

Conference Presentation

The potential of painting: unlocking Disenfranchised Grief for people living with dementia

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The potential of painting: Unlocking Disenfranchised Grief for people living Dementia

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Abstract

How painting can access a means of communication for people living with Dementia?

The potential of painting to unlock experiences such as disenfranchised grief for people living with dementia.

This paper investigates the potential of painting to unlock experiences of crisis illness and loss, and in particular, disenfranchised grief for people living with dementia.

experiences of illness, crisis and loss were captured to create new understandings and models of engagement through art for people living with dementia and their carers.

Within the United Kingdom, dementia presents as a huge health care challenge with currently 850,000 people living with the disease in the UK (Alzheimer's Society, 2017). Without significant research and intervention, this will have doubled to one million by 2025 and by 2051 will have doubled again.

Diagnosis of dementia can have significant '*emotional, social, psychological and practical impact*' with people often experiencing a sequence of losses (Alzheimer's Society, 2018b). It is often misconceived that that people living with dementia cannot experience or sustain grief due to this progressive decline in their memory and mental capacity. This societal misunderstanding means that grief can often become disenfranchised and this his can occur at any point of someone's journey with dementia and often occurs on a daily basis.

Disenfranchised Grief and people living with Dementia

Thompson and Doka (2017) identify disenfranchised grief as a sociological concept that arises as a result of social expectation. Their work has been influential in locating grief in broader theoretical applications which have been utilised in this study.

'Self-stigmatization, a process whereby stigma is absorbed by the individual, also plays a role. It encourages people with dementia to remain invisible and withdraw from social contact' (Milne, 2010: 228)

Using art as a research tool

Our study adopts an art practice led approach with us the authors as practicing artists not art therapists.

Arts based research allows for unexpected outcomes (Till, Mottram and Rust, 2005), and can be used to capture new perspectives and emotions, something which would otherwise go unknown (Eisner, 2008). As Eisner (2008:12) states:

'If the arts are about anything, they are about emotion, and emotion has to do with the ways in which we feel. Becoming aware of our capacity to feel is a way of discovering our humanity. Art helps us connect with personal, subjective emotions, and through such a process, it enables us to discover our own interior landscape. Not an unimportant achievement'

Methods

In a workshop setting at Ruthin Crafts Centre, North Wales we worked on a one to one basis with participants, giving them the opportunity to paint alongside us whilst we painted. The intervention was not therapeutic in its aims, but part of a programme called *Lost in Art*, organised by Denbighshire Arts , which provides enjoyment and friendship.

Four female and four male participants all over the age of 65 who had early to mid-stage dementia and sufficient mental capacity, agreed to participate and for the purpose of anonymity, pseudonyms have been used throughout this study.

Data Collection

Participants and their carers were provided with a selection of different coloured acrylic paints, paintbrushes and canvas boards and were asked to paint whatever they wanted while they sat next to us as we painted alongside them.

A loose semi-structured interview guide was utilised during the workshops to gain a more of an in depth understanding of the creative painting process for participants.

Each workshop was video recorded which allowed re-examination of the participant's behaviour, painterly process and speech. Observations were also recorded through field notes throughout each hour workshop.

Analysis

Emergent inductive themes were developed, one of which was the emotions that participants faced during the art workshop.

Findings

Analysis suggests that all four participants felt some form of grief. Disenfranchised grief that can be defined under three main headings. These are; grief that cannot be openly acknowledged, that is not socially sanctioned or grief that is not publicly mourned (Thompson, & Doka, 2017).

This was embodied in the workshop participants negative emotions of: anxiety, frustration, crying and an awareness of their own difficulties.

Grief that is not openly acknowledged relates to grief which has some level of secrecy or confidentiality attached to it and receiving a dementia diagnosis can result in a feeling of social dislocation. Findings from the workshops suggested that all four participants felt some level of grief that was not openly acknowledged.

James

James found it difficult to communicate on entering the room. Once his wife left he immediately began to cry. When asked if he was ok, James said he could no longer do anything for himself anymore and that he had to rely on his wife for everything. He expressed his frustrations, saying with a sense of loss that he had once been very independent and had a good career. He spoke of how this independence had been taken away from him and that his complete reliance on his wife was something he found upsetting.

When engaged in the activity of painting James's strong emotions subsided-and he was immersed in the process of painting for the majority of the one hour's workshop. He was making up the imagery of a small man like figure in the corner of his canvas through applying repetitive delicate marks of different coloured paint. Mid way through the art work shop, James' wife commented on his painting saying:

'he recited a poem this morning that he remembered, about a friend of his and with black teeth and blue legs. He's done this painting with blue legs now'.

James did not verbally respond to this statement, however he then began to speak of his memories of old school friends and walking to school in the morning. He was very animated and appeared happy.

James felt dislocated socially in the workshop setting but the painting activity enabled these strong feelings to subside. Perhaps the painting workshop gave James the opportunity to express the grief associated with the loss of independence.

Poppy

At the beginning of the session, Poppy's speech was very fast and rambling and was largely incoherent. She was talking about how she had been asked to take part in a questionnaire the previous day and she was concerned that she hadn't been able to think of the right answers. This made her very anxious and socially dislocated.

Initially Poppy said '*my pictures are no good*'. She then went on to say that she was '*hopeless*' and that '*every time I do it, it comes to a blob*' whilst tapping her head and appearing frustrated.

Flossy

At the beginning of each of the workshops, Flossy appeared anxious. She repeatedly asked, what she was supposed to be doing. Once engaged in painting, she became immersed in the process and her anxieties lessened. Flossy also stated 'I don't know what I'm ending up with I don't know what I'm doing'. 'I'm not a talented painter you see'.

At the end of the session however, Flossy stated 'I think it's magic' when referring to her painting, something which can suggest that that she felt a certain sense of achievement whilst Poppy said 'The only thing you get out' of this is a laugh isn't it'

Rose

At the beginning of the workshop Rose did not show any emotions Rose but said 'I'm not a talented painter'. Could this imply that she could not openly acknowledge her feelings or felt some level of secrecy towards them.

At the end of the workshop and she looked at her painting and said ‘wow wow’ which indicate that she had enjoyed the workshop.

Summary

Neither Flossy, or Rose initially could openly acknowledge their feelings or felt some level of secrecy towards them.

This could indicate that they were worried what others would think of their paintings, trying to hide symptoms in a new setting and withdrawing into themselves. It is important to note however that people without dementia may also be critical of their own abilities.

Poppy and Flossy also both questioned the purpose of the session. with Flossy repeatedly asking questions throughout the workshop such as ‘*are you not going to give us anything to paint, is it just out of your head*’ and ‘*what do you reckon I’m painting here*’. There was a lack of confidence and anxiety surrounding their abilities and purpose of the workshop.

The presence of the artist researcher as witness helped restore confidence and placed them in a more relaxed frame of mind, opening them up to the creativity within them.

Our lives are improved by having a network of social connections for example art groups, clubs and associations which are of benefit in times of need (Thompson, N & Doka, 2017).

Findings suggested the participants experienced the second element of Disenfranchised Grief – ‘grief that is not socially sanctioned’ (Thompson, N & Doka, 2017). Something which is prevalent for people living with Dementia is the feeling of being stigmatised with anxieties relating to their own behaviour and the responses of this from others (Kuriakose cited in Batsch and Mittelman, 2012).

The Immersive Experience of Painting and Dementia

All four of the participants engaged in the process of painting and appeared immersed. Although their mood and behaviour fluctuated throughout the session, it was noted that their negative emotions were not as profound at the end as they were at the beginning.

McNiff (2008: 32) states:

'I give examples of how the arts help us improve the way we interact with others by learning how to let go of negative attitudes and excessive needs for control, learning how to foster more open and original ways of perceiving situations and problems, gaining new insights and sensitivities toward others, learning how the slipstream of group expression can carry us to places where we cannot go alone, learning how to create supportive environments that inspire creative thought, and realizing that nothing happens in creative expression unless we show up and start working on a project, even with little sense of where we might ultimately go with it'.

Painting encourages a dialogue that can have therapeutic effects for people living with dementia allowing access to an expression of grief through activities that focus on the present. The lives of people living with dementia can be improved through engagement in art activities with their focus on growth, humour, and emotional connection rather than memory (Basting, 2009).

Implications for Practice

An Arts Council Wales (ACW) survey mapping the arts in health provision across revealed the need to strengthen the evidence base stating that, *'if we don't we risk not being able to confidently demonstrate the impact the arts engagements are having on people's health and well-being'*. (ACW, 2018: 91)

This paper builds upon good practice in N Wales and demonstrates on a small scale *'how'* being immersed in painting can access disenfranchised grief for four people living with dementia; contributing to evidence of the positive benefits of Arts in Health more generally. This painting intervention has forged friendships with those living with dementia and their carers, created partnerships between local galleries, local authority arts officers, the local health board and the University who are now working collaboratively to establish funding for further research projects.

The work produced at the workshops by the participants and the artist/researchers were exhibited in a Oriel Sycharth Gallery Wrexham in June. Audiences can engage with the artworks to help understand the dementia condition through a carefully curated show with accompanying literature that aims to de-stigmatise. This professional context for the artwork produced by those with dementia being shown alongside professional artists elevates the status

of the artwork. This exhibition explored the lived experience of dementia through looking beyond the negatives and highlighting the positives of the condition similar to that led by us here. Museums and galleries are increasingly

becoming socially engaged spaces that tackle human challenges with public audiences.

Conclusion

Research shows that people with dementia still maintain a '*rich inner life*' (Johnson, 2016). It is also evident however, from the findings of this project, that participants in the study felt the varying negative emotions. Engagement in the creative process can help develop knowledge and understanding about how these feelings represent the processes of loss and grief; and can through facilitating provision of an outlet that can explore '*how*' the loss effects an individual through recognition of that loss and grief as it is encountered. It can also help with developing appropriate responses for both those living with dementia and their carers as they create artworks together. This research contributes to new ways of communicating with people living with dementia. Sharing and exhibiting the artwork can help de-stigmatise dementia and raise awareness and public understanding of the condition to combat isolation and give validation to the grief experienced by those living with dementia and their carers.