking what came at me didn't do for me at all. I had to decide, I had to be in control, it's worked so far.

Lydia:

When you look at work that you've done, you can think that was quite a bleak piece. ... There's a black and orange piece that I've done..., it's almost like all this blackness with these colors bursting out, it looks as though it's escaping from being trapped. I think I felt like that when I first got the illness, completely trapped by this disease. I didn't really understand it, nobody did, no-one could completely explain it to you, there was no cure, the only drug that I could take didn't work for me, and then you think I'm never going to get better. And although now I know I'm never going to get rid of it, I'm not letting it rule me, and I'm thinking 'yes I can do what I want to do', well - most of it, but I have to learn to control it, and say 'no, I am going to do that whether you like it or not'! (Laughs) It was becoming a bit of a monster trapping me in the house, trapping me into doing what I didn't want to do... Yes, you can see how my work's changed, as I've gone through it a few bad times, and I've gone through good times.

Catherine: (late 40's, part-time teacher, chronic pain, hip/back problems):

As pain levels have increased I have gone for bigger challenges {projects} - something to be in control of, I suppose, hence the City and Guild course.

Expression of religious/ spiritual values

Some women regarded both the artistic process and the artwork product as suffused with religious and spiritual values. Art was not seen as simply pleasurable or decorative, but reflected a process of thoughtful appraisal and clarification of core values and philosophy.

Sue: (48, multiple sclerosis, wheelchair user, former social care worker):

Yes I'm very spiritual, I'm a great believer in God, and I find when I've been working sometimes and I'm really tired and my eyes don't work very well, my hands... I get this great sense of warmth, very spiritual, and very warm happy feelings, completely flow through me. I can't describe it really, basically.

Emily(early 40's, progressive neurological disease, graphic artist, former translator):

I really want to embroider partly because I can see it gives other people pleasure and it gives me pleasure and hopefully it gives God pleasure, I hope so. A God who can make flowers must like it if you can take pleasure in things..... The first thing I embroidered was an angel. They say to work is to pray and I think there's something in that actually.

Shelley (69, chronic asthma, retired administrator):

Primitive man used pattern to express wonder, to identify property, to ward off evil spirits, and to welcome and glorify benign ones. I believe I am fortunate to be able to recognise this inherent spirituality and to be able to tap into it. Combining color with pattern can produce work which is satisfying, beautiful, challenging, magical and, at times, can be a prayer.

Transcendence (global and historical connectedness)

The word 'transcendence' comes from a Latin root meaning 'to climb over, to go beyond'. It is often used in therapeutic writing to refer to the human capacity to move beyond one's usual material or psychological confines and limits (e.g., Malchiodi, 1999). Some of the women taking part in this study described feelings of transcendence during needlecrafts, in that they felt connected to the larger world, to the spiritual world, to nature or to human history. They no longer felt isolated, confined by illness or self-absorbed.

Bridget: (late 50's, housebound with severe rheumatoid arthritis and osteoporosis):

I also feel, very often feel that I'm in direct link with all the women that have gone before me, I get that strange feeling sometimes, I look down at me doing my work and it could be anybody's hands down there, doing something else, it's a strange feeling, it's like a continuity, a link with the past. I don't know, I can't explain it very well, I feel that it's my little bit of immortality, it'll last a bit longer than me. I get a thrill to know that pieces of my work are all over the world, no great masterpieces, don't get me wrong. It was always one of my great loves to travel, I haven't done too much of that, and now I will probably

do even less, but my stuff is going all over the place. There's a bit of me in Montana, in Switzerland, Spain, Australia. That's important. I like that.

Cheryl (50's, earlier treatment for breast cancer, currently recovering from peritonitis):

What I always feel, is that my work is in the church and that lighting a candle and leaving a prayer behind, you know, it's leaving a bit of me behind. It's in the church, and it's being seen by people and appreciated.

Dorothy (70, osteoarthritis, chronic pain):

I have done pieces of work for a lot of people. You wouldn't open a museum with them, no, but they have taken me into other people's lives, you see, and I like to think of myself on their walls.

Strengthened identity

Serious illness and impairment threaten the sense of self, and raise questions in some people's minds such as 'Who am I?' The women in this study were generally - by virtue of the process of recruitment into the study – coping with illness in positive ways. Not surprisingly therefore, many saw their textile artwork as forming a record of their personal journey, and providing evidence of a new, self-actualising self.

Lydia:

I've always felt I wanted to do something and it's starting to come out, I would quite like to do something that says something (pause) about me, but without being too controversial or upsetting, but just about the illness really.

Something about being trapped and then bursting out, it's starting to come into my mind, but that's as I'm getting more into thinking I'm free now to do what I want to do.... I feel like a different person, ... I had a real flair for it {therapy career}. And it was knocked quite hard when I had to give up. But now my confidence is back....and it's the skills that have finally emerged, it's a different side of me. The old one is gone. It's still there, but there is a new side.

Holly (51, non-Hodgkins lymphoma, bone marrow transplant, osteoporosis):

It's very important to me now, embroidery, to my fulfilment, to everything that I do, yes, so it has altered me, has changed me. My sister says I've actually changed as a person and I've become (pause) I know my mind more.

Shirley (late 50's, rheumatoid arthritis, hip replacement, chronic pain, ex-teacher):

I try to think I'm me not I'm a disability first. I do find it very difficult to talk about it simply because to me talking about it is negative, and I try to build on the positive more. That is another thing which I think the textiles has brought out because I am actually producing amazing stuff which is something I thought I would never be able to do..... it's a positive thing that's coming out. I do think the important thing is to remember life's too short. That's what needlework has done for me. Perhaps there's always been a positiveness there and it's given me something to channel that into.

These various themes all appear to illustrate the central issue – that artwork, through the oblique expression of core concerns and values, was understood to transform the

experience of chronic illness. Over time, immersion in artwork had helped the women find a way of locating and communicating a renewed sense of self, a sense of mastery over the stress of illness, and clarified values and beliefs. Some of the women regarded these positive outcomes as influencing their physical health itself. One participant summarized this process as follows:

Jane:

It {embroidery} has been a mix of inspiration and somewhere to go, all the lifestyle coathangers if you like, to hang your life on to (pause) and for me that was actually quite important. And I think it is ill-health ... that makes you look at creative things in a different light, they are absolutely essential. I think without it, it would have been harder to get back to the level of health that I've got to.

Discussion:

This study explored the subjective perspectives of a group of women who all regarded their textile artwork as helpful on many levels for living with long-term health problems. For many, art had come to occupy a central role in coping with illness even when it had been taken up in later years, in the aftermath of their diagnosis. Some women had clearly developed a high level of expertise in embroidery and other techniques, but an enhanced quality of life by no means depended on this. Textile art filled time productively, offered mental stimulation, provided social contacts and enhanced quality of life in many other ways. This paper has focused specifically on the symbolic aspects of artwork, and has shown that a substantial minority of the

women who were interviewed believed that their artwork enabled expression of deeper motives and meanings.

To some extent, the findings are supported by other studies into people's strategies for coping with chronic illness. Strategies such as positive reappraisal of one's self, functioning and life, a sense of contribution to others, and a strengthening of religious or spiritual values all seem to enhance well-being (Day, 1991; Do Rozario, 1997). It appears from this study that, for some women, such shifts in attitudes, priorities and values are expressed meaningfully through artistic pursuits.

The core category refers to the transformation of the illness experience via artwork. This mirrors findings in some other studies. For example, Malchiodi (1999) described art as transformational, from helping people to "...rise above illness, overcome pain, and get past fears and anxieties associated with the disease" (p.19). Crossley (2000) discussed how some people with long-term health problems describe their experience in terms that affirm the value of their lives and capacity for personal growth. This study suggests that art can help people to re-author their life story and achieve new personally acceptable meanings.

In line with theoretical perspectives that suggest personal issues are largely expressed obliquely through art, a consistent finding was that the women believed that the deeper meanings of their work could only be interpreted in retrospect. These less conscious meanings were rarely available at the time of the artwork. Interestingly, these lay perspectives confirm the therapeutic value of retrospectively reviewing artwork, as advocated by some art therapists (e.g. Schaverian, 1993).

It has been suggested that visual art is a powerful therapeutic medium because, among all the arts disciplines, it provides a tangible, long-lasting record of the person's own creative processes (Lippin, 1999, Warren, 1993). Several women appeared to share this view, commenting on how their 'back-catalogue' of textile arts – exhibited on walls, in portfolios, in household objects such as cushions, and among gifts to friends - provided a record of their journey through illness. This provided many with evidence for personal growth, resourcefulness and self-esteem. The therapeutic effects of sending one's artwork out into the world in the form of gifts to others has been discussed in previous work (McNiff, 1992).

In conclusion, the study has shown that for some women textile art offers a potent vehicle for symbolic expression and achievement of a renewed, robust sense of self. It is intriguing that a substantial minority of women - without psychological or art therapy backgrounds - regarded their creative artwork in these terms. Even so, other important, less symbolic outcomes of artwork should not be overlooked - such as structuring time, distraction from worry, and making a valued contribution to others. There is a need to expand public awareness of the value of involvement in creative arts for people living with chronic illness, who are facing loss of function and difficulties such as early retirement. Research is also needed into the objective as well as subjective benefits of creative arts involvement on physical health and well-being.

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