

Hunt, L., Nikopoulou-Smyrni, P., & Reynolds, F. (2014). "It gave me something big in my life to wonder and think about which took over the space... and not MS": managing well-being in multiple sclerosis through art-making. *Disability & Rehabilitation*, 36(14), 1139-1147.

Abstract:

Background and Aim: Individuals living with Multiple Sclerosis (MS) often face progressive loss of function, uncertainty, and disruption to self-image and valued roles. Previous studies show that creative self-expression is valued by some people living with long-term illness, yet its meaning for people living with MS is unclear. This research study explored the meanings of leisure-based visual art-making for people living with MS.

Method: This qualitative study followed guidelines for Interpretative Phenomenological Analysis (IPA). Single semi-structured interviews were conducted with five adults (2 males; 3 females; 40-65 years), recruited from MS Ireland.

Findings: Participants valued art-making for contributing to a more satisfying way of life; for filling occupational voids and using time well. Deep immersion offered respite from worry about illness. Creative classes offered social camaraderie and opportunities for learning and development. Art-making processes and products were highly affirmative, increasing emotional well-being and promoting self-worth. Most felt that they expressed valued aspects of self through their art. Art-making appeared to assist with identity maintenance, accommodating functional losses associated with MS whilst opening 'new doors'.

Conclusion: Art-making offered a multi-faceted means of supporting identity and increasing fulfilment in lives that were restricted in many ways by MS.

Key words: multiple sclerosis, occupation, art, creativity, well-being, flow, self-esteem.

Introduction

The purpose of this study was to explore the meanings that individuals living with Multiple Sclerosis (MS) associate with participating in art-making as a leisure occupation. Multiple Sclerosis (MS) is a progressive neurological condition that affects physical, psychological and social health and well-being [1,2]. Regardless of type (such as progressive, or relapsing-remitting), MS poses distinctive physical challenges such as impaired mobility (ataxia, spasticity and muscle weakness), incontinence, fatigue, visual disturbances, problems with memory and concentration, and pain associated with muscle spasms [3].

MS has been described as profoundly altering the lifeworld of the individual [4]. Toombs [5:p12] described her own experience of MS as entailing '*a changed relation with one's body, a transformation in the surrounding world, a threat to the self and a change in one's relations to others*'. Moreover, its uncertain trajectory may impose constant challenges to adapt and maintain valued roles, activities and identity [6,7], even among those who have lived with the disease for many years [8]. Such permanent uncertainty and unpredictability of daily life has been described as the most difficult aspect of the condition [5]. Achieving a desirable quality of life with MS seems to involve constant negotiation and a range of coping strategies that are rarely static [9]. Despite these challenges, many individuals with MS develop practical and positive coping strategies [2,7,9,10]. These include developing an

increased appreciation for life, finding realistic ways to enhance or maintain mutually satisfying relationships, maintaining self-worth, and resisting stigma. Some participants describe filling occupational voids resulting from early retirement from work (on grounds of ill-health) by adapting pre-illness leisure occupations and social roles; others report reviving interests that had been kept on hold during their working lives [9]. These various strategies help to challenge the biographical disruption that chronic illness can entail (11). However the specific meanings of creative leisure occupations for people with MS have not been explored.

People living with other physical conditions such as cancer have described engagement in creative leisure occupations as assisting them to pursue meaningful goals, to achieve life satisfaction and relationships based on mutual interests outside of illness, and as maintaining a reassuring sense of continuity. In some cases, these occupations offer a means of symbolic self-expression [12-15]. People engage in creative leisure occupations, including art, music-making, and creative writing, in many environments, including the home and in guilds or educational classes. Participation is voluntary, playful and personally involving, and may be distinguished from creative arts therapy which explicitly has a psychotherapeutic purpose.

The meanings of creative leisure occupations for people living with neurological conditions have been largely neglected, although recognized as a valuable topic to explore [16]. The limited research to date has tended to focus on creative opportunities provided by occupational therapists and arts facilitators. For example, a weekly arts programme held over two months was found to offer community-dwelling stroke survivors various benefits such as improved confidence, and quality

of life, as well as experiences of community participation, although the stroke-affected limb was noted to cause some difficulties in the art activities [17]. This creative outlet for self-expression enabled some participants to explore and represent their stroke journey. A rehabilitation programme offering weekly art classes to people living with neurological conditions (including one person with MS) found similar benefits [18]. Art-making enabled participants “to focus on what they could do rather than on their deficits” [18;p.50].

Whilst there is a very limited number of briefly described case studies of people with MS engaging in art therapy [19-21], there appears to be no research into the meanings of art-making as a long-term *leisure* pursuit for people living with this neurological illness. Given the under-explored nature of this field of enquiry, as established above, and the need to understand subjective experiences, a qualitative approach was appropriate.

Aim of this study:

This qualitative study explored the meanings of leisure-based art-making for people living with multiple sclerosis.

Method

Phenomenology as a methodology is capable of detecting and generating unique contributions and significant insights regarding the meanings of human occupation [22]. This study was grounded more specifically on the principles of interpretative phenomenological analysis (IPA) [23]. IPA studies aim to elicit stories, thoughts and feelings about a major life experience, usually through in-depth interviews. A recent

review [24] indicates that IPA is one of the most commonly used qualitative methodologies used for exploring the personal lived experience of illness, and it has underpinned several previous studies of people's experiences of art-making when living with chronic illness [e.g. 25,26]. This method provides participants with the opportunity to speak freely and reflexively, offering insights into their lifeworlds which are inevitably interpreted by the researcher. In the authors' view, there are helpful guidelines for conducting and evaluating the quality of IPA studies [23,24], which increase its accessibility. Beyond pragmatic considerations, we value the IPA process for identifying general (convergent) experiences whilst also respecting the unique perspective of each individual in the sample.

Ethics

The School of Health Sciences and Social Care Research Ethics Committee at Brunel University provided ethical approval for this study. Furthermore, the study received support from a regional coordinator of MS Ireland (the Multiple Sclerosis Society of Ireland).

All participants were provided with a detailed information sheet and consent form. They needed sufficient verbal communication to participate in the interview and were able to give their own informed consent to take part. In case participants became distressed during the interview, details of relevant MS Ireland supportive contacts were provided on the information sheet and participants were informed of these contacts before the interview commenced. Anonymity and confidentiality were assured both in writing and prior to each interview. All participants have been referred to by pseudonym. Other highly identifying details such as their specific age,

names of family members, previous employment and exact duration of illness have also been masked to reduce the possibility of identification within this relatively small community.

Sample

Members of a local branch of MS Ireland were contacted via email explaining the study in detail, the dates of interviews and the contact details of the researcher should they have any questions. Participants were eligible for the study if they were living with a diagnosis of MS by their own self-report and currently engaging in visual artwork as a creative leisure occupation. Five participants volunteered, three females and two males, aged 40-65 years (Table 1).

--Insert Table 1 about here--

The small sample size is in line with IPA recommendations [23], enabling a detailed case-by-case analysis and interpretation process. All participants were white, resided in a small town in Ireland, were married or living with partners and had adult children mostly living away from home. The elapsed time from when the participants were first diagnosed with MS ranged from 1 to 30 years. Further individual details are not given in order to preserve anonymity as far as possible within a small community. All participants had discontinued regular paid work and/or were medically retired following their diagnosis of MS.

Data Collection

Individual face-to-face semi-structured interviews were conducted with each participant by the first author. Each lasted for about an hour, and was audio-

recorded. The first interview was treated as a pilot, to confirm that the topic guide elicited sufficient rich data, and that anticipated prompts or probe questions were appropriate. No changes were made to the topic guide so the initial interview data were incorporated into the main study. In addition to gathering rich in-depth accounts of the meanings of art-making, participants were requested (if willing) to provide examples, or photographs, of their artwork to discuss in detail during the interview process to encourage further reflection. Interviews were conducted at an easily accessible setting, familiar to the participants, free from interruptions. A physiotherapy clinic where the participants regularly attended for treatment agreed to offer a private room for the interviews. The interview began with a 'warm up' question 'Could you tell me a little about yourself?' The topic guide then elicited discussion of participants' experiences of art-making, and its meanings for them:

1. The origins of participants' interests in arts and crafts
2. The development of interests in art-making during the course of MS
3. Feelings about creative activity
4. Themes expressed through artwork
5. Meanings of artwork - focusing on the specific pieces/photographs of the participant's artwork
6. Perceived relevance of MS to art-making processes and products

Data Analysis

IPA recommendations guided the data analysis [23,24]. Each transcript line was annotated with a line number and each participant's transcript was colour-coded to aid the analysis process, allowing for easy reference. An idiographic approach to the analysis was followed, focusing on one interview transcript in detail at a time and

developing emergent themes before moving on to the next transcript. Each interview transcript was analysed individually, read and re-read until the researcher was immersed in and familiar with the content of the data. Initial observations were recorded in the margin and a tracking system was used to code relevant quotations. This process was repeated for all participants. The authors participated in coding and interpretation and met to explore discrepancies and to deepen the analysis. The codes from each transcript were organised into provisional phenomenological themes and sub-themes. Titles were created transforming initial codes into phrases that aimed to capture the essential quality of what was found in the text. For each identified theme, an individual document on a standard word processing package was created and all relevant quotations with attached codes were then listed under each appropriate theme title using the copy and paste function. Comparisons across participants enabled identification of shared themes and highlighted individual differences between participants. IPA presents a continuous iterative struggle, challenging the researcher to remain focused on the phenomenon being studied while managing the impact of lingering pre-understandings and evolving understandings [27]. Initial reflections were recorded after each interview by the first author and were noted throughout the analysis process by all authors, to heighten sensitivity.

Findings

Contextualising the Sample

Participants varied considerably in the length of time they had lived with MS (1-30 years). Four were fully ambulatory and did not use any walking aids and one (Ella) was a wheelchair user. Even those who remained able to walk described restrictions

imposed by MS including profound fatigue, muscle pain and a history of falls. All had felt obliged to discontinue paid employment because of their illness, with consequent loss not only of financial security but also their familiar identities. Art-making was taken up (or intensified in Liam's case), as part of a broad strategy of coping with MS. Since taking up art-making, Rachel and Liam had established an area in their homes where they could work on their projects, whereas Diane and Matthew did their artwork in non-dedicated areas at home such as the kitchen or living room. All attended workshops or classes at least monthly. Participants varied in whether they specialised in one type of art or craft or enjoyed a variety of media. Pre-illness experiences of art-making also varied (see Table 1).

Meanings of art-making

The main findings were clustered into five superordinate themes and related sub-themes (Table 2).

--Insert Table 2 about here--

It should be noted that these themes were somewhat intertwined with one another, reflecting the complexity of the experiences that were being explored. For example, participants identified time afforded by MS as allowing for participation in creative occupations, which consequently increased positive feelings, assisted in adjustment, and provided an outlet for self-expression.

i) Adjusting to a new way of life: *'My world has totally shrunk...but I'm not unhappy about that'* (Diane)

The above quotation indicates the huge impact of MS on participants' lifeworlds. Yet amidst loss, participants described learning to make adaptations to their lives over time:

People [with MS] have to get used to the idea that they have a disability first, but as soon as they learn to live with it [MS] then they can start focusing on something else. (Ella)

Participants portrayed their regular involvement in creative activities as increasing the quality of their everyday lives through offering new routines, relationships and learning experiences in ways that not only accommodated their illness, but that brought satisfaction. Nonetheless, as Ella hinted above, some had engaged in a protracted period of coming to terms with illness before devising new ways of looking 'outwards' beyond disability and finding fulfilment. Some remained mindful that continuing adaptations might be necessary if symptoms progressed. Participants describing seeking control over everyday life in the face of a body that was unreliable but not rejected.

- ***Accepting a New Way of Being***

Diane was the participant most recently diagnosed (within the past year) and a sense of determined adjustment to a new life was apparent in her narrative. Diane had established that sewing was an enjoyable leisure occupation that could be integrated into her current lifestyle whilst accommodating the symptoms of MS, most notably fatigue.

The thing about MS is that you have to give in to resting...so the thing that I can do and [so] that I'll stay in the one position is the sewing. (Diane).

For Diane, MS imposed certain obligations ('*you have to give in...*') yet she retained some control by choosing to sew during such periods of enforced rest. Ella had lived with MS for the past 30 years and now used a wheelchair. She described taking up art approximately six years ago, and found that it had changed her perspective on life, opening up a 'new world' about which she now felt more positive. A clear turning-point in her life was highlighted when she described art-making as:

...a concept that I thought I'd never be able to do, never, but it ... opened up a whole new world to me... MS in itself doesn't mean the end of the world. For some people it's the start of a whole new life. (Ella)

Liam was the only participant to capitalise upon having a life-long interest in art. He referred to MS as providing him with the opportunity to take a new avenue in his life whereby he could concentrate more fully on his artwork, studying the subject at degree level at university:

Because of the MS I had to stop that [work] and it was like a new door opened. It [art] is something I had done since I was a child. (Liam)

Similarly to Ella, he described facing a turning point. Had MS not intruded into his life, Liam thought it was likely that he would have remained in full-time work, enjoying art much more sporadically in his leisure time. He presented himself as finding benefit in adversity. Whether he was able to do this because he judged his artwork as largely unaffected by illness is unclear. The likely process of adjustment to MS

seems very truncated in his account, as if one door shut and another simply opened. Whether he wished to keep private any struggle experienced in relation to early retirement, or wished to maintain a positive self-image to the younger interviewer, is unclear. Matthew expressed a similar view, in both minimising the impact of diagnosis and maximising the positive consequences for his art-making:

I enjoy it [art] so much, so had I not been diagnosed with MS I probably may never have taken up painting... OK, MS is a bit of a downer, but the upshot of it is I have taken up painting because of it...with MS giving me all this time on my hands it's given me the opportunity to paint all the time if I want to.

(Matthew)

Clearly participants experienced MS as having had constricting effects on their lifeworlds, for example through imposing fatigue and limiting certain familiar occupations. However, as a result of MS, they described uncovering new opportunities, in a world that offered different prospects, as well as the time to engage in a more sustained way in creative activities.

- ***Loss of Worker Role and Re-establishing a New Identity.***

Matthew referred to a previous life consumed by work. When his worker role was no longer possible due to MS, he was left with an occupational void to fill, and art provided a solution.

When you're working you were thinking about work a lot of the time and when you've no work, you've kind of an empty space to think about, whereas if you're doing art it gives you something to think about and something that reflects your life. (Matthew)

Art-making was not only regarded as a 'time-filler'. As Matthew suggests above, art-making offered a meaningful way of engaging and expressing the self. Similarly, this appeared to be the case for Diane, Liam and Rachel all of whom described substituting art and crafts activities for certain aspects of their previous paid work.

Liam described his artwork as '*a surrogate*' for his previous profession, which he also considered a creative process. Whilst 'surrogate' can simply mean 'substitute', it is intriguing to consider that a more resonant, layered word was used, and whether he felt that his artistic occupation was bringing forth, or symbolising, a new self, and whether or not he anticipated having any regrets about this.

- ***An Unknown Future - Worries of Potential Symptom Progression and the Possible Impact on Artwork***

Whilst participants mostly described their art-making in positive terms, as opening 'new doors', three expressed worry relating to the unpredictability of future progressions in their condition and its potential to 'close doors' again and disrupt their participation in creative activity.

Probably a big fear is that I will lose the use of my hands or my sight...which depreciates to the point that I couldn't sew... (Diane)

Such fears did not only relate to sewing, an occupation which requires high levels of dexterity. Rachel also expressed similar fear in relation to the possible impact of MS progression on her card-making, although she attempted to minimise her concerns, as suggested by her switch from 'I' to 'you' in this statement:

If I got to a stage [where] I'd have to rethink the whole thing (pause) but at the minute it [MS] is, I suppose part of who, part of your life, who you are and you just incorporate it. (Rachel)

Ella was somewhat doubtful about her ability to take part in future art classes due to the recent decline of function in her dominant hand, but again expressed determination to try. In contrast, the two (male) participants reported that MS did not affect their artwork. They spoke in the present rather than the future tense.

When it comes to art, the MS doesn't affect me at all. (Liam)

Clearly the participants, both male and female, were unwilling to express any fears about the potentially destructive effects of progressive deterioration on their wider lives, functioning and selves. In their accounts, they almost always represented its potential disabling consequences as manageable.

**ii) Managing Time Meaningfully: 'Now I have a lot of time on my hands'
(Matthew)**

All participants described experiencing an abundance of 'time' as a highly stressful aspect of MS.

I had a huge fear six months ago, I had a huge fear when I was first diagnosed how I would put in my time, that I would sink into depression because I was looking at the four walls. (Diane)

Diane, the most recently diagnosed, was most open about the 'huge fear' that MS had brought into her life. The expression 'put in my time' carries echoes of the

prisoner's phrase of 'doing time', connoting the ticking off of unproductive days and gradually losing touch with life outside (in Diane's case, outside of illness). As did the other participants, Diane described deciding to be proactive to manage this time well. All participants described the usual occupiers of everyday life, such as work, domestic activities and family roles as threatened by MS symptoms. As a consequence, they not only had more 'empty' time to fill, but a need to fill it meaningfully, in ways that supported self and social relationships. Three sub-themes were identified relating to time and the productive use of time.

- ***Time Afforded by Multiple Sclerosis – Artwork Identified as a Good Solution***

Participants described having time on their hands, afforded to them by MS. Not only had they discontinued work as explored above, but also several other familiar activities. They found themselves with an occupational void that required filling in a novel way.

So then there was a kind of a space, I could do something else. (Liam)

As in previous quotations, Liam did not dwell on any protracted struggle to manage the 'space' in his life that MS had opened up. His decision to take on a new way of life was portrayed as enacted rapidly and confidently. In saying 'I could do something else', Liam might not be simply describing finding occupation for his work-free days but perhaps implied that doing something different from his former job might be liberating. Similarly, Matthew reported that painting not only '*occupies my time*' but went on to acknowledge its profoundly 'life-saving' role:

Well, one thing I'd say I got from it [painting] is it involves all my time and gives me a new reason to live really. (Matthew)

Participants' accounts also suggested that creativity involved thinking time, where they planned what they were going to do next with an ongoing or new project. It appeared that participants focused much of their thinking through a creative lens almost as if artwork was constantly in the back of their minds.

...I think it [card-making] keeps your mind active...I think when I'm going to sleep, if I have an order coming in... I'm thinking what will I do about that now, where could I go with that one [next card]. (Rachel)

- ***Timelessness: Completely Engrossed in and Absorbed by Artwork***

Participants indicated that they spent a lot of time involved in art whether it was doing, reading or thinking about it. This occupation offered deep absorption and a sense of timelessness.

...I get quite caught up in it [painting] and I wouldn't see time going by...when I'm painting I'd be totally engrossed. (Matthew)

Liam's experience of artwork provided him with a feeling of being 'in the zone' and so engrossed by his artwork that he could forget his bodily needs for considerable periods of time:

I am absorbed by it [painting]...when I'm painting I forget even to eat. (Liam)

- ***Time free of worry: Artwork Distracts the Mind from Thinking about Multiple Sclerosis***

Linked to the experience of being deeply engrossed, art-making was described by three of the participants as reducing worried preoccupation with MS:

I think it [card making] takes your mind off it [MS]. (Rachel)

Matthew described his thoughts as constantly revolving around his paintings even when he was not actually painting. Both planning and painting so consumed his attention that he was able to resist dwelling during those periods on his illness:

It [painting] gave me something big in my life to wonder and think about which took over the space...I could have been wondering, thinking about having MS whereas I found once I took up painting I was wondering and thinking about the painting that I was doing and not MS. (Matthew)

Matthew, similarly to Liam above, described MS as imposing a 'space', an emptiness with the power to attract worrying thoughts and fears. His art-making was presented as sufficiently challenging to take over this space and give him back some sense of control.

iii) Creative Classes – a multi-faceted experience: *'The social side [of classes] is important whereas sewing at home is very singular'* (Diane)

All participants regularly attended classes or workshops associated with their artwork, and four also described engaging with their various arts and crafts at home. They all made positive reference to these classes, both for the social camaraderie and for the shared learning opportunities experienced there.

• *Social Side of Classes: Valuing Camaraderie and a Shared Focus on Artwork.*

Each participant appreciated their art classes for offering opportunities for sharing a mutual interest in arts and crafts as well as socialising more generally. For example,

Rachel maintained a variety of social relationships through attending the card-making workshop, appreciating that the women shared not only equipment and tips but also what was going on in their daily lives. Illness was not a regular topic of conversation. Rather, events that entailed the production of hand-made cards such as weddings or birthdays would become a natural focus for the group.

It's not all about cards, it's about what's going on in their lives and what's going on with their children. (Rachel)

The male participants placed more emphasis on sharing artistic expertise and the academic exchange of artistic views regarding their artwork, and reported that attending their classes was less about social 'chit chat' or friendship. Their views are further explored in the next theme.

- ***Artwork provides Opportunities to Learn, Receive Criticism, Challenge the Self and Develop Skills.***

All of the participants referred to their classes as providing opportunities to learn and receive feedback from fellow students and the teacher:

She's [class teacher] full of ideas and you're not just sitting there doing something very mundane. (Diane)

A good teacher could help them 'break new ground' in their artwork, fostering more advanced skills, a sense of achievement and even exhilaration. Matthew stated that he gained inspiration and learned from the feedback he received from the experienced art teacher at his weekly art classes:

... so I will look forward to doing that [painting] this week and see what the art teacher has to say about it next week, because you get criticism and that criticism is good, 'cause I think it's good you learn from that. (Matthew)

It appeared that the art teacher, in offering 'good' criticism, offered a welcome contrast to the everyday experience of stigma that he could encounter as a disabled man in many alternative social situations.

iv) Art-making as an affirmative experience: *'To do things that you love doing, it's great, anybody wants to do that'* (Liam)

All of the participants described their art-making in very positive terms, as a source of enjoyment, proof of capability, positive feedback and self-esteem.

• ***Positive feelings before, during and after art-making***

All of the participants' accounts were replete with descriptions of positive feelings and experiences associated with participation in artwork as a leisure occupation. Reference was made, for example, to feelings of enjoyment, pride, achievement, relaxation and confidence, which could arise before, during and after engaging in this pursuit. In response to *'what do you get from painting?'*, Liam replied *'Joy...and that's so important'*.

Matthew considered what his life might have been like in the absence of painting, once again alluding to the space or emptiness of life that is potentially created by MS:

I think my painting has given me satisfaction with my life, my life could easily have been empty otherwise...I think painting has brought a very satisfying aspect to my life. (Matthew)

For Matthew, painting appeared to help him integrate past and present, so that perhaps he no longer felt defined by his illness. Referring to a painting of Africa that brought back earlier memories, he said:

I find that I like painting ... it brings back memories ... I like to try and paint these memories and I get satisfaction from that. (Matthew)

- **Self-worth through visible achievement and feedback**

Most of the participants expressed gaining self-worth from their art- and craft-work. Rachel was modest about her achievements but nonetheless disclosed that she had a good reputation for quality hand-made cards as she sold these without advertising:

*It's just word of mouth ... so I suppose that makes me feel good as well.
(Rachel)*

Some linked self-worth with reaching unexpectedly high standards in their artwork.

Ella, for example, said she was astounded by what she had achieved:

It amazes me ... I couldn't draw to save my life... I had set out to do something that I thought I could never do and I did. (Ella)

The visibility, uniqueness (and in some cases utility) of the creative product helped to affirm self-worth, with many participants, like Diane, often repeating the phrase 'I can do...', rather than dwelling on their loss of function:

It's very fulfilling, it's very much I can still do things, I can do different things, I can do things I didn't know I could do ...I'm doing something that you can't go and buy in a shop. (Diane)

Gift-giving for Diane also seemed to reinforce her confidence in her abilities and her self-worth, and helped her to reciprocate the care and support offered by others since her diagnosis of MS. Liam did not refer explicitly to deriving self-worth or confidence (as shown in Table 2), and yet his identity seemed firmly grounded in his artistic endeavours. Perhaps he even felt that he would leave a legacy to others through his art:

Well, I recognise I was put on this earth to make art, this is my role on earth.
(Liam).

v) Self-expression of feelings and personality through artwork: *'You can't help but express yourself...if you're drawing at all you express yourself'*
(Liam)

Four participants valued their art-making for expressing something about themselves and their lives, although *not* their illness. Only Rachel, even when asked directly if she expressed something of herself in her artwork, remained unsure. This theme was most clearly elaborated in conjunction with the examples of artwork that participants brought to the interview. For example, Ella brought her painting of a favourite musician to the interview. When asked about what this painting expressed, she replied *'fiery'* indicating that she perceived an aspect of her own personality that was reflected (or contacted again) in this piece.

Well, when I see that [referring to artwork] I see fiery, but I was always a bit fiery. (Ella)

Matthew was well-travelled in his previous career and felt that his paintings allowed him direct engagement with the world:

I think I'm expressing myself, my feelings toward the world. (Matthew)

Liam also believed that he expressed himself through his artwork, although he did not offer more detail.

That's the kind of person I am, I am a sort of a person that needs to express themselves by drawing... the way you are also has an effect on your painting 'cause it's all connected, you can't separate it. (Liam)

Interestingly, none of the participants felt that their artwork expressed in any way their feelings about MS. Instead, it communicated other non-illness aspects of their identities. However, all found it quite challenging to articulate in more detail the inner feelings and aspects of self that were being communicated visually through their artwork.

Discussion

These findings largely resonate with previous literature regarding the positive experience of creative leisure occupations for those living with chronic ill-health. However, previous research has included participants with a variety of chronic illnesses but not specifically MS. This study found that people with MS described

similar positive benefits associated with art-making as have other groups such as older adults [28], those living with cancer [12], or mental health problems [29,30].

Previous research [31,32] has recognised that people report an experience of altered time, reduced self-awareness, relaxation, and distraction from worry about health whilst absorbed in creative occupations (both planning and making), although previous work has not included participants with MS. Whilst engrossed in this way, participants experienced respite from worry about their illness. This finding resonates with the state described as flow associated with challenging tasks that require full attention and that draw upon, without overwhelming, the person's repertoire of skills [33].

Art-making also provided a means by which participants could experience positive emotions, and express valued aspects of themselves and their lives in durable objects that others could appreciate. Participants found it difficult to articulate the expressive nature of their artwork. None reported expressing their illness, but instead considered that positive aspects of their personality, feelings and valued memories provided inspiration for their work, perhaps preserving biographical continuity. These findings resonate with previous research on creative leisure occupations (in contrast with art as therapy), which has found that participants only rarely suggest that they have explored feelings about their illness through their art [12,17,25,26]. Participants' denial that they expressed illness in their artwork might be questioned as a defensive strategy, and yet we need to consider that art-making was engaged with for pleasure and not as an emotionally daunting form of

psychotherapy. They identified many aspects of self to express and explore in their creative work, not only MS.

Some of the findings may be helpfully interpreted through phenomenological and sociological frames of reference. In phenomenological terms, the lived experiences of time, body, space and relationality have been proposed as four fundamental existential themes within the lifeworld [34]. Participants made much reference to the challenge of filling empty time that expanded as work and other roles were lost to MS. The need to use limited, and therefore precious, time well has been noted previously among people with cancer [35,36,37]. However, the 'burden' of having too much time to fill has not been explored in such detail and emerged as a key existential challenge of MS. Previous studies have recognised that lived time (temporality) can subjectively speed up, or slow down to a point where it feels like a burden. Sutton et al [38] link this experience of lived time with the person's level of occupational engagement. Without meaningful occupation, a person may feel trapped in an 'endless present with no progression from past to future' [38; p146]. In this study, MS appeared to open up 'holes' in the fabric of time and space, creating an occupational vacuum that was all too readily filled by illness-related worries and regrets. Art-making (both planning and doing) helped to fill these 'holes' meaningfully, giving life purpose and confirming a positive self.

The challenges to identity that participants described can be interpreted in sociological terms. Corbin and Strauss [39] suggested that chronic illness poses a need for biographical work, which includes coming to terms with illness, and identifying a new path in life. Participants' accounts did not foreground the body and

its difficulties, but instead conveyed a strong impression of personal continuity and resilience. Their arts and crafts were portrayed as drawing upon longstanding pre-illness interests, skills, and creative traits, confirming that many aspects of self remained and continued to develop. All valued the social context in which at least some of their art-making took place, welcoming both camaraderie and 'good' criticism of their artwork. Learning new skills and receiving praise from fellow students and tutors in art classes have been appreciated by stroke survivors and others in previous studies [17, 31], and visible achievement may promote relationships and a sense of self that is not predicated on illness. From a phenomenological standpoint, 'learning ...takes as its starting-point the lived body, which at an initial stage is often experienced as unusable—I cannot' [40; p263]. With the growth of artistic skills through classes and engagement at home, together with evidence that they had created socially valued artistic products, participants felt more confidence in what they *could* do rather than dwelling on what they could not. Although it may be queried whether their positive accounts reflected illness denial or an impression management strategy, they could indeed reveal a complex lifeworld in which illness was not permitted to dominate.

The discovery that art-making held positive meaning and was feasible in the context of MS appeared to give participants back a sense of control or resistance.

Resistance seems to be a common strategy among people attempting to live positively with MS, perhaps because there is relatively little effective medical treatment available [40]. Art-making offered opportunities not only for resisting the impact of MS but for achieving positive personal development. For people with neurological conditions, the ability to learn new skills has been found to provide a

sense of mastery [18], an experience that might have special value for people facing an uncontrollable progressive disease such as MS.

Creative activities provided participants with a different way of viewing life with MS. Participants may have experienced a 'reconstruction of possibility' [42; p321]. People making a better adjustment to life with MS have been identified as redefining life purpose, and benefit finding, linked with a belief that MS is a catalyst for opening new opportunities and directions in life [2,43]. The participants stated that over time they regarded their diagnosis of MS as having 'opened doors' for them. It had provided new opportunities to pursue different occupations, namely arts and crafts, in a 'new world'. This finding resonates with a previous qualitative study [9] in which women with MS described seeking out new meaningful occupations, that expressed long-standing personal skills and interests. These occupations provided fulfilment and helped them to interpret some positive aspects arising from having MS (whilst nonetheless acknowledging ongoing challenges within their lives).

Critical Evaluation of the Study

This qualitative study has a number of strengths and limitations. Given the paucity of research in this area, this study advances understandings of the meanings of leisure-based art-making for people with MS. Research investigating the meanings of art-making among people with neurological conditions is rare [17,18] and is limited to the investigation of structured arts programmes, not art as a committed leisure occupation. This study was enhanced by a focus within the interview on the meanings of pieces of artwork selected by the participants. This assisted a deeper

exploration of art-making and the self-expression of self and memory associated with the pieces.

The recruited participants were purposefully sampled for their interest and current participation in artwork. Therefore the sample was not representative of all individuals diagnosed with MS and it cannot be assumed that people who lack interest and confidence in art would gain similar benefits to those found in this study. Although typical of Interpretative Phenomenological Analysis (IPA) [23], this study was limited by the small sample. The data collected were restricted to the demographic of white Irish participants. All were recruited from the same branch of the MS Ireland group. It is possible that regular contact and support from the MS Society may have provided a high level of practical and social support, potentially enhancing their involvement in creative occupations, as well as reducing distress. In addition, all lived with partners and seemed to have a good support network of family and friends.

A more diverse socioeconomic and cultural sample in future research would broaden the understanding of the experience of engaging in artwork for people with MS. This might be achieved through, for example, requesting participants diagnosed with MS through national arts and crafts magazines (a method used in a previous study of people living with arthritis [26]). There are also various art and craft groups for people with MS that might be approached, mostly provided in partnership with the MS Society or MS Ireland. However, whilst this recruitment method would be helpful for gaining a larger sample, it might not achieve a culturally diverse sample.

It should not be assumed that art-making is readily accessible to everyone with MS, as certain arts and crafts require a high degree of dexterity. Reference to disability/physical limitations was not prominent in the participants' accounts and this may reflect the mostly ambulatory nature of the group. People with more advanced forms of MS could experience more frustration with the art-making process, and more barriers to accessing art classes.

The validity of the findings was enhanced by an audit trail consisting of annotated scripts, tables of themes and illustrative quotations. In addition, as recommended [23], both divergent and convergent aspects of the participants' accounts were provided in order to remain idiographic whilst also recognising shared experiences. However, IPA necessarily involves personal engagement with, and interpretation of the participants' experiences by the researchers. An awareness of this was maintained throughout the study. It is acknowledged that the first researcher has a similar socioeconomic and cultural background to the participants, which possibly influenced the data collection and analysis process, and yet this also might have increased rapport. The first researcher's experience in occupational therapy may have increased awareness of time use issues raised by the participants. The third author's involvement in previous related research could have sensitised her to certain themes (e.g. that immersion in the creative process may reduce preoccupation with illness), although care was taken by all authors to consider divergences in participants' accounts and also to relate findings to other sources of research evidence.

The participants' difficulty articulating whether and how they used art in self-expression may have been due to the deep, somewhat unanticipated reflection required. Interestingly, some participants came to a revelation during the interview regarding their expression of self through art. To provide greater insight and elicit more detailed reflection on the role of art-making in self-expression, participants could use a reflective diary for a period of time prior to interview process. Diaries have been suggested as an excellent means of accessing rich detailed, first-person accounts of experiences, facilitating the elicitation of stories, thoughts, and feelings about the target phenomenon [23].

Conclusions

Most of the themes echo findings of previous qualitative research on creativity among people living with chronic conditions, indicating that people share similar needs and positive experiences in relation to their leisure-based art-making, regardless of diagnosed health condition. However, MS seemed to present a particular burden of empty time following loss of work and other roles, which art-making was deemed to fill meaningfully. It has been previously suggested that "professionals working in MS rehabilitation need to broaden their repertoire of interventions" [6: p772], and this study has illuminated the multi-faceted potential benefits of art-making.

Few health and counselling professionals are able to offer arts and crafts interventions but might liaise with community resources instead. There are examples of art groups for people with MS that are delivered at MS Support Centres, or in community groups in conjunction with the MS Society, or supported by a Healthcare

Arts Trust, or Arts in Healthcare group. Resources may be problematic, although some groups in the UK have received Lottery funding (e.g. Cheshire MS Support centre), as well as charitable support. Whilst many arts and crafts can be created in the home environment at relatively low cost, clearly some people with MS may wish to attend social classes and other groups, potentially facing various access difficulties. Barriers to accessing art and art groups need to be studied in order to recommend tailored strategies that people with MS will find helpful if they wish to 'open new doors' and explore creative occupations.

.Declaration of interest:

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Table 1: Sample details

Participant Pseudonym	Creative Leisure Activity	Previous Experience of Arts and Crafts	Engagement in Creative Activity (approximately)	Class Attendance
Rachel	Card making	Used to do some sewing and made dresses for family members. Discovered card making in the years following diagnosis	7 years	Monthly card making workshop
Matthew	Watercolour painting	Interest in art but never pursued pre-illness as a hobby-increased involvement since diagnosis	12 years	Weekly painting class
Liam	Charcoal life drawings and painting	Maintained a similar amount of participation before and after diagnosis	Entire life	Attending University - Arts degree
Diane	Sewing, patchworking, sugar craft (cake decorating)	Small amount in youth – increased involvement following diagnosis	11 months	Various weekly arts and crafts classes
Ella	Pottery and chalk art	Discovered artwork in the years following diagnosis	6 years	Weekly arts class at a local disability group

Table 2: Summary of main findings

Superordinate and Sub themes	Diane	Matthew	Rachel	Liam	Ella
i) Adjusting to a new way of life: ‘My world has totally shrunk...but I’m not unhappy about that’ (Diane)	√	√	√	√	√
• Accepting a new way of being	√	√		√	√
• Loss of worker role and re-establishing a new identity.	√	√	√	√	
• An unknown future - worries of potential symptom progression and the possible impact on artwork.	√		√		√
ii) Managing Time Meaningfully: ‘Now I have a lot of time on my hands’ (Matthew)	√	√	√	√	√
• Time afforded by Multiple Sclerosis – artwork identified as a good solution	√	√	√	√	√
• Timelessness: Completely engrossed in and absorbed by artwork		√	√	√	
• Time free of worry: Artwork distracts the mind from thinking about Multiple Sclerosis	√	√	√		
iii) Creative Classes – a multi-faceted experience: ‘The social side [of classes] is important whereas sewing at home is very singular’ (Diane)	√	√	√	√	√
• Social side of classes: valuing camaraderie or a shared focus on artwork.	√	√	√	√	√
• Artwork provides opportunities to learn, receive criticism, challenge the self and develop skills.	√	√	√	√	√
iv) Art-making as an affirmative experience: ‘To do things that you love doing, it’s great’ (Liam)	√	√	√	√	√
• Positive feelings before, during and after art-making	√	√	√	√	√
• Self-worth through visible achievement and feedback	√	√			√
v) Self-expression of feelings and personality through artwork: ‘You can’t help but express yourself...if you’re drawing at all you express yourself’ (Liam)	√	√		√	√