Creativity & Dementia in Everyday Life

A report on the ‘Dementia and Creativity’ Project, at University of Manchester.

by

Sue Bellass, Andrew Balmer, Vanessa May, John Keady, Christina Buse, Andrea Capstick, Lucy Burke, Ruth Bartlett, Anne Connolly, James Hodgson and Lynne Chapman.
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A report on the University of Manchester UMRI-funded 'Creativity and Dementia' project, exploring the potential of a broader, critical approach to the study of dementia, creativity and everyday life.

In partnership with Manchester Carer's Forum: http://www.manchestercarersforum.org.uk

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Who we are:

Our team comprises academics, artists and practitioners. Our work was informed by interactions with carers and people living with dementia. The academics come from a range of disciplines including sociology, the humanities and health care and are based at several universities (Manchester, Manchester Metropolitan, Southampton, York and Bradford). We have been meeting regularly since March 2017 to discuss how we can explore and learn more about creativity and dementia in the context of everyday life and arts therapy.

Further information on the authors can be found on the back page.
We propose a *broadening of research and practice* agendas to bring *critical attention* to the myriad *forms of creativity* that occur in *everyday life* when *living with dementia*. 
Our Project

In recent years there has been a proliferation of arts-based activities for people with dementia. There are more opportunities than ever for people with dementia to engage in visual arts, poetry, dance, drama and music, and many of these activities have significant positive effects for people with dementia.

However, it has been our aim to think not just about the arts but more broadly about 'creativity' - what it is, how it might feature in the everyday lives of people with dementia and their families and friends, and how we can research it. From research we’ve done in the past, we’re aware that people adapt to dementia in a range of ways, for example by modifying the home, developing ways of helping people with dementia to navigate social interactions, and making changes to language and communication when finding words becomes difficult. We view these adaptations as different forms of creativity in everyday life and we expect that conducting more research on creativity in the context of dementia will unearth many more ways in which people with dementia and their family members and friends adapt to the changes that dementia brings. In looking at dementia in this way, we aim to challenge prevailing ideas about loss and deficit, and focus instead on the ways in which people with dementia and those around them use creativity to maintain existing strengths, to bring about or respond to changes and to embark on developing new skills. At the heart of our approach is an emphasis on the similarities rather than the differences between people with and without dementia.

To develop research into creativity and dementia, we have been meeting for several months in a series of workshops to try out new ideas, methods and to develop grant applications to present to research funders. We have also captured and presented our ideas in an academic article, published in Dementia, an interdisciplinary journal.
Workshop 1:

We met to share ideas about what creativity is, how creativity features in the lives of people with dementia, their family and friends. Amongst other ideas, we discussed how creativity figures in the ordinary and mundane, focusing on the everyday lives of people with dementia, how it is enacted in spaces and places of routine interaction and the difficulties inherent in measuring such creativity.

Workshop 2:

In the second workshop we explored previous research in the general area of creativity and dementia, and several group members gave brief presentations about dementia and ordinary everyday life from their perspective. We started working on ideas for two projects, one on time and belonging and one on creativity in everyday life with dementia.
Workshop 3:

We discussed what kinds of methods we might use in the studies. In the time and belonging study, we considered the use of interaction diaries to explore daily rhythms of life. For the everyday creativity study, we discussed creating an online platform of creative solutions that could be populated by and accessed by people living with dementia, their family and friends.

Workshop 4:

In the fourth workshop we returned to the belonging bid and refined our thoughts and ideas about how the study could be carried out with the novel use of technology such as SenseCam, a device that is worn and takes photographs as people engage in their daily life.

Workshop 5:

In workshop five we focussed on the everyday creativity bid, agreeing that we wanted to study instrumental forms of creativity, e.g. practical adaptations to the home, and non-instrumental forms of creativity which would involve, for example, the creative use of language and humour. This would help to show how creativity is skilfully used by people with dementia, their family and friends, as they negotiate changes in everyday life.
We must develop an understanding of creativity and dementia that is *neither grandiose nor tragic*.

That is about *how we live*; about the *pockets of possibility* in *everyday life*. 
Exploring the Potential of Our Approach

To test and reflect on the potential of an approach to creativity and dementia that emphasises people’s existing creativity as part of their everyday lives, and their hopes for future creative endeavours, we found two participants, people living with dementia, who had interests they wanted to explore further.

We met Julie, who had previously maintained a large, tropical garden, but who now lived with her daughter without much outside space. We paired her up with people at Hulme Community Garden Centre. Julie spent a day exploring the gardens, engaging in gardening activities, learning about the Community Garden’s projects and signed up as a volunteer for future activities.

Two members of the research team worked in the gardens with Julie, her daughter, and gardeners from the Centre. We reflected with them on how creativity had figured in her life, for example in how she designed, tended and adapted the gardens around her house when she lived independently. We explored what it was like to talk about creativity whilst getting her hands dirty in the Community Gardens, and thought about how this type of activity could be used as a method to inform academic research.
We met Peter, who had previously been a school teacher and had long wanted to further develop his literary and creative writing skills. We paired him up with James Hodgson, a creative writer and academic.

Peter developed his creative writing techniques over a series of mentoring sessions with James, wrote short fiction for fun, and used his writing to reflect on his experience of living with dementia, people’s interactions with him, and how dementia is understood in British society.

“Peter wrote some fantastic work, exploring his pre- and post-dementia self. One thing that sticks with me is how a character living with dementia in one of Peter’s stories chose to change his name as a way of indicating his embrace of a new life. In another story, the main character took photographs which he then left anonymously in public places, to encourage other characters to think about the perspectives he had on the world and to remember him. They were challenging pieces that showed sophisticated, creative exploration of living with dementia in everyday life.”
James Hodgson
We should seek to understand how the ability to form a sense of belonging is affected as people's sense of time changes & what role creativity plays in maintaining a sense of belonging as things, places and people change.
Broadening the Debate on Creativity and Dementia: A Critical Approach

One output of our project was a co-authored publication in *Dementia*, an interdisciplinary journal of academic research, titled, “Broadening the Debate on Creativity and Dementia: A Critical Approach.” The paper reports that existing approaches to creativity in the lives of people with dementia has tended to focus on helping them to ‘live well’ and, whilst this is important, argues that as a result, the creative work that people get up to in their everyday lives is often overlooked. The paper proposes six dimensions that should be considered in a broader, more critical approach to dementia and creativity. Some excerpts from the paper are below.

1) everyday creativity

“A critical approach to creativity and dementia might attend to the way people with dementia and those around them are creative as part of their everyday lives, in everyday spaces and places and in the context of their ongoing, complex relationships. Since the majority of people with dementia live at home, it is important to gain an understanding of these everyday, distributed forms of creativity if we are to better understand what it is like to live with dementia, how people cope with or embrace change, how dementia affects everyday practices and what it is that might constitute ‘living well’ with dementia when set within this mundane setting.” (Bellass, et al., 2018: page 11)

2) power relations

“Discriminatory practices and differential access to resources may constrain the creative agency of people with dementia, and lead to creativity being construed as inappropriate or risk-taking activity rather than being recognised and acknowledged as a rightful expression of embodied agency, as a form of legitimate resistance or a means of coping with a situation of inequity. A critical approach to studying creativity and dementia remains mindful of such power dynamics and focuses attention on whose creativity is at stake, how this is negotiated in the context of personal and professional relationships, and with what consequences.” (Bellass, et al., 2018: page 13)

3) ways to operationalise creativity

“In terms of critical research into creativity, we propose that it is possible to take this a step further, by not just observing creativity as it emerges in everyday life, but also by making use of participants’ everyday practices as research methods. For example, if a
person with dementia creatively arranges ornaments, the researcher could use this as a form of object elicitation and as a form of art, to understand more about such actions and about the experience of dementia. Similarly, a researcher could identify and partake in any traditional creative practices that the participant enjoys, observing their sensory engagement not only with the process, but also with the outputs of the creative work.” (Bellass, et al., 2018: page 14)

4) sensory and affective experience

A value implicit in much of the interventionist research is that for creativity to be worthwhile it should engender positive affect to improve quality of life … A critical approach to dementia and creativity must recognise that working creatively may inspire both ‘positive’ and ‘negative’ emotions, ‘good’ and ‘bad’ affect … The surfeit of human feeling should not be reduced for people living with dementia any more than it should be for people without such a diagnosis … ‘living well’ might mean much more than ‘feeling good’. Art, perhaps especially amongst forms of self-expression and political action, is characterised by its capacity to represent, examine or conjure all parts of human life. A critical approach to arts interventions and creativity offers a chance not just to counter bad feeling but to explore it, gain comfort in the sharing of it with others, aim it appropriately and challenge its sources collectively, and, yes, to let it go when possible and healthy. (Bellass, et al., 2018: page 14-15)

5) difference

“In addition, marginalised groups who experience the intersection of more than one type of discrimination, for example those from an ethnic minority or LGBT community, are almost entirely overlooked in the body of interventionist studies. It has been suggested that people from minority groups have delayed access to dementia care services and a lack of tailored service provision… A critical approach to creativity and dementia must attend to difference. In terms of diagnosis, stage of illness, marginal experiences, and so forth, the modes of creativity which might be appropriate to explore, elicit or deepen within a study could change.” (Bellass, et al., 2018: page 16)

6) reciprocality

“A critical approach seeks both to contribute to understandings of dementia, but also to explore what the experiences of dementia can tell us about creativity, socio-political order, practices and everyday life … The creative work exposed in the management and negotiation of change in the context of dementia offers potential to explore everyday life more broadly and reflect on how we might all 'live well' together… using the lens of
dementia it is possible to gain insights into how normative creativity is constructed and accounted for, and with what impact upon health and illness experiences and inequalities.” (Bellass, et al., 2018: page 16)

You can access the paper here:
http://journals.sagepub.com/doi/abs/10.1177/1471301218760906?ai=1gvoi&mi=3ricys&af=R (or contact andrew.balmer@manchester.ac.uk for a pre-print copy)
Author List

Sue Bellass, Health Sciences, University of York sue.bellass@york.ac.uk, ORCID: 0000-0001-9383-4116.

Andrew Balmer, Sociology and Morgan Centre for Research into Everyday Lives, University of Manchester, University of Manchester andrew.balmer@manchester.ac.uk, ORCID: 0000-0002-7146-0448.

Vanessa May, Sociology and Morgan Centre for Research into Everyday Lives, University of Manchester, Vanessa.May@manchester.ac.uk, ORCID: 0000-0003-1547-9352.

John Keady, School of Nursing, Midwifery and Social Work, University of Manchester, John.Keady@manchester.ac.uk, ORCID: 0000-0001-8243-6913.

Christina Buse, Department of Sociology, University of York, christina.buse@york.ac.uk

Andrea Capstick, Centre for Applied Dementia Studies, Bradford University, A.J.Capstick@bradford.ac.uk.

Lucy Burke, Department of English, Manchester Metropolitan University, L.Burke@mmu.ac.uk, ORCID: 0000-0002-9870-5118.

Ruth Bartlett, Health Sciences, Southampton University, R.L.Bartlett@soton.ac.uk, ORCID: 0000-0002-3412-230.

Anne Connolly, Manchester Carers Forum, anne@manchestercarersforum.org.uk

James Hodgson, Creative Writer and Academic, Sociology, University of Manchester, james.hodgson-2@manchester.ac.uk, ORCID: 0000-0003-2327-6125.

Lynne Chapman, Artist and Illustrator, contact@lynnechapman.co.uk