

Diverse Rhythms: co-creativity and wellbeing in dementia care home settings

Introduction

This article considers artistic co-creativity with people with dementia in residential care home settings. Co-Creativity is an approach that has been central to the work of Unmapped (a research group that is led by Julian West and Hannah Zeilig: www.unmapped.space) and was developed during their residency at the Wellcome Hub, Created Out of Mind. The article opens with a brief overview of the wider socio-cultural context for our work. This includes the role of the arts for people with dementia, arts in care home settings, some of the reasons that creativity has not been associated with people with dementia and the importance of co-creativity. We then focus on 'Creative Encounters' a recent project that Unmapped are collaborating on with Spitalfields Music. This project has demonstrated the ways in which co-creativity can also extend our understanding of wellbeing both for care home staff and also for residents with dementia.

The wider context

There has been a growing body of evidence in support of the value of the arts for health in both the US and the UK. In particular, the beneficial role of the arts for all older people is increasingly accepted (Camic et al, 2018) and research is mounting that evidences the potential of the arts to impact positively on the health and wellbeing of people living with dementia (APPG, 2017). Similarly, across Europe, the US and in Japan governments are funding arts based projects for people with dementia. Overall, recent studies (published between 2014-2020) demonstrate that the arts can be transformative in terms of changing perceptions, encouraging communication, promoting creativity and sustaining selfhood and interconnectedness for people with dementia.

Whilst the predominant emphasis in these studies has been on arts for people with dementia in community settings, there has recently been growing recognition that the arts can and even should be an integral part of residential care provision (Broome et al, 2019). In line with this, research has indicated that engaging care staff in creative art activities supports deeper personal connections with residents, enhances understanding of communicative strategies and supports the needs and abilities of residents (Broome et al, 2017, Zeilig et al, 2015, Windle et al, 2019). There are a number of UK based organisations that have found innovative ways to introduce the arts into care homes, including Spare Tyre, Magic Me, Age Cymru in Wales who delivered the cARTrefu project, Ladder to the Moon, Creative Minds and others. Other recent arts based approaches for people with dementia and their carers that have also involved a research component, include: the use of theatre (Kontos et al, 2020), the development of a creative toolkit for use in residential care and day care (Robertson & McCall, 2020) and artist residencies in care homes (in the *Imagine Arts* project described by Broome et al, 2019, and also Magic Me's *Artists Residencies in Care Homes 2017*). These initiatives have all outlined the importance of integrating arts and creativity within residential dementia care and the central role of care home staff in this process.

Above all, the arts offer more flexible and therefore alternative ways of engaging with people with dementia and can help everyone to re-imagine 'dementia' (Zeilig et al, 2015).

As noted elsewhere (Zeilig & Hughes, 2019) art can help us to engage 'feelingly' with dementia and can thereby help combat many of the prejudices we may have about this condition. Importantly, the arts also offer opportunities for people with dementia to interact with others. There has also been an essential growth in the role of the arts for those living with advanced dementias.

The purpose of the majority of participatory arts projects, whether these are in the community or in residential care homes for people with dementia, is predominantly to promote health, wellbeing, cognitive function and communication (Zeilig et al, 2019). This is quite different from working with the arts for their own sake, in order to engage the innate creativity of people with a dementia. The tendency to overlook the purely creative possibilities of the arts for those with a dementia is connected with entrenched ideas about what creativity is, where it is located and how it is manifested (Henley, 2018). Indeed, the terms "creativity" and "dementia" are not two words that are often linked. Part of this disconnect is the result of years of creativity research that has focused on eminent creators in science and industry, artists of various sorts, and gifted "geniuses" (Csikszentmihalyi, 1996) with very little research exploring creativity and people with mental or physical health problems, the exception being the 'mad' artist. Indeed, people with dementia have only recently been recognised as being capable of creative activity on a day to day basis. The extent to which people living with dementia might contribute to a fuller and deeper understanding of our shared creativity is mostly overlooked, as are the social, relational and emotional features of creative activity.

Unmapped have started to try to think in new ways about creativity as collective rather than individual, and as affected by a person's relationships and wider context rather than located solely in their brains. This then, is the wider context within which the Creative Encounters project is situated.

Creative Encounters

Creative Encounters is three-year project (2019-2021), introducing the co-creative arts into three different care homes in East London. Each care home is being offered three sets of eight weekly, half day sessions, and is managed by Spitalfields Music. Project sessions are delivered by a small team of artists who are experienced in working co-creatively with people living with dementia in residential care settings.

Co-creativity, which emphasises non-hierarchical participation, represents a novel method for involving people with dementia in ways that are flexible and responsive (Zeilig et al, 2018, 2019). Although there is not currently a single agreed definition for 'co-creativity' it is characterised by a number of key features including: shared process, the absence of a single author or outcome (and instead the idea of shared ownership), inclusivity, reciprocity, exchange and relationality. Co-creativity makes necessary and creates openness, receptivity and imaginative space. Above all, it contrasts with the ideas of the lone creative 'genius' that have tended to dominate views of creativity. On the contrary, here creativity is understood as something that exists within and is shared by the group. We believe that through co-creativity we can challenge people's perception of a loss of agency in dementia by showing that people living with dementia are still able to exercise their creative agency.

The overall aim in Creative Encounters is to engage creatively with residents and to positively influence their confidence, self-expression and wellbeing.

The project involves a research component which has evolved in response to the traumatic events that care home staff and residents have been confronting during the COVID-19 pandemic, although our main focus will be on staff. We will investigate and highlight the unique ways in which care staff have coped with the pandemic, the emotional effect that this has had and the resilience and learning that has emerged during this extraordinary time. Our aim will be to articulate the experiences and concerns of the care staff with an emphasis on peer learning and support. An outcome will be, through this co-creative exploration, to improve staff wellbeing. Co-creativity is central to this, providing an ethos of equality and a means of engaging and expressing oneself creatively.

The wellbeing of care home staff is an important focus due to the many challenges that confront this sector – including low pay, limited opportunities for career progression and professional development (as outlined by Nuffield trust, 2020). In addition, further challenges are linked with the nature of care home work, which is pressured, tends to be task oriented and allows little scope for meaningful interactions with residents (Hussein & Manthorpe, 2012, Windle et al, 2019, Zeilig et al, 2015).

Co-creativity and wellbeing

Creative Encounters, with its emphasis on co-creativity, presents an opportunity to further develop understanding of the concept of wellbeing. Our recent work (Zeilig et al, 2019) proposes that an understanding of wellbeing must also take into account the 'illbeing' which is a necessary part of living with dementia. Our research showed that working co-creatively using the arts could provide a context for this illbeing to be safely acknowledged and expressed, and for artists and others to express solidarity with those living with dementia. This has also been evident in Creative Encounters where a resident living with dementia observed:

'I'm very glad I met you on my death-bed' - care home resident

We have also been very interested in a definition of wellbeing that sees it as an ever fluctuating and dynamic state, and a balance between an individual's assets / resources and the challenges that they encounter (Dodge et al 2012.) This concept of wellbeing as deeply individual and yet also relational has considerable promise in furthering understanding of how the arts when practised co-creatively might promote wellbeing. Artistic co-creativity is sensitive, spontaneous and responsive - it therefore facilitates delicate, moment-to-moment shifts in shared creativity. In addition, co-creativity which nurtures inclusivity helps to address imbalances that can exist between people living with dementia, carers and artists. Importantly, this approach has potential to positively affect not only the wellbeing of those living with dementia, but all who are involved.

The Creative Encounters project uses a unique co-creative approach which aims to involve residents, staff and artists as equal participants in creative activities. This has necessitated taking a very broad view of 'participation', which can be considered in a huge variety of ways and does not always have to be active. For instance, it may range from playing instruments or dancing, through to walking past the door to the room and perhaps glancing inside, sitting quietly and listening, or watching and witnessing. As one of the artists on the project reflected:

'sometimes it is intangible, sometimes it seems that someone is not active. But it doesn't mean they're not part of the creativity. Everything we play and do is influenced by the energy coming from the people in the room. Someone who cannot move can still be part of the creation - without them it would not exist.'

There have been many instances where those living with dementia and also care staff were able to contribute to the co-creative processes spontaneously, drawing upon their individual abilities and skills. In co-creativity, there are no preconceived expectations, this is necessarily inclusive - encouraging and allowing a diversity of responses to the session. The following vignette of a resident during a session, illustrates one such instance, :

'She sits quietly and carefully rolling a till roll for the majority of the session, chatting away about her memories of her family, and also commenting on the atmosphere and what's happening in the wider space – "Everybody's very happy at this place, that's what I notice, cheerful together." And instructs "Enjoy. You only live once my dear"' (Project Producer's field notes)

Here, a person living with dementia, while not taking part in making music or dancing, is contributing through her support for the group, and her appreciation of others. Her effect upon the wellbeing of others is also evident.

A series of reflective development sessions with the care staff produced some important insights into the nature of wellbeing for those living with dementia, the care staff themselves, and also the artists taking part. The ideas that they expressed were nuanced and sophisticated, extending beyond commonly accepted tropes (for instance that wellbeing is straightforwardly associated with happiness or health). The insights of the care home staff indicate that there are new ways for conceptualising wellbeing for people with dementia. These are captured in a number of observations:

'It's just us – being all of us, the happy, the sad...'

'Feelings are important...allowing them to go deep into their feelings'

'Allowing the residents to express everything with you'

'We need to pay attention to people'

'It is a joy to watch some of them (residents) evolving into the person they are.'

These thoughts highlight complex attitudes towards the residents, dementia and creativity, inspired, in part, by the Creative Encounters project. For instance, there is an emphasis on feelings and the need to explore these, the importance of paying attention and the possibility that co-creativity allows residents to evolve into themselves. Thus, Creative Encounters provoked the care staff to think differently about the concept of wellbeing.

Concluding thoughts and future directions

Creative Encounters is an ongoing project and will enter its third and final year in September 2020. However, much has already been learned. The iterative nature of the project, with sustained connections, dialogue and reflection over time has enabled the skills, confidence and understanding of artists, care staff and residents to grow in a cumulative way. This would not be possible within single sessions, or even a single project. The co-creative practice itself has accelerated this process, creating a shared experience and therefore community where individuals can step outside their perceived roles and connect and contribute as equals. Working co-creatively has also prompted all those involved in the Creative Encounters project to think again about wellbeing. We are beginning to understand wellbeing as it is affected by delicate exchanges of interpersonal and individual resources and also as it is both an individual and relational phenomenon.

Working with skilled professional artists, who have a high level of technical expertise to draw upon has also proved to be crucial. In order to respond effectively to the creative contributions of staff and residents, artists need to have a level of technical mastery and imaginative resource to be able to meet that contribution instantaneously and reflexively. When this can be achieved, staff and residents know that they have been 'heard' and are encouraged to continue to risk further exploration and self-expression.

Clearly, the future for this way of working in care settings remains unknown, with care homes in the UK currently under lockdown, and with visits by artists and others likely to be severely curtailed. In any attempts to create alternative remote work, it will be crucial to consider the learning that has been achieved so far. Co-creative work using the arts creates a community, or an ecology, in which artists, those with dementia and care staff are all able to contribute and to receive from each other, enhancing the wellbeing of all.

(2369 words)

information about authors

Social gerontologist Hannah Zeilig and musician Julian West first met in 2014, and quickly established a shared interest in the role that creativity and the Arts might have in advancing understanding about dementia. Drawing on their combined individual experiences of working creatively with people living with dementia, they founded Unmapped, a transdisciplinary group of researchers dedicated to academic and artistic experimentation in order to find new ways of thinking. They were invited to take up leadership roles in Created Out of Mind, recipients of Wellcome's prestigious Hub Award from 2016-18. Here, they broke new ground in their exploration of co-creativity and the possibilities that might exist in adopting this approach when working with people living with dementia. They are currently working with Spitalfields Music on the Creative Encounters project.

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