



RESEARCH ARTICLE

REVISED Making a living moment more resonant: an exploration of the role of the artist in co-creative work with people living with dementia

[version 3; peer review: 5 approved]

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Abstract**Background**

Despite a growth in interest in recent years in the benefits of working co-creatively with the Arts for people living with dementia, little attention has been given to understanding the role of the professional artists within this context. Our main question here is ‘How do professional artists apply their skills and knowledge in co-creative arts groups with people with dementia?’ This paper has been informed by the insights gained from a series of conversations, observations and journals that were kept by four UK based artists (two musicians and two dancers) who reflexively interrogated what they were doing during the course of an 8-week co-creative arts project with people living with dementia.

Methods

The research used an empirical case study methodology, with the authors adopting a thematic approach to the analysis of the data.

Results

Thematic analysis resulted in three main themes: Authenticity, Enabling Risk and Togetherness. These themes characterise the skills, techniques and specialised knowledge used by the artists during the

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Any reports and responses or comments on the

co-creative sessions.

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article can be found at the end of the article.

Conclusions

Following this analysis, the article argues that the beneficial effects for people living with dementia of co-creative art-based work come about through the conscious application by the artists of their shared skills and knowledge, acquired through training and ongoing artistic practice. Rather than an assumption that 'The Arts' are in themselves beneficial for people living with dementia, we must consider the active role played by the artists who are so integral to the process.

Keywords

Dementia, Arts, Co-creativity, Wellbeing, Authenticity, Music, Dance

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REVISED Amendments from Version 2

In this third version of this article we have responded to comments from the reviewers as follows:

- We have addressed concerns regarding unsubstantiated comments
- We have clarified the distinction between the efficacy of Lecanemab and concerns around its safety
- We have included information about which version of NVivo was used in the analysis
- We have given more contextual information about the artists

Any further responses from the reviewers can be found at the end of the article

Introduction

The purpose of this paper is to contribute to a deeper understanding of the role of the professional artist within co-creative projects with people with dementia. As an approach, co-creativity involves a way of working that is non-hierarchical, where power is shared, and where the process is privileged rather than the end product (Matarasso, 2017; Matarasso, 2019; Zeilig *et al.*, 2018). Despite the sense that co-creativity is of increasing relevance to both artists and cultural institutions alike, the approach has not been widely explored, either practically or conceptually. To date, co-creativity as an approach has been investigated primarily from the point of view of those who take part and the artists' perspective has been neglected (Zeilig *et al.*, 2019). Here, we are concerned to examine co-creative work, from the point of view of the artists who are so integral to the process. In doing so, we aim to achieve a more integrative understanding about the way in which co-creativity works for *all* those who are involved. In ESRC and Wellcome funded projects, the authors have worked with artists who practice co-creatively with people living with dementia both in the UK and in Japan.

Our aim is to identify the artistic methods and approaches that artists adopt, the tools that are used, and to explore the role of technique. In this way, we hope to add to the nascent evidence base concerning the invaluable role of professional artists in co-creative contexts.

Arts, dementia, and co-creativity

As noted in the World Health Organisation (2017), dementia is a syndrome that can be caused by a number of diseases which may affect memory, cognition, and behaviour. Many people who live with dementia will eventually need help and support from others for daily activities. In January 2023, Lecanemab was approved by the US Food and Drug Administration as a treatment for early Alzheimer's disease. However, although Lecanemab has been shown to have limited efficacy, persistent concerns about its safety remain (Reardon, 2023) and there have to date been no significant breakthroughs in prevention or cure for dementia. This is a global issue. Whilst dementia is not a normal part

of the ageing process, it is known that ageing is the main risk factor in developing the condition. The United Nations *World Social Report 2023: Leaving No One Behind in an Ageing World*, states that 'the number of persons aged 65 years or older worldwide is expected to double over the next three decades, reaching 1.6 billion in 2050, when older people will account for more than 16 per cent of the global population.'

Consequently, strategies and policies have been developed to address this significant public health issue. The Global Action Plan on the Public Health Response to Dementia 2017–2025 (WHO, 2017) outlines areas for action for moving towards better physical, mental, and social wellbeing and reducing the impact of the condition on people with dementia their families, carers and communities. The WHO report also notes the importance of developing person-centred and cost-effective interventions (2017). It is important to acknowledge that dementia manifests differently in different people and there are variations in cognitive, emotional, and physical symptoms. What has increasingly been recognised is that despite the inability to cure this condition, art projects are one way of enabling people with dementia to continue to participate in social life and have meaningful interactions (Camic *et al.*, 2018; Fancourt & Finn, 2019; Mittner, 2022; Tischler *et al.*, 2023; Windle *et al.*, 2017; Zeilig *et al.*, 2019). Moreover, co-creative arts projects have also shown that the arts can offer new and important ways of being in the world with a dementia (Mittner, 2022 & Lukić, 2023).

More attention therefore must be given to the ways in which people living with dementia can be cared for and included. We must also consider how public attitudes and perceptions can be challenged to address the associated stigma. Artistic practice with people living with dementia is widely appreciated as an important way of addressing stigma and enhancing wellbeing (All Party Parliamentary Group Creative Health on Arts Health and Wellbeing, 2017; Cutler, 2015).

Artists and arts projects

As highlighted by Clift *et al.* (2021), the importance of artistic quality, the role of individual artists, and the ways in which they apply their skills and knowledge within the field of Arts and Health has been largely neglected in the academic literature. Similarly, there is a dearth of knowledge about the effect of co-creativity within health and wellbeing contexts upon artists' own practice. This necessarily results in a one-dimensional understanding about such arts projects, which are only seen in terms of what they 'do', or their effect on those who participate, thus contributing to an instrumental view of arts projects and artists themselves. In addition, the ways in which co-creativity may enrich the lives of artists is unknown.

Nonetheless, there has been some interest in the unique contribution of professional artists to arts-based projects for people with dementia (Coaten & Newman-Bluestein, 2013; Gilfooy & Klocker, 2009; Rose *et al.*, 2008). For instance, Coaten & Newman-Bluestein (2013) note the relevance of the dance artist as an outsider who is gradually accepted within the day

centre environment. It is stressed that the dance artist may have few preconceptions about the abilities of people with dementia and was not constricted by the environment. The knowledge that artists have of existing art work, and how this can usefully inform their processes when working with people living with dementia has also been explored; for example, [Jayne Lloyd \(2019\)](#) describes how her knowledge of the video piece by Bruce Nauman, *Walking in an Exaggerated Manner Around the Perimeter of a Square (1967–68)* informed her approach to creating work which challenges perceptions of walking with people living with dementia in care home settings - a context where walking without an explicit purpose is often described as 'wandering', and associated with the pathology of the syndrome. [Smilde et al. \(2014\)](#) identify the use of improvisation by musicians as a way of expressing the identity and personhood of the person with dementia. This process involves the musicians working reflexively, with a high degree of self-awareness, and with an ability to be present in the moment. The benefits of working as part of a group of artists, who are able to support and inspire each other has also been noted ([Harries, 2013](#)), especially when this group is multi-artform.

The literature shows that the professional artist can open pathways to communication, via their expertise. In addition, professionals are likely to have aesthetic standards and technical proficiency that can be positively applied when working with those who live with dementia. Thus, the evaluation of the "Finding Penelope" project ([Basting et al., 2016](#)) reports on the importance of ensuring that rigour and high standards (in ensemble work and theatrical craft) were integrated into the process of devising and performing a play with people with dementia. The 'Music for Life' model is similarly based upon collaborative possibilities between professional musicians and participants ([Garrett & Crickmay, 2013](#)); thus 'exceptional players' use their musical abilities to connect with even those who are living with advanced dementia. Similarly, moments of musical connection or 'flow' between the group members were highlighted. High aesthetic standards served to validate the whole group and raise the general level of expectation. Moreover, the benefits of having some experience of performing was noted by the artists who led the 'Our Day Out' project. For instance, one of the musicians recalled an occasion when he realised that he could also perform *on behalf of* the group. The work of the Artful Dementia Research Lab at UiT has importantly drawn attention to the role of relational aesthetics ([Bourriaud, 2002](#)). The emphasis in relational aesthetics on the primacy of human relations and social context, and on art as democratic is particularly pertinent for understanding co-creative arts projects and has guided work in this area ([Lotherington, 2023](#); [Lukić, 2023](#); [Mittner, 2022](#)). In relation to 'With All', the concept of Microtopias within relational aesthetics ([Bourriaud, 2002](#)) sheds light on the importance of spaces that encourage dialogue and shared experience, and which foster a sense of connectedness.

As discussed earlier, co-creative practice involves working non-hierarchically with a focus upon the process. Working

non-hierarchically does not imply that we elide the differences between artists and other participants – rather that the knowledge and skills of artists are used within and by the whole group to facilitate equal participation in co-creation. For artists, this has relevance because it enables an emphasis on improvisation and shared decision-making that is not always integral to their training ([Smilde, 2016](#)). Similarly, the ability to participate fully as a member of a team is unusual for people living with a dementia and their carers. In the 'With All' group during a co-creative session there was no strong distinction (although there are differences) between the artists and everyone else who participated. To this extent everyone was an 'artist'. However, in this article our specific focus has been on those members of the group who had received training as professional artists and therefore have a more practised and explicit facility with musical and dance skills and knowledge. Working co-creatively with the arts with people living with dementia has been shown to be an effective way of exploring creativity, encouraging expression and connection practically and experientially, although the field is emerging and requires further and broader research, and, we argue here, the insight from artists themselves.

Ethics

All of the artists involved gave written informed consent for their journals to be analysed as part of the research process, and ethical approval was granted by the Ethics Committee of University College London (approval number: 8545/002). Each of the four artists have over a decade's professional experience as professional performance artists. Improvisation forms an integral part of each of the artist's practice. Three of the four artists had worked with people living with dementia previously.

This article builds on the work published by the authors in two previous publications. The first of these ([Zeilig et al., 2018](#)), is a conceptual piece, which outlines the concept of co-creativity, and used data from interviews conducted remotely with artists who considered their work to be co-creative. It outlines broad concepts and guiding principles for co-creativity. The second ([Zeilig et al., 2019](#)) analyses data collected from people living with dementia who took part in the 'With All' project that took place during the *Created Out of Mind* residency, and comprises interviews, questionnaires, and video. The article describes the benefits for people living with dementia of working co-creatively through the arts. In this study, the intention has been to elucidate the particular role of the artists who facilitate the sessions - i.e., attempting to move towards an understanding of *how* artists work co-creatively. Although the data was generated by the artists during the 'With All' project, this study analyses it for the first time.

Methods

An empirical case study approach was used as a means of collating, framing, and making sense of the data. Following Yin who defined case study as a research method ([2018](#)) the authors adopted a qualitative, realist approach. The case study comprised 4 × 1 hour co-creative group arts sessions that

took place weekly at the Hub at the Wellcome Collection in London over a four week period. The four artists were embedded units within the case. This is in line with Yin (2018: 54) in which he outlines that subunits of analysis may be incorporated within the single-case study thereby creating a more complex (embedded) design. A case study facilitates the investigation of a contemporary phenomenon (here: the role of artists in one co-creative arts project for people with dementia) within their real-world context. A case study approach relies on multiple disparate sources of evidence which all relate to the case being studied. In this instance, we have analysed reflective journals, observations, and insights from collective discussions. The musicians and dancers who participated in the 'With All' project took part in preparatory and reflective discussions in advance of and following each of the sessions. Drawing on these collective discussions and their own personal reflections, each kept an unstructured reflective journal throughout the project, in which they considered the ways that they were approaching working co-creatively with people living with dementia and their partners. In these journals, the artists reflect upon their individual as well as their collective practice.

Code and theme development

The four artists each kept detailed reflective journals during the two-month project. Observational notes kept by the researchers were also included in the analysis.

The two lead authors used NVivo (version 12) qualitative data analysis software to analyse and then independently code the data from these journals. An inductive approach was adopted, with the intention of identifying the ways that the artists were using their skills both consciously and reflexively during the sessions. Following an initial process of familiarisation with the data, each researcher followed a process of coding. The researchers then merged their codes, which totalled 190 in number. Through iterative coding and discussion, the two researchers collapsed the codes into code groups and finally into the three overarching themes which are discussed below. This was a process of emergent thematic analysis which is more concerned with patterns rather than frequency. In contrast to classic content analysis, this form of thematic analysis, as used by Dodds *et al.* (2008), uses empirically emergent, rather than theoretically generated themes (Searing & Zeilig, 2017). This is a small-scale qualitative study. While our sample of five artists is limited, the data is rich and illuminative. We use it here to make some points that are relevant and interesting for scholarship on co-creativity and the role of the artist, rather than to claim any wider representative significance.

Results

The following section describes the findings from the thematic analysis. Three main themes emerged which characterise the skills and techniques used by the artists during the co-creative sessions – Authenticity, Enabling Risk and Togetherness. Each of these themes is informed by a series of subordinate themes. The relationships between the main themes and the subordinate themes are illustrated in Figure 1 below, with the main themes represented as larger circles, and the subthemes as smaller

circles. As can be seen in the diagram, there is also interaction between the three main themes, and this is described later in this Results section.

Authenticity

In their journals, the artists recorded that vital to the success of the work was the importance of working openly, honestly, and trustingly with each other and with the participants. This resonates closely with the accepted understanding of authenticity which is being true to oneself. Authenticity here, refers to the artists' relationship with themselves and hence with the co-creative process. The act of self-reflection can be seen as a key requirement for authenticity. The artists' reflections clarify that their willingness to explore and express their own vulnerability contributed to working authentically during the sessions, as they also explored and expressed a range of emotions alongside the other participants. One artist recorded that the sessions were for them about 'becoming seen', and that there was 'no hiding place' –

There is no hiding place in this project and I am terrified and excited to see what I can reconnect and discover anew in myself in this area.

Authenticity, which emerged as central to the artists' practice, was reinforced by the co-creative sessions. There have recently been a number of scholars interested in authenticity in relation to the lives of those with dementia (Bartlett, 2022; Hughes, 2019; Swaffer, 2014). This analysis revealed the possibility that authentic practice for artists is enhanced by collaborating with people with dementia. The techniques employed by the artist are explored below through the subordinate themes that emerged through the coding process: *holding back, non-verbal communication, awareness of time and space, aesthetic sensibility.*

Holding back. The conscious technique of holding back emerged as key aspect of authenticity. The artists who participated in 'With All' identified 'holding back' or 'waiting' as fundamentally important, as it allowed opportunities for participants to initiate activity of their own choosing and at their own pace. Holding back also gave time for the artists to formulate genuine and authentic responses. These periods of apparent inactivity were described as 'lulls':

Treasure the lulls - it's where everyone knows it's co-created and improvised.

One of the artists likened the 'lulls' to his experience of surfing; when in the water, he never felt any anxiety about whether the next wave would come or not - it was just a matter of waiting. This same sense of trust was echoed by one of the dancers, who also reflected upon the possibility that holding back and waiting not only allows for the atmosphere in the room to change, but also allows the people within it to accept that change and respond to it:

There is also the need to trust that if nothing is happening, if one stays true and waits the space may possibly transform.

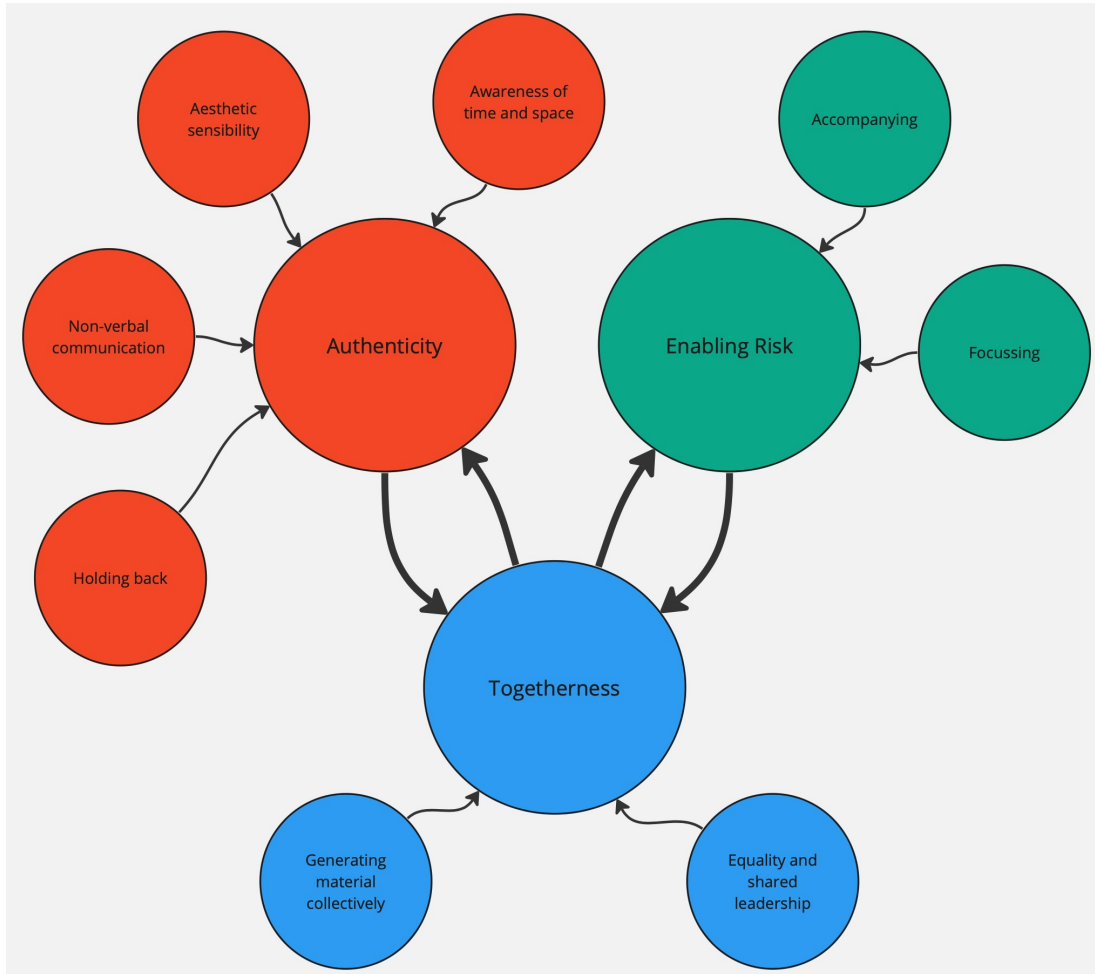


Figure 1. Main and subordinate themes.

This waiting can often result in silence - something which people can find uncomfortable. However, in the ‘With All’ sessions, allowing silence was enabling, in that it afforded opportunities for consolidation and renewal. As one of the artists reflected:

*Silence is the winter that enables the spring...
 Silence is the conversation making itself.
 Silence is the previous words and sounds affirming themselves.
 Silence is us descending out of the air, back into the body and back onto the chair.*

Holding back can also allow for moments that feel open-ended, uncertain, unresolved - or polysemous. This leaves space and opportunity for participants to find their own personal responses or resolutions, or indeed to allow things to remain unresolved, experiencing this ambiguity collectively.

Non-verbal communication. In their reflections, the artists identified that for much of the time, they were interacting and communicating non-verbally. For example, by choosing to become silent, they were able to cede power:

Silence is handing over the baton. Non-explicit exchanging of leadership.

One artist even wondered whether the communication that was possible through the art form was superior to that which could occur verbally:

Strangely it was those with whom I have spoken to less/ have less words themselves that I felt I saw more

Non-verbal forms of communication in the pursuit of making music and dance together may prompt more eye contact and touch within a session, with the innovative use of an artists’ technique and skills being more direct, truthful, and authentic than the formulaic phrases that are more often used in exchanges with people living with dementia. Examples from the artists’ journals illustrate the depth of the communication and connection that occurred through their confidence to work as trustingly and openly with the project participants as they would with their trained colleagues:

C wanting his history, but in the dance his hands held so tight his gaze went so deep, yes, he said, my gaze goes right into you – I see you.

C musically fantastic on the tambourine. Seems like he engages in his own time, in his own way, on his own terms. Was very nice not to be leading the rhythm, but following /decorating.

The moment where I placed the side of my face against the palm of his hand and he moulded to me, read me.

Awareness of time and space. Through their training and ongoing practice, musicians, and dancers acquire an acute awareness of time and space. Both art forms respond to the physical spaces in which they take place. Musicians take into account the acoustics of a physical space and also the positioning of players in relation to one another. Dancers are keenly aware of their position and orientation within space, and to one another. Both art forms are also ephemeral, with works existing only in the moment in which they are being practised, unfolding over a period of time. In bringing this acute awareness to the co-creative sessions, artists were authentically bringing the fullness of their practice.

This awareness of time was reflected in the artists' journals. Artists were aware of how long pieces lasted:

I held the drum for J who had been co-creating with C – he had been there a long time

Watching the salt/dust in the egg timer, its white salt like appearance taking 7 minutes, I traced the air

There was also an awareness of things needing to be given enough time, and for the artistic processes to unfold at their own pace in order to express their full and genuine meaning and value:

giving ourselves the time to render ourselves to that moment which widens the field.

The idea of 'space' occurred often in the artists' journals, with different meanings. The data shows an awareness of the actual physical space that the sessions took place in, and how people were positioned within it, and the effect of this upon the group. In the following quote, one of the musicians reflects upon the possible negative impact upon the integrity of the group, with a division being made by the seating arrangements:

I also felt uncomfortable about where I was sitting. I felt the circle was a little unbalanced- there was an artists side and a participants side.

The term 'space' was also used often with reference to 'leaving space', thereby maintaining the possibility of unexpected contributions by the participants, and the shared sense of creative exploration:

*The 'not- knowing', the shared lack of direction/the SPACE.
because that is where the possibilities lie... and where the shared experience begins*

Aesthetic sensibility. An appreciation of beauty and sense of personal taste is part of the human condition. However,

intrinsic to the training of an artist is the notion of creating and/or performing and presenting discreet works or pieces. In bringing this quality of their training and practice to the project, artists shared themselves more fully with participants. In the 'With All' project, there was often a sense that the co-created artistic material fell into a series of discreet pieces, each of which had its own distinct character and identity. The artists frequently referred to pieces, or even gave names or titles to episodes within the sessions, for example:

'Leaf dance' was a release after (the) profound moment before.

The piece with singing was a lullaby to A

D- wit- performance wonderful first piece with words

As a result of their training and experience, the artists brought an appreciation of the material being created by participants, seeing the beauty in it, and responding accordingly:

C and I making grids with our hands across the ground which felt a response to C

objects arrayed on the ground became passageways to move through

The artists' knowledge of the arts sometimes gave them references that assisted this, providing them with a basis to respond that was concordant and enhancing of the participant's improvised material:

The 'relief'... set up K, M, J all in a row could be Egypt 3 high priests section, wooden crown on K's head

R is in a John Cage world..

For artistic material to attain a sense of being a piece, it is necessary for it to have structure. The artists noted that throughout the improvisations, they were considering and working towards this sense of structure. This included being aware that a physical movement, or sound made on an instrument by one of the participants could be interpreted and responded to as an intention to begin a new piece. As one of the artists noted:

It was a completely instinctive reaction to what he (participant) was hearing and for me this was when the session truly began.

Once a piece was underway, there were various ways in which the artists developed and sought to give it a coherence and integrity. These included a recognition and repetition of musical or physical gestures, motifs, that served as anchor points for the group to return to within the improvisations:

A first small one then a return through the session

Later I used the tiny light, it kept coming back so a composition of the whole piece contained this return

Artists were also aware of pieces coming to an end, or being completed, either by themselves or collectively. Acknowledging this completion was important for the sense of group identity:

We had a moment after completing a piece where we sat there in companionable silence

Moments such as this also support the theme of Togetherness which will be explored later in this article.

Enabling risk: improvisation

For the artists, improvisation was central in facilitating spontaneous responses to the participants - who were also improvising. Improvisation was also noted as a way of connecting with the artists' own personal creativity, and as a way of bringing them into relationship with others:

What is improvisation? This is personal and there are distinctive degrees. For me it is a process of falling into a moment in time and being alive to the choices presenting themselves in that space. Normally and in my own experience this is felt amongst fellow participants.

Improvisation is loosening control and being a witness to yourself.

Listening becomes more important than making sound.

Leaving space becomes essential

Improvisation as described by these artists is a method for accessing creative risk and thereby the generation of material, both individually and collectively. As has been mentioned, the importance of facilitating a context where participants felt able to take creative risks was highlighted by the artists:

there needs to be an element of creative chaos before something of clarity can emerge from it

The artists considered enabling a willingness to improvise, and with that a growing confidence in taking risks, experimenting, and stepping into the unknown, as fundamental to the group's creative process:

I was aware of how difficult it is to allow people to feel the uncertainty of not knowing what will happen next and yet I am so aware that ..that is the very essence of the starting point for co-creativity.

In their journals, the artists explored the ways in which they drew upon their artistic skills and knowledge to support participants in engaging positively with this sense of uncertainty.

In the following sections, the subordinate themes of *Focussing*, and *Accompanying* explore techniques that were employed by the artists to facilitate improvisation and creative risk taking in the group.

Focussing. At points in the *With All* sessions, the freedom of improvisation resulted in several different musical or movement ideas happening simultaneously. Mindful of the possible negative effects of this upon the participants living with dementia, and thereby the erosion of their confidence to improvise, the artists reflected upon the ways in which they mitigated against this. One technique was to consciously draw the group's focus to one individual's emergent creative material by supporting it with their own improvisation, creating material themselves that was sympathetic

with it and thereby amplifying or reinforcing it. This had the effect of drawing the group's attention and focus to a single artistic idea, a cohering of the group's creative process, and a renewed sense of clarity. One of the artists wrote of the way in which they used their knowledge of musical elements to attempt to do this:

(by employing) clarity in musical textures to help bring focus.

In contrast to this technique of reducing the different artistic ideas happening concurrently, the artists also on occasion improvised material that brought together and included these differences, thereby creating an over-all sense of inclusion and acknowledgement. In this sense, the artists were widening the lens of the group, bringing the focus to the group as a whole, and creating a piece within which everyone's individual ideas formed a coherent whole. Artists reflected upon the ways in which they remained aware and sensitive to all members of the group, ready to improvise, acknowledge and include any creative response:

I am constantly trying to be intuitive, to 'read the room', the moment, to watch for any signals, any moment that someone is initiating/responding.

Both of these approaches can be seen as methods that were employed by the artists to enable individual creative exploration and risk taking whilst maintaining a sense of psychological safety for the group.

Accompanying. Accompanying was used by artists to support participants in taking creative risks, extending the groups' creative exploration. The artists paid attention to and focussed upon the emergent material being created by the participants, while simultaneously generating material of their own which was supportive and complementary. In musical terms, this is known as accompanying, and refers to supporting the main line of the music with an additional musical part, for example a guitarist might both support and enhance the vocal line of a song. Accompaniment is not just 'going along with' but is active and enabling. For example, a tentative musical gesture offered by someone can be accompanied in such a way as to acknowledge it as artistic material - maybe by repeating it, harmonising it, extending it, adding pulse and rhythm or ornamenting it. As one of the artists noted:

By supporting them you empower them to go further

It should be noted here, that in a reciprocal fashion the artists were enabled to 'go further' by working in tandem and alongside people with dementia and that this reciprocity was one of the distinctive features of the co-creative process. Whilst the subordinate theme of Accompanying can be seen to be an enabler of creative risk-taking, there are also clear ways in which it contributes to the next main theme to be discussed - that of Togetherness.

Togetherness

A sense of Togetherness, or of collective belonging, emerges from the artists' reflections as an over-arching theme. The

work described in the preceding themes of Authenticity and Enabling Risk was pursued in order to create an experience of collective belonging that included artists and project participants equally. The artists wrote in their journals about some of the techniques and approaches which they were able to employ once the sense of Togetherness had been established, and which also reinforced it. These were techniques to facilitate the collective generation of material, which is a crucial aspect of co-creativity, and actively supporting equality within the group through consciously sharing leadership with them.

Generating material collectively. The artists' used multifarious techniques for the collective generation of artistic material. It was possible to utilise these techniques because the sense of togetherness had been established, and they were also important ways of building upon it.

Waiting and allowing space for participants to initiate has already been discussed. However, as equal members of the group, at times artists followed their own impulses, sharing their own creative offerings:

I started with a twisting turning on a chair

I let my feelings take me to an internal place, was there for them, but for once I was staying with my inspiration, my own journey of improvisation

Artists also actively invited participants to share their own creative response to a stimulus in non-directive ways:

Instruments were handed around, offerings towards a mightier contribution

A. at the start, three times did not want the flower, then did. The game of it, the choice of it

Once initial material had been created, either by one of the artists or by an individual participant, there were then ways to build on this to develop the material co-creatively. This might be through the artists improvising material responsively in a turn-taking, back and forth fashion (call and response), repeating material back sequentially (echoing), copying material concurrently (mirroring), and developing musical motifs and physical gestures by adding their own additional material to that generated by participants. It also happened by adding further layers of accompaniment to the material as discussed above. Typically, other participants also engaged in some of these accompanying techniques, with artistic material being added or responded to by all members of the group, with pieces evolving in unplanned ways. As one artist noted:

Like building a building, block by block without knowing the final design.

This organic, unplanned evolution of pieces was a significant way in which the shared identity of the group was enhanced.

Equality and shared leadership. The sense of togetherness was dependent upon an equality within the group, with relationships

between artists and other participants being parallel rather than hierarchical. As described above, the artists consciously sought to foster shared leadership within the group, and thereby a context where each person was able to exercise power as and when they chose to. This was referred to as an ebb and flow:

I was thinking about the ebb and flow of co-creativity. I think in my mind I have thought of 'equality' being at the very heart of co-creativity. As I reflect more I see that there is a real power in these moments of equality but that the balance in partnership to achieve those moments is in constant ebb and flow

Also present in the data was a recognition that both the artists and the people with dementia were growing and developing together, that everyone was able to make a contribution, and that responsibility for the group was shared:

Do I change, do they change? One needs the other

*At one point I danced with R and she held me and rubbed my back
who was holding who
we did both*

Discussion

The findings that have emerged from our analysis of four artists' reflections reveal some of the ways that co-creativity works and how the artists draw on their knowledge and skills, in order to co-create. The artists were all involved in a single project with people with dementia and were able to interact in ways that were not solely cognitive. As noted elsewhere (Hughes, 2014; Lukić, 2023; Mittner, 2022; Zeilig, 2014), artistic practice can help to understand dementia in a broader context – more feelingly. Similarly, collaborating with people with dementia can give artists new perspectives on what art is. This important reciprocity is fundamental to co-creative practice, hence the professional artist is not privileged 'over' other participants, rather they are enabled to work alongside (Lukić, 2023) and with the whole group.

Wellbeing and authenticity

As recognised by the artists in their reflections, authenticity was a central part of their practice. Recently authenticity in relation to both ageing and specifically dementia has been cogently theorised (Hughes, 2019; Hughes *et al.*, 2022; Sabat, 2019). Similarly, the authors' previous work identified the importance for wellbeing of acknowledging unease, discomfort or illbeing. This renders the concept of wellbeing more truthful or authentic (Zeilig *et al.*, 2019). The philosopher and psychiatrist Hughes cites Laccelle (2018) (Hughes *et al.*, 2022), who provides compelling reasons why authenticity should be used in the socio-cultural narratives that surround ageing. Authenticity is a notion which allows both an acknowledgement that there is the potential for growth in later life as well as recognition of increasing vulnerability and the nearness of death. Thus, the notion of 'authentic ageing' provides a richer conception of ageing than those usually discussed. Moreover, on Hughes' and Sabat's conception (2019; 2021; Sabat, 2001) if we understand ourselves as

socially constituted, then we are ourselves partly because we exist alongside others. To be a self is to be embedded in a context and therefore authenticity involves being true not simply to yourself but also to others. Art is about connection with others and the artists cogently reflect on how fundamental authentic connection is and outline some of the ways in which this can be achieved. For instance, they outline that holding back and showing awareness of time and space can facilitate more authentic, creative connections. The lack of forcing activity or artificially filling a moment contributed to the sort of social and relational authenticity also explored by [Hughes \(2021\)](#).

Normalisation of creative risk-taking

For artists, experimentation and creative risk is a necessary element of their development and their practice when making new work. Indeed, Vincent van Gogh, an artist revered for his creativity wrote to his friend Anton van Rappart ([Van Gogh, 1885](#)):

I keep on making what I can't do yet in order to learn to be able to do it.

Miles Davis expressed something similar in this quote ([Szwed, 2012](#)):

I'll play it first and tell you what it is later.

This study demonstrates the ways in which the professional artists were able to draw upon their own experience, technique, and higher level of comfort with experimentation, uncertainty and risk-taking in order to support the participants in exploring their own creativity together. The artists were enabling conditions which were optimised for creativity to flourish, both in terms of psychological safety and freedom as theorised by [Carl Rogers \(1954\)](#) and [Mihaly Csikszentmihalyi \(1996\)](#). In the words of community musician Lee Higgins ([2009, 2012](#)), the artists were able to give the group a sense of 'safety without safety', in which creative risk taking became normalised. For people living with dementia, opportunities to take risks of any kind may be much reduced as a result of the perceptions and concern of others who judge that any kind of risk (including emotional risk) must be avoided at all costs. This study shows that the training and experience of professional artists can give them important skills, ability and confidence to engage people living with dementia in creative risk. That this has the potential to be beneficial and empowering for people living with dementia has been shown in our previous work ([Zeilig et al., 2018](#)).

A shared artistic language

The training and the practice of the artists have given them a shared language and implicit understanding of artistic processes that enabled them to work together. Being able to communicate with one another through the tools and techniques of their art forms enabled them to work spontaneously and non-verbally. Musicians and dancers shared a common, internalised understanding of elements of their art forms, such

as roles to be taken (solo / duet / accompanist), tempo (the speed of the pulse of the material), articulation (whether the material was smooth / flowing or detached / angular) and the structures of pieces being created. This shared understanding enabled them to respond in ways that were most appropriate for the material generated and offered by participants, appropriately combining elements for maximum effect. The conductor [Daniel Barenboim \(2008\)](#) considers this need for the careful balancing of the elements of a piece of music in order for its full meaning to be conveyed:

In music, everything must be constantly and permanently interconnected; the act of making music is a process of the integration of all its inherent elements. Unless the correct relationship between speed and volume is established, such integration is not complete and it therefore cannot be called music in the fullest sense of the term.

In addition, knowledge of and reference to existing works of art sometimes brought the artists together in a shared understanding of how to respond collectively to material generated by participants, so that the participant's work was supported and enhanced. For example, Clare's comment 'R is in a John Cage world' immediately communicated that R's rhythmic, non-sensical repetition of words could be related to in the same way as the *Story* movement from Cage's *Living Room Music (1940)*. This not only served as providing a 'way in' for the artists, but also re-contextualised R's words as purposeful and meaningful when they might more commonly have been seen as problematic symptoms of her dementia.

Going further together

The artists experienced a sense of collective belonging within the project. Thus, material was generated collaboratively and the sense of equality amongst all those within the project was both established and then reinforced, leading to the ebb and flow of power and a truly shared leadership. Underlying the togetherness experienced by the artists was a profound mutuality of trust. The importance of a feeling of togetherness has been cogently theorised by [Sennett \(2013\)](#) in his book *Together: The rituals, pleasures and politics of cooperation*. Here he outlines the relevance of cooperation as a social asset and as a craft:

Cooperation oils the machinery of getting things done, and sharing with others can make up for what we individually lack. Cooperation is embedded in our genes but... it needs to be developed and deepened. This is particularly true when we are dealing with people unlike ourselves (2013:ix)

These observations have resonance for the ways in which the artists forged togetherness with a range of 'unlike' people, including themselves. This points to the possibilities that artistic co-creativity has for encouraging ethical collaborations, ways of working in which we embrace our own limits and extend these by cooperating with others.

Limitations

This study is the first to consider the ways in which the specific skills and knowledge of professional artists contribute to co-creative work with people living with dementia. Although the data from the artists' journals is rich and extensive, our findings are limited in that the study is small scale, limited to four artists who are demographically similar – all four are white British, living at the time in the Southeast of England. With All, like most arts projects, was tightly time-limited due to funding constraints – this limited the amount of data collected. The study is limited also in that it draws only upon the data from the artists' reflective notes and journals. Moreover, the authors' perspectives as researchers and artists within a Western aesthetic and using a traditional qualitative research paradigm imposes certain limitations on how the data were created, analysed and interpreted. Replication of the study may be challenging, in that the study worked with a particular group of artists who are experienced in co-creative practice with people living with dementia, and sharing of their methodology with others may present difficulties.

Future studies should seek to gather data from a larger and more diverse group of artists, and over a more sustained period, using a wider range of research methods.

Conclusion

This exploratory study suggests that the knowledge and skills of professional, trained artists contribute significantly to the beneficial effects of co-creative work with people living with dementia. Although risk is not something generally

encouraged in work with people living with dementia (in fact, work with this population is more often risk-averse), it is an essential aspect of co-creativity, and the artists employ and distribute their experience and skills to promote creative risk-taking. Through co-creativity, and the deliberate actions of the artists, togetherness, connection, and community are created. The benefits of co-creativity are therefore not necessarily inherent in the art form itself, but in the equality and shared creative journey. Authenticity is a key element to the success of the attempt to work co-creatively, with artists sharing their skills and artistic methods with transparency and generosity, engaging fully in the creative process themselves as equals.

Data availability

Figshare: With All Artists Journals.pdf

<https://doi.org/10.6084/m9.figshare.22759322.v1> (West, 2023)

This project contains the following underlying data:

- With All Artists Journals.pdf

Data are available under the terms of the [Creative Commons Zero “No rights reserved” data waiver Attribution 4.0 International \(CC BY 4.0\)](#).

Acknowledgements

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Reviewer Report 15 August 2024

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Andrew Newman

Newcastle University, Newcastle upon Tyne, England, UK

This should be changed 'As noted in the World Health Organisation (2017)' – should be 'as noted by the World Health Organisation (2017)'.

The below is a misunderstanding of methods – of course the study could not be replicated, no one would expect it to be.

'Replication of the study may be challenging, in that the study worked with a particular group of artists who are experienced in co-creative practice with people living with dementia, and sharing of their methodology with others may present difficulties'.

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: I'm professor of Cultural Gerontology in Newcastle University – I've undertaken work on arts activities for people living with dementia.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 08 August 2024

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Robyn Dowlen

The University of Manchester, Manchester, England, UK

Thank you for taking the time to address the comments made on the previous version of this article. I think this is a very clear and well articulated article which highlights the important role of artists in co-creating work with people living with dementia.

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Music and dementia, specifically 'in the moment' and embodied approaches

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 07 August 2024

<https://doi.org/10.21956/wellcomeopenres.25165.r90726>

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Elizabeth Barry

University of Warwick, Coventry, England, UK

No further comments.

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Literary studies, medical humanities, age studies.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 06 August 2024

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Richard Ward 

University of Stirling, Stirling, Scotland, UK

No further comments / suggestions.

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Dementia Studies

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Version 1

Reviewer Report 20 June 2024

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Richard Ward 

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Many thanks for the opportunity to review this paper. It is well written, reflective and makes a useful contribution to the field of dementia studies. The paper has a clear structure, further supported with the addition of the thematic map/diagram and careful use of headings and subheadings. I have a handful of thoughts and suggestions to share with the authors and one or two questions to pose.

1. You make the point that the role and perspectives of artists themselves has often been overlooked in the dementia studies literature and this provides the rationale for your paper but I wonder if it is worth reflecting on why this gap exists and the implications of it, not least in terms of how the arts are framed within dementia care and research.
2. In the opening paragraph you talk of co-creative projects as characterised by a non-hierarchical and power-sharing approach and this point is echoed a number of times throughout the paper. The impression given, is that these are prerequisites to co-creative working, almost as a starting point rather than something that co-creative endeavours are working towards or aspiring to. I would encourage you to reflect a little further on the assumptions that underpin these assertions. Your data certainly supports the impression that the artists are offering a degree of control to the participants in terms of how the sessions progress and the direction they take but I'm not convinced the evidence supports your claim that the balance of power is being shifted between artist and participant or that we can even assume that the artists are in a position to relinquish power even they wished to. And, when you talk of the non-hierarchical nature of the encounters, my question is how this is judged and from whose perspective. You've made a case within the paper for the specific skills and understanding that the artists bring to the encounters as facilitators and as a catalyst for action, so what are the grounds for arguing this is a non-hierarchical encounter given this degree of expertise?
3. The paper does well to both explain and flesh out notions of authenticity and how the data

illuminates our understanding but perhaps slightly less so in respect to ideas of risk, which is a hugely loaded term for dementia care and carries specific meanings and logic associated with notions of harm. It seems to me that you're talking about something very different when you refer to risk in this paper and perhaps it would be worth expanding on that a little given the likelihood of a practitioner audience for this paper?

4. I was really struck by the quotes that you shared from the artists themselves, in part because their language an interpretation is very different from the kind of reflective discourse used in areas such as nursing or social work. Collectively the data make an important point about the unique contribution of the arts to our understanding of relations with people living with dementia to an extent that I wonder if there is scope to reflect on this toward the end of the paper. These encounters appear to be opening up new knowledge but also new ways of knowing that have direct implications for care and support.
5. On this question of the data, you have used them largely in an illustrative fashion to support a series of well made points but are there grounds to focus a little more on how things are said by the artist as well as what they re saying? There were a number of succinct and very insightful points being made that stood out for me as I read the paper, for instance one of your artists reflects 'silence is the previous words and sounds affirming themselves' which captured something significant about pace and engagement in a dementia context.
6. I really appreciated your emphasis on process (distinct from the more outcome driven framing that so much healthcare research leans toward for interpreting arts-based encounters). I wonder if there's an undercurrent here that might be pulled out a little further in the discussion? Throughout your analysis you are touching not only on the ephemeral and emergent nature of these encounters but also the value of accommodating uncertainty, possibility and even chaos which resonates with wider debates in ethnographic research (Akama Y. et al, 2020 [Ref 1]) which speak to the value of a relational ontology.
7. And building on this point, I also would have liked to see a bit more reflection in the discussion on what outlasts the encounters being described. Not least in terms of creating a sense of collectivity and belonging (but also perhaps in helping people feel more comfortable in the face of uncertainty) that goes beyond the usual research focus on measurements of wellbeing or quality of life and efforts to specify how long such effects continue after the event.
8. Finally, and in respect to the three main themes identified in the paper, is there something to say about their connection and interaction? Is authenticity a prerequisite for enablement of risk? Is a sense of togetherness a product of collective risk-taking?

I hope at least some of the above points are useful and thanks again for the chance to review this lovely paper.

References

1. Akama Y, Pink S, Sumartojo S: Uncertainty and Possibility. 2020. [Publisher Full Text](#)

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Not applicable

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Dementia studies

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 18 Jul 2024

Julian West

Thank you so much for your engagement with this article, and your comments and questions have raised many fascinating lines of enquiry which we would like to pursue. For example, it would be interesting to reflect more deeply on why the role and perspective of artists have been overlooked; we suspect this is intimately connected with how the arts are framed in dementia care, as an 'intervention' which can lead to specific outcomes. There has therefore been much less focus upon the craft of the artist. However, this does need much more careful and considered thought.

As the lead author of this article and practising musician working in this field and have noted the difficulties in finding shared language with researchers. This may be another contributing factor as to why the perspectives of artists are often overlooked.

We agree that it would be very interesting to reflect further upon what a non-hierarchical and power-sharing approach means in the context of co-creative work. This is something that would like to explore more deeply in other work. However, we do think that the **intention** to work non-hierarchically is a prerequisite to co-creative working, even though this is difficult to achieve in practice. It is true that artists are not always in the position to relinquish power, even when they wish to, but even the desire to share power is important here – you may be interested in concepts of nutrient power which are explored by Rollo May in his book 'Power and Innocence' (1998).

Thank you for highlighting the topic of risk, and we agree that this is a loaded term in relation to dementia care. When working on the With All project, there were several occasions when we had to think really carefully about how to negotiate risk. On reflection, we do think in the article that we make it clear that we are discussing creative risk, but there is more to explore in thinking about how this interacts with both emotional and physical

safety.

Your point about the connection and interaction of the three main themes was also helpfully noted by other reviewers – we have addressed this in the revised version of this article.

With regard to your other points, we agree that these are all incredibly important, but feel that they lie beyond the focus of this article. We hope to explore them further in future work.

Competing Interests: No competing interests were disclosed.

Reviewer Report 20 June 2024

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This is a very rich, important and distinctive article about the artists' role in, and experience of, co-creation in applied arts work involving people living with dementia. It is original and valuable in considering the experience of artists in the co-creation process of such work, identifying what their abilities, experience, skills and techniques offer to the work. It is also notable in considering the role of aesthetic factors and even aesthetic value in such work--a revealing aspect of the current study that bears on the authenticity of the work and people's relationship to it, and the importance of doing something meaningful together. A high level of skill on the part of the artists and musicians involved also facilitated the use of improvisation and 'safe' creative risk-taking within a carefully and skillfully maintained artistic whole with a beginning and end. The article gives a nuanced exploration of these factors in the co-creation of activities with genuinely shared leadership and collective decision-making, which thereby fostered togetherness and connection.

The methodology was considered, appropriate and well-explained, and the work built on previous activity and research by those in the group, as well as the most pertinent scholarship in applied arts and dementia studies. The use of emergent thematic analysis allowed for the most significant themes to come to light in a reflective and authentic manner--as befitted the role that these principles had in the design and conduct of the project.

My only qualification to a warm support for the indexing of this piece is to suggest that the authors consider including a reflection of the role of aesthetic standards and factors in the

conclusion as a distinctive aspect of this research.

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Not applicable

Are all the source data underlying the results available to ensure full reproducibility?

No source data required

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: literary studies, age studies, cultural gerontology, medical humanities

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 13 May 2024

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Andrew Newman

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This is an interesting paper that I've enjoyed reading. The topic is not one that has been effectively addressed elsewhere – professional artists tend to struggle to articulate their roles in ways that are easily understandable by non-artists.

On page 3 you say Lecanemab's efficacy is contested – is this the case? A reference is needed.

There are concerns about its safety, but that's not efficacy. See [Ref-1]

The literature review is useful – covering the relevant material effectively.

Is a traditional thematic approach going to work when dealing with the work of a professional artist? What epistemology have you adopted and why? I suggest you start with this and then work forward to the method. Do some wider reading on non-positivist research methods. A scientific approach is not always appropriate, maybe an observational or ethnographic method might capture the work of a professional artist more effectively. What version of NVivo was used?

Most of the themes identified are not unique to arts co-creation – what does a professional artist contribute that others can't? For example, togetherness could be achieved through any sort of collective activity. The subordinate themes perhaps work better than the main ones, which are too general. It might be that bringing these themes together is what is important rather than them individually, I'm not sure. I think a deeper engagement with creative practice (theory and practice) might be helpful. Perhaps authenticity, which is very different to the other themes, captures the topic most effectively.

When you quote a respondent it's worth giving some context – without identifying them. For example, an experienced artist might say something different to an inexperienced one. This allows the reader to make a judgment about what has been said.

With qualitative non-positivist studies sample size is unimportant, a sample of one can be appropriate. You wouldn't get a more 'reliable' result with a bigger dataset. Also, these studies don't have to be replicated – it's not relevant. If you were scientifically testing an intervention – then yes replication might be important, but you are not, you are exploring a topic. These sorts of studies are not of lesser value than a scientific one, they have a lot to offer.

Generally, the paper is well written – however, there are some unsupported statements that need to be addressed. Page 1 'Dementia is a syndrome that can be caused by a number of diseases' is taken from the WHO report directly – you need to reference it. I've not checked the referencing in the rest of the paper – please take care with your referencing.

Have a look at:[Ref:2,3]

References

1. [Reference Source](#)
2. Boddy, C.R: "Sample size for qualitative research", *Qualitative Market Research*. 2016; **19** (426-432).
3. O'Reilly, M Kiyimba: *Advanced qualitative research, a guide to using theory*, London. 2015.

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Partly

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Not applicable

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Cultural Gerontology - arts and dementia

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 18 Jul 2024

Julian West

Thank you for clarifying the distinction between the efficacy of Lecanemab and the concerns around its safety. The Nature article does indicate some efficacy over the first 18 months of treatment, but safety concerns are persistent, and there is uncertainty concerning whether Lecanemab's effect will endure over time. We have addressed this in a revised version of the article.

Thank you for the really interesting query around whether a traditional thematic analysis is appropriate and agree that it would be difficult to capture the artistic processes through this method. However, we were analysing the artists' reflective journals, and feel that the thematic analysis has revealed interesting findings.

We agree that a non-positivist approach will be interesting for deepening understanding of the artistic processes and emotional / relational aspects of this work, and this is something we are keen to address in future work.

We agree that there needed to be a better relationship between the main themes. This was also pointed out by other reviewers and has been addressed in the revisions of the article.

We have amended the article to give more information about the artists and their level of experience. We have also addressed your concern about the unsubstantiated comments – thank you for bringing this to our attention.

Competing Interests: No competing interests were disclosed.

Reviewer Report 06 March 2024

<https://doi.org/10.21956/wellcomeopenres.21442.r72930>

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Robyn Dowlen 

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This is an important piece of research in the area of co-creative work with people living with dementia. There is a dearth of research in this complex area of practice and this article illuminates important role and experiences of the artists who are central to the successful delivery of co-creative work. The themes really resonated with my experiences working with artists in the field of co-creative work with people living with dementia, and I am excited for where this work may go in the future.

Areas that could be developed further:

Introduction

1. The authors note in the 'Arts, dementia, and creativity section' that '...arts projects are one way of providing meaningful ways for people living with dementia to continue to participate and engage' – but it is not clear what they are continuing to participate and engage in
2. The second paragraph of 'Arts, dementia and co-creativity' does not follow on logically from the points made at the end of the second paragraph and this information could be included with information about the condition earlier in this section.
3. I think there could be a greater emphasis made on how you are differentiating from the 'professional artist' and the 'artist who happens to be living with dementia' – this seems to be really important in the context of co-creativity where everyone is working in a non-hierarchical way. While I think it is really important to focus on the role of the professional artist working on this context, some consideration should be given to how people with dementia are artists in their own right, in line with creative citizenship approaches which cross-over with your theoretical development of co-creative approaches. Consideration of this could be made in the Arts, dementia and co-creativity section

Methods

1. There could be more clarity in the case study approach, and the units within the case should be defined. Is it a case study of the With All project, with the artists as embedded units within the case; or is each artist an individual case study (multiple-case analysis)
2. It would also be useful to have a breakdown of the data, as it is unclear how much data you are working with. E.g. how many diary entries, lengths of entries, whether certain artists made more entries than others, the period over which diary entries were written (no. of weeks/days etc), whether all entries were written or whether artists made use of diagrammatic drawings, musical notations etc.

Analysis

1. While there is sufficient detail on the thematic analysis process, there needs to be more information in the methods about what the units of analysis were within the case study (Which is essential from a Yinian perspective) - illuminate whether it was a case study of the

- programme (with artists embedded as units within the overarching project) or artists acting as individual case studies (multiple case-study analysis)
2. Given the emphasis placed on reflexivity of artists, it would be useful to have a reflexive statement from the authors to showcase how their interpretation of the data may have been guided by their professional backgrounds, research interests, etc.

Results

1. I think the definition of improvisation used by artists could come earlier in the enabling risk section to allow the reader to understand what is meant by improvisation in this context.

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Partly

Are sufficient details of methods and analysis provided to allow replication by others?

Partly

If applicable, is the statistical analysis and its interpretation appropriate?

Not applicable

Are all the source data underlying the results available to ensure full reproducibility?

No source data required

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Music, creativity and dementia, with specific knowledge on in the moment experiences held by people with dementia.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 11 Apr 2024

Julian West

Thank you very much for your comments and the important points made in your review. We have found them incredibly useful in revising the article in the following ways:

Introduction 1. This lack of clarity was also noted by Lilli Mittner, and we have altered the sentence (please see above). **2.** Thank you for this comment. We agree and have placed this information earlier in the section. **3.** Thank you for this important point – we agree that it is tricky and yet relevant to distinguish between the ‘professional artist’ and the ‘artist

living with dementia' and indeed this was also commented on by Lilli Mittner. We have included discussion on how we might consider the professional artist as they make use of their skills and knowledge alongside other participants within the co-creative group and how therefore together the whole group can co-create. **Methods 1.** This is needed and we have subsequently added the following to the methods section: 'The case study comprised 4 × 1 h co-creative group arts sessions that took place weekly at the Hub at the Wellcome Collection over a 4-week period. The 4 artists were embedded units within the case. This is in line with Yin (2018: 54) in which he outlines that subunits of analysis may be incorporated within the single-case study thereby creating a more complex (embedded) design.' **2.** Due to word count limitations, we have not included this information in the main text. However, the diary entries are all dated and available to view – please see data availability section (a link at the end of the paper). We hope this sufficiently answers this query. **Analysis 1.** Thank you for pointing this out. We have now clarified this is a single case study and that the artists are the embedded units of analysis (please see above). **2.** Due to word count we have not included a full statement, but in the limitations section we have added further reflections on how the authors were all approaching the study from a Western aesthetic and using qualitative paradigms that affect the overall interpretation. **Results 1.** This definition of improvisation has now been moved to the beginning of the Enabling Risk section.

Competing Interests: No competing interests were disclosed.

Reviewer Report 21 February 2024

<https://doi.org/10.21956/wellcomeopenres.21442.r72926>

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Lilli Mittner 

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The paper examines the concept of co-creativity from the perspective of professional artists working co-creatively with people living with dementia. It builds on previous studies of the same material in which perspectives of those living with dementia have been explored as well as the concept of co-creativity itself.

The authors analyze their empirical material (reflective journals, observations, collective discussions) by means of a thematic analysis which aims to identify specific artistic methods and approaches in order to highlight the role of professional artists in co-creative settings.

Co-creative practices with shared decision-making, non-hierarchical working practices and focus

on the process is unusual for both people living with dementia and their carers as well as for many artists who are trained in the current higher arts education system. Thus, investigating co-creative practices may be beneficial for both people living with dementia, artists as well as society as a whole. If co-creative work is needed to tackle societal challenges, what does this mean for the future training of artists?

The question of what the artists bring into co-creative work is underinvested and needs to be made explicit in interdisciplinary research. Thus, this study is of great value for future research projects in the field of art and dementia as well as other research projects that apply the arts as a method for study design, data collection, analysis, and communication of research findings.

Shifting the research focus from the question 'what is art' to 'what does the artist' seems to me an interesting move that opens up for new knowledge that the arts and humanities bring into interdisciplinary research.

The paper is well-written, and I have only some minor comments. In addition, I would also share three questions that are meant to inspire further thinking.

Can everyone become an artist?

I understand the point of privileging the training and competencies, skills and knowledge of professional artists. Still, I wonder, if everyone can become an artist in co-creative settings? And if so, probably we need to shift the focus from people to knowledge: it is not the art itself, nor the artist and what he/she is doing, but rather the specific knowledge/skills/way of being in the world/way of seeing/approaching things and people that is of specific research interest. E.g. if there is a person living with dementia with an artistic education in the group, is this person be seen as an artist or as a person with dementia? And what would it mean for research design if one person could have different roles during the research process? If roles are not fixed, how can the specific knowledge/skill you are investigating, be captured in the data?

It seems to me that you are arguing the artists are enhancing/making sense of chaos that appears very often in creative and liminal spaces. However, I wonder how this relates to co-creativity. If the specific training/skill/aesthetic of the artists decides (collectively) when a piece emerges and comes to an end, how does this relate to non-hierarchical practices? I think relational aesthetics (Bourriaud, 2002) can be one key to solving this dilemma. The specific aesthetic (Western, linear, rational?), that the professional artists are bringing into this study, needs to be somehow addressed in the discussion.

How does authenticity connect to the master narrative?

The discussion of authenticity is not fully convincing to me and seems to lead back to an understanding of something real, realistic, positivistic, and true, which I find highly difficult in relational aesthetics. If there is someone who decides what is a piece, how to go along with it when it comes to an end and what is authentic, how does this connect to non-hierarchical practices and shared decision-making? Is authenticity something in the 'thing itself'? I guess you mean that it emerges in intra-action, but how? And what is authenticity when we work beyond the rational mind?

What is it that people are engaging with?

"What has increasingly been recognized is that despite the inability to cure this condition, art

projects are one way of providing meaningful ways for people living with dementia to continue to participate and engage.»

Here you could problematize what it is people living with dementia are engaging with, without feeling the need to reach up to a norm. One major implication of the *With All* project seems to me to move with co-creative arts beyond care and inclusion paradigm and towards re-shaping different ways of being in the world, both for those living with and without dementia. Recent contributions in the field of critical dementia studies might be of interest to the authors (Lotherington, 2023; Ward & Sandberg, 2023). In addition, you could refer to the work by Anne Bogart (2021): *The Art of Resonance*. Though coming from applied theatre she outlines some interesting principles that might be similar to what you find in the study and that are significant for what 'the artist brings in'.

Minor comments

1. Abstract

You could consider adding a more specific research question. By now it is not clear from reading the abstract only, what it is that the results (three themes) are answering.

2. Introduction & Artists and arts projects

There are some insights in the area that have been overseen by the authors, e.g. when addressing moments of musical connection. Here the authors could draw on the 'Resonance' project (Mittner, 2018) and other co-creative work conducted in Artful Dementia Research Lab at UiT The Arctic University of Norway.

Have a look at quotation marks. I suggest using them for projects only ('Finding Penelop', 'Our Day Out', 'The Music for Life'), but not for concepts such as flow.

2. Method

You refer to previous papers that report the study in detail. Still, you could give a brief overview of the music & dance session, so the reader can gain a better understanding of where the data derives from.

Have all authors been involved in data collection? If so, this point could be strengthened since it adds an important layer to how data is collected and processed and goes far beyond the qualitative realist approach. You could consider drawing on the performative paradigm (Østern et al., 2021) or situated art intervention research (Mittner & Gürgens, 2021) that moves beyond the qualitative paradigm and privileges the knowledge creation through co-creative art-making as an integral part of the research apparatus.

3. Results

The themes are highly interconnected and I wonder if this could be made visible as a network instead of a linear visualization of sub categories. Since you inserted cross-references already in the analysis, those could be made visible in figure 1.

4. Discussion

This study would benefit from a note about from which specific aesthetic framework the artists are operating/speaking.

In your material the artists reflect on their role to 'support participants in taking creative risks' and ask 'Do I change, do they change?' -> This needs to be reflected from a non-hierarchical standpoint.

Who needs support, why, and how? If the co-creative sessions are equally valuable for artists as they are for people living with dementia and their careers, this should be addressed in the discussion. The quote 'by supporting them you empower them' seems to me symptomatic for a thinking practice that creates a hierarchical divide between we (who are trained/skilled) and them (who are in need of care and help) rather prohibits/be in opposition to the whole idea of co-creativity as a non-hierarchical practice. The danger of privileging professional artists as art makers in co-creative practices needs to be addressed in the discussion. The whole idea of differentiating into artists and participants seems to me problematic in co-creative art practices.

The reciprocity in co-creative practices and the impact on artists could be brought to the forefront in the discussion. «This study shows that the training and experience of professional artists can give them important skills, ability, and confidence to engage people living with dementia in creative risk. «

-> Here I would add 'and the other way around'.

A shared artistic language seems to be crucial to me when artists enter co-creative practices as a group; to facilitate the 'piece' making they need to share a specific aesthetic and understanding; how this process works, could be shown in the empirical material: who do artists collaborate and tune into each other to be able to co-create beyond the rational mind and with people living with dementia? What is the difference between one 1 artist working co-creatively or being 2-4 artists? And what is the role of research artists, which means researchers who become artists in co-creative artistic and arts-based research projects?

«This sense of togetherness importantly brought coherence to the acts of co-creation and simultaneously was an essential means of facilitating the co-creation. «

-> For whom is coherence important and why?

5. Conclusion

I would not consider the study as a small study, but rather as an explorative study that is in its method highly novel and complex.

All in all, I highly enjoyed reading this paper and appreciated the way the authors advance knowledge within the arts & humanities and privilege the perspectives of professional artists on co-creative work.

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3. Lukić, D. (2023). Dementia as a material for co-creative art making: Towards feminist posthumanist caring. *Journal of Aging Studies*, 67, 101169. <https://doi.org/10.1016/j.jaging.2023.101169>
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Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Not applicable

Are all the source data underlying the results available to ensure full reproducibility?

No source data required

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Arts-based research, feminist theories, performative research, arts & dementia

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 11 Apr 2024

Julian West

Thank you very much indeed for your insightful review and for your questions – these are much appreciated. Your review has helped us to clarify our thinking in a number of ways, and we have made changes to the article as a result. We would like to respond to your questions and points in turn.

Can everyone become an artist? In the ‘With All’ group during a co-creative session there was no strong distinction between the artists and everyone else who participated and to this extent everyone was an artist. However, in this article our specific focus has been on those members of the group who had received training as professional artists and therefore have a more practised and explicit facility with musical and dance skills and knowledge. We have been interested in HOW these skills and this knowledge is deployed within the group. Some sentences have been added to this effect in the section Artists and Art Projects. You also ask the question, *what would it mean for research design if one person could have different roles during the research process? If roles are not fixed, how can the specific knowledge/skill you are investigating, be captured in the data?* This is a very interesting question, and we have some experience (within other projects) of working with people with dementia who are ALSO professional artists. However, in terms of ‘With All’ (the case being investigated in this paper) there was a distinction between those who were artists (musicians / dancers) and others, and the former are our focus here. We recognise that this is complex in terms of our discussion about the non-hierarchical nature of co-creative arts groups for people with dementia and this is something we start to address in the Discussion.

How does authenticity connect to the master narrative? Thank you for your interesting thoughts about authenticity. We have clarified this in the text as it refers specifically to the artists’ sense of themselves, their ways of working honestly, openly and with integrity such that this allowed them to have meaningful interactions through their music / dance. We are not thinking about authenticity in relation to the art created but recognise that this was not clear in the first draft.

What is it that people are engaging with? This was also highlighted by Robyn Dowlen in her review, and we have clarified the sentence to outline that we mean that arts projects allow people living with dementia to continue engaging in meaningful interactions. This now reads thus: ‘What has increasingly been recognised is that despite the inability to cure this condition, art projects are one way of enabling people with dementia to continue to participate in social life and have meaningful interactions (Mittner, L. 2021, Tischler et al, 2023, Zeilig et al, 2019). Moreover, co-creative arts projects have also shown that the arts can offer new and important ways of being in the world with a dementia (Mittner,L, 2021 & Lukić, 2023).’ Thank you for referring us to the work of those in critical dementia studies, we have added references where applicable.

Minor comments

1. Abstract Thank you for this observation – we have added the following research question to the abstract: ‘How do professional artists apply their skills and knowledge in co-creative arts groups with people with dementia?’

2. Introductions and Artists and Art Projects Thank you for pointing out that we need to include references to the Resonance project and to Artful Dementia Research Lab projects. This was an oversight in the first draft, and these have now been included. Quotation marks have been amended.

3. Method The need for more information about the music and dance sessions was also noted by Robyn Dowlen. We have now added further details about the ‘case’ that was central to this paper and brief details about the music and dance session. With regard to your questions about whether all authors were involved in data collection; the authors were all involved with creating the data (through their journaling and observations) but they were not responsible for collecting this (this was done by the two first authors). Knowledge creation in terms of the

focus of this paper did not happen through the co-creative art making rather this took place reflectively, afterwards. **4. Results** We agree that the themes are indeed highly interconnected and have amended Figure 1 to more accurately represent the ways in which they interconnect as a network. **5. Discussion** Concerning your point about the aesthetic framework within which the artists were operating, the musicians were all trained at UK based conservatoires and the dancers in UK and US dance schools. They all work within a Western aesthetic framework, and we have acknowledged this in the Limitations section – this was also mentioned by Robyn Dowlen. We have also added reference to relational aesthetics as far as this is relevant to our work. We agree that there is the possibility of reinforcing hierarchical distinctions if we privilege professional artists as the sole or only art makers within a co-creative arts project. We have considered this in the discussion and found the use of the concept of making art ‘alongside’ one another not necessarily to the same ends (as noted by Lukić, 2023 in turn quoting Latimer, 2013 and Zeilig et al, 2018) is pertinent for explaining difference in role and recognising complexity rather than privileging the artist over other participants. We agree with your point about the need to foreground the reciprocity in co-creative practices more clearly. People living with dementia also enabled the artists to take creative risks, and this has been included in the discussion. You ask the question about the following sentence from the first draft: ‘This sense of togetherness importantly brought coherence to the acts of co-creation and simultaneously was an essential means of facilitating the co-creation.’ On reflection we think this is unclear and detracts from the main point being made concerning collective belonging. We have therefore deleted it. **6. Conclusion** Thank you for your suggestion that this study is better described as an explorative study – we have amended this.

Competing Interests: No competing interests were disclosed.
