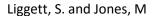


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Conference Presentation

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



This is a presentation given at the 1st European Association for Health Information and Libraries (EAHIL) Conference, 9-13 July 2018, Cardiff, UK.

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

Susan Liggett & Megan Wyatt





Abstract

- Painting and communication.
- Unlock disenfranchised grief for people living with dementia.

Key Findings

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.



Introduction

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 Sociaty (2014) Dementia 2014 report statistics, Alzheimer's Sociaty. Available at: https://www.alzheimers.org.uk/statistics.)

Without significant research and intervention, this will have doubled in the UK to one million by 2025 and by 2051 will have doubled again. (Alzheimer's Society, 2014).

(Alzheimer's Society (2017) Public health, prevention, and dementia. Available at: https://www.alzheimers.org.uk/info/20091/what_we_think/209/public_health_prevention_and_dementia (Accessed: 19 February 2018).

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.



William Utermohlen, Self Portraits 1967-2000

'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, A. (2010) 'The "D" word: Reflections on the relationship between stigma, discrimination and dementia', Journal of Mental Health, pp. 227–233. doi: 10.3109/09638231003728166.)

'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'.

(Eisner, E. (2008) 'Art and Knowledge', in Knowles, G. and Cole, A. L. (eds) Art and Knowledge.

In: The Handbook of Arts in Qualitative Research Perspectives,

Methodologies, Examples and Issues.

California: Sage Publications.)



Lost in Art group, organised by Denbighshire Arts, which provides enjoyment and friendship.



https://denbarts.wordpress.com/

http://ruthincraftcentre.org.uk/



Data Collection

- A loose semi-structured interview guide was utilised 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.



A qualitative thematic analysis approach was used to identify themes and patterns from the data.

(Braun, V. and Clarke, V. (2012) 'Thematic Analysis', APA Handbook of Research Methods in Psychology: Volume 2, 2, pp. 57–71. doi: 10.1037/13620-004.)

Key Findings

Disenfranchised Grief:

- Grief that cannot be openly acknowledged.
- Grief that is not socially sanctioned.
- Grief that is not publicly mourned.

(Thompson, N & Doka, K. (2017) 'Disenfranchised Grief', in Thompson, N & Cox, G. R. (ed.) Handbook of the Sociology of Death, Grief, and Bereavement. 1st edn. London: Routledge).

James





Poppy





Flossy

Rose





Using art as a research tool

Mcniff (2008: 32):

- How to foster more open and original ways of perceiving situations and problems
- Gaining sensitivities toward others,
- Group expression can carry us to places where we cannot go alone
- create supportive environments that inspire creative thought
- 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'.

(Mcniff, S. (2008) 'Art-Based Research', in Knowles, J. & Cole, A. L. (ed.) Handbook of the Arts in Qualitative Research. 1st edn. Sage Publications Limitied, pp. 29–40.)

Forget Memory

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, A. (2009) Forget Memory.

United States of America: John Hopkins University Press.)

Creating Better Lines for People with Dementia

Forget Memory

ANNE DAVIS BASTING



Implications for Practice



Museums and galleries are increasingly becoming socially engaged spaces that tackle human challenges with public audiences.



Conclusions



Research shows that people with dementia still maintain a 'rich inner life' (Johnson, 2016).

Thank you for listening

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