

The meanings of arts participation for people living with mental health problems and long-term illness

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Outline

- Creativity, art as therapy, art as serious leisure
- Common challenges for adults living with long-term illness/ mental health problems
- Summary of research studies to date
- Exploring some of the findings: leisure-based art-making as a resource for living with long-term health problems
- Some implications

Machine embroidery by Jenny, affected by severe osteoarthritis for 17 years.



"There aren't many people in the country who do what I do."

What is creativity?

- "Creativity is the process of bringing something new into being. Creativity requires passion and commitment. It brings to our awareness what was previously hidden and points to new life. The experience is one of heightened consciousness..." (Rollo May, 1975, p. 39)



A painting created by a participant coping with chronic back pain; wheelchair user

Living with ill-health in adulthood

- **Physical and psychological barriers to participation** (e.g. chronic pain, limited mobility, loss of dexterity, fatigue, intrusive thoughts)

"What's happened yesterday and what's going to happen tomorrow, what's going to happen this evening, all this negativity that you are full of..." (Participant with enduring mental health problems, community arts project)

"I've always enjoyed using my hands. I used to love doing the gardening, ...decorating in the house, and my needlework. I used to make lampshades ... clothes for the children, for myself. I always liked that creative aspect, but since the RA [rheumatoid arthritis], so many of those things I just, I can't do. And I suppose, in a way, it's like feeling starved of something, there's creative took ea affected has taki in rece



Living with ill-health in adulthood

- **Threats to personal and social identity** (e.g. loss/ change of valued roles, activities, and relationships; changes in appearance and body image; social stigma)
- **Loss/lack of confidence/ self-worth**
- **Feelings of 'difference', rejection and isolation**
- **Fears for the future** (e.g. anxiety about prognosis, awareness of mortality, concerns for family, fears of social isolation, occupational voids)

"I've known people hide in Marks & Spencers ... because they don't know what to say to you and you get comments. Someone came up to me and said, 'Oh, if I had to have a mastectomy, I'd kill myself.' Very helpful!" Jessica, recovering from breast cancer

"I suppose my whole approach to the whole problem with my health is put it on one side and do the best I can with it. Otherwise, it can consume you. And it will". Marie; living with life-limiting cancer

Art as therapy and art as 'serious leisure'

- **Art therapy** is highly self-expressive, usually spontaneous (rather than carefully planned and executed), supported by the emotional containment of a therapist
- **'Serious leisure'** occupations offer opportunities for deep fulfilment through gaining relevant skills and (in some cases) participating with like-minded others (Stebbins 1992)
 - Positive sources of identity
 - Goals, achievement, affirmation
 - Relationships based on mutual interests



Marie, mid-50s, terminal cancer; perceived symbolic meanings in her fragile textile art (5/12 participants with cancer perceived symbolism in **one or two** items of their artwork)

Research methods

- **Nine qualitative studies** (to date) to explore the meanings of leisure-based art-making for people living with:
 - Long-term health problems (any) (N=60)
 - Cancer (N=12)
 - Chronic fatigue syndrome/ME/fibromyalgia (N=13)
 - Arthritis (N=12)
 - Stroke (8)
 - Mental health problems (8) (also 35 submitted written accounts about coping with depression through art-making)



Research methods

- **How have participants been recruited?** Via arts and crafts magazines, local support groups, and a museum arts project (“Ways of Seeing”)
- **Semi-structured interviews** about:
 - the origins of participants’ interests in art-making (and craft-making) as a leisure activity
 - the context in which they create art
 - the satisfactions (and frustrations/adaptations) which they encounter when art-making
 - The contribution of art-making to living with health problems and promoting well-being
- **Additional exploration of the meanings of 3-4 selected pieces of artwork**



“It’s just been a gradual progression ...not be afraid to do something different, ... to do a colour that you can’t actually see...so I suppose I am actually expressing something more of myself ... I’m expressing something that is coming from inside” Alison

Interpretative phenomenological analysis

- Descriptive and interpretative phases
- Values ‘insider’ accounts
- Explores both convergent and divergent (idiographic) themes
- Seeks a rich, nuanced understanding of participants’ lifeworlds
- Accepts the inevitable **presence** of the researcher in the research process
- See Smith et al (2009)



“I try to pretend that I’m not ill. My art does that” (Terry, 65, severe pain for >20 years following spinal injury, arthritis).

Meanings of art-making: Recurring themes:

Arts participation fulfils **multi-faceted needs** (provides a ‘lifestyle coathanger’) increasing well-being, through:

- **Escape from discomfort/ intrusive thoughts**
- **Confirming positive identity** (visible achievement, self-expression of personal interests, respect from others)
- **Connection with the ‘healthy’ outside world (beyond the confines of body and home)**
- **Fostering reciprocal social relationships (based on mutual interests rather than ill-health or care)**
- **Providing hope, future goals, confidence to try new activities (‘ripple out effects’)**

“An escape from the pain”: the deep absorption of art-making

“It’s definitely an escape from the pain. When I can paint, I don’t think about the problems with my heart, with my hips, you know. Before Christmas, I couldn’t walk for a few weeks, every time I was walking I couldn’t sit down without screaming pain, and when I was painting, I thought what are you crying about? Look what you’ve done today. I was excited and it’s a real escape. Wonderful” (Sophia, 62, arthritis, heart & eye problems)



Sophia’s ‘Pot of Quimper’: “When I make [a] still life, they are very much how I feel when I look at them, I feel warm and comfortable”.

Escape from discomfort: channelling the pain experience into art-making

- “It [colour] depends on how much pain I’m in. The more pain, I seem to paint brighter pictures ... I love oranges, reds and ochre colours and I think they are quite therapeutic to me. I seem to paint more in those colours if I get up in the night to paint, and I use more ink, and I use more contrast in the night.”
- (Lorraine, has lived with osteoarthritis for 10 years; also has severe osteoporosis).



“Curly carrots”: exhibition piece by Lorraine

Art restores a positive identity: via new skills, mutual respect

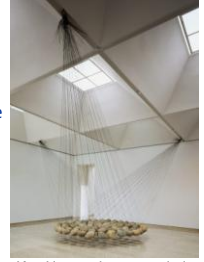
- “I thought it [sculpture] would be a wonderful new experience to get involved in it ...it's a Gaudier-Brzeska, and it's mother and child and ... the mother is sort of holding the child ...it's the most beautiful piece of work I've ever seen in my life and I've actually touched it. It is made of bronze and is so wonderfully tactile. A lady let me touch it... and so I decided to work on that [making his own artistic response]” (Paul, had lived with severe mental health problems for many years: ‘Ways of Seeing’ arts project)



One of Gaudier-Brzeska's sculptures
<https://www.pinterest.com/heidis-eetzen/sculpture-mother-child/>

Art –making and personal identity

- Following a stroke, David immediately developed a passion for making structural art pieces (influenced by an artist Ken Unsworth), instead of his former style of abstract painting
- “So like navigation, the triangulation side of it has been in my mind, like the idea of satellites pointing positions, I don't know where it came from”
- His **new** creative interests seemed to reinforce his personal identity (as a former officer in the merchant navy, and lecturer in navigation), which was threatened by the disabilities following on from stroke
- David also felt this occupation assisted in his physical rehabilitation/ recovery.



Ken Unsworth: suspended stones sculpture
http://www.artgallery.nsw.gov.au/media/collection_images/3/356_1988_penny%20view02%23S.jpg
 – inspired David's artwork

Art confirms a positive identity: through personal development and unique products

- “There aren't many people in the country who do what I do. Which makes it fairly specialised. I have exhibitions here [in my studio]... And people come and say, “Oh, I've never seen anything like this before”. And I say, “Well, you probably won't!” (Jenny)



(Jenny, 65, osteoarthritis for 17 years; turned to machine embroidery when arthritis prevented hand- sewing).

Connecting with the world outside home (and outside illness)

“We found a little house with a tiny garden, and it has got a bit of a sea-view, and I can walk down, walk the street past two houses, I can go down 5 steps, there's a little bit off the road to go down, not much, and I cross the road and there is the sea. And since we have moved there I have noted that September, October, the sunsets there are breathless, you cannot believe what you see...I try to express beauty, sunshine [pause] and [pause] I cannot possibly put my illness in it” (Sophia, RA for 25 years; also eye and heart problems)



Sophia's sea-side view

“It was like...stepping into their world and being welcomed in” (Tina) – WoS project

Enjoying reciprocal social relationships (based on mutual interests)

- “I think one of the biggest factors in that is that your disability or your ill health, or whatever, isn't the most important thing in your life. I don't think about it when I'm out and about at all. I keep that for family. I think it's boring listening to someone else's health problems and I think by having the art and the craft and everything, it gives you that interest that you can talk about. I mean what do people talk about? They talk about their work, their family, their hobbies, their health. In that order.” (Jessica, 47, recurrent breast cancer)



Enjoying reciprocal social relationships (based on mutual interests)

- “It's good to have something to talk about...that... isn't necessarily mental health and how you're feeling and what's going on... It's more what you are **doing**” (Harriet)
- “But with the Ingram collection... it's not about mental health, it's about art” (Tina)



A more positive relationship with the future: hope, goals, confidence

- Art-making helped some to create a future that seemed less controlled and curtailed by illness
- For some, artistic projects almost 'guaranteed' a future, or gave strength to continue when symptoms were very distressing
- Most of the participants living with **cancer** expressed this theme—placing more emphasis than those living with other illnesses



"The enchanted path"

"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 projects on the go at once and never ever get them all finished" (Eleanor, cancer, depression, mid-40s)

Discussion of findings

- For these participants, art-making offered **multi-faceted** experiences that contributed to well-being:
- **Not** through denial
- **Not** through simple distraction or diversion
- Sometimes – but not always – through 'simple' enjoyment

"I managed to get myself absorbed into the work that I was doing particularly in the... drawing class that we did. And I found myself sliding myself into what I used to call... well... we call it 'the zone' in racing... I was churning out work like there was no tomorrow because I was, I was in that creative element ... totally oblivious to everything around me, I would just create." (Caroline, living with MH problems after brain injury; WoS project)

Limitations?

- Most participants were diagnosed some years previously – few were living with a recent 'biographical disruption'
- Most participants engaged in art as 'serious leisure' (e.g. had moderate to advanced artistic skills)
- Samples have been skewed towards older women – who may have felt entitled to invest themselves in leisure activities rather than paid work AND many had previous experience of craft/ dressmaking skills that could be applied to art
- Participants' recourse to art-making **and** their styles of coping with ill-health may have been shaped by other personality and social resources

Endings may be problematic in time-limited arts projects (interventions)

- "And I do worry now about the more I get... the more I dig into this... I worry about the end. I'm frightened about that (pause) but it will come to an end I know, and I'll have to face up to it" (Paul, enduring mental health problems; had not been able to use the arts project as a stepping stone to other activities)



Discussion: Transformational coping through occupation

- A form of **thriving amidst stress, trauma and grief** (Calhoun and Tedeschi, 1998; Maddi and Hightower, 1999) – previous research emphasises cognitive shifts rather than creative participation
- Art-making helped to address **identity threat and the need for identity preservation**
- The 'creative adventures' of art-making help provide an antidote to the illness experience (positive control **and enjoyable** unknowns)
- Deep absorption in creative activity and 'flow' helped some to withdraw attention from **pain/ intrusive thoughts**
- Accounts also revealed a need to experience **meaningful, respectful transactions with the 'healthy' world outside the confines of the body and home**

"It's incredibly challenging... when you get an idea for a new project, it's not knowing how to do it at all ... how to get there is just a complete unknown... it's a real spirit, a voyage of discovery, really. So you've kind of got your goal in mind, but not a really clear idea of the path it's going to take" (Marie, mid-50s, former academic, life-limiting illness).

Earlier professional advice could be helpful

- Participant with CFS/ME:

"The door could be opened to people earlier . . . It's very dramatic, but I feel that had I had the options or just someone to talk to me and say, 'Well, look, stop thinking about what you've achieved in the past, look at your skills and see what you can achieve now... [or] look at achieving other skills'. It's just a sheer feeling of optimism, rather than pessimism". (Jackie, 62, ME for 20 years leading to early retirement and then prolonged feelings that she had let her family down)



Jackie knits toys as gifts and for charity; buys cheap patterns from eBay: "I take each knitting project as the next thing forward"

Example pattern from:
<http://www.ebay.co.uk/itm/HAND-KNITTING-PATTERN-FOX-2-FOX-2-ANUS-SCHUBBEL-SCHUTZ-FOX-2-APPROX-14-CM-HIGH-071921500184?hash=item1c5d21ccc5a729ba4c09a959115e12>

Questions?



References

- Calhoun, LG & Tedeschi, RG. (1998) Beyond recovery from trauma: Implications for clinical practice and research. *Journal of Social Issues*, 54, 357.
- Maddi, S. & Hightower, M. (1999). Hardiness and optimism as expressed in coping patterns. *Consulting Psychology Journal: Practice and Research*, 51, 95–105.
- May, Rollo (1975). *The courage to create*. New York: W. W. Norton & Company
- Smith, JA, Flowers, P, & Larkin, M (2009). *Interpretative phenomenological analysis: Theory, method and research*. Los Angeles: Sage.
- Stebbins, RA (1992). *Amateurs, professionals and serious leisure*. Montreal: McGill University Press.

Further reading

- A list of papers reporting on the various aspects of these art-making projects are presented separately.