

Engaging people with dementia in designing playful and creative practices: Co-design or co-creation?

Emmanuel Tseklevs

Lancaster Institute of Contemporary Arts, Lancaster University, UK

Amanda F Bingley

Division of Health Research, Centre for Ageing Research, Lancaster University, UK

Maria A Luja'n Escalante and Adrian Gradinar

Lancaster Institute of Contemporary Arts, Lancaster University, UK

Abstract

Stimulating active, social interactions for people with dementia is an important and timely challenge that merits continuing attention in design research. The idea of using participatory co-design to engage people with dementia is attracting increased interest. In this paper, we draw on our qualitative study that used a playful, participatory arts approach to explore the ways co-design could be implemented in a group of 12 people with dementia and their carers, and developed practical recommendations, in the form of a set of playing cards, for other researchers and caregivers to work in similar ways. The emphasis is on the value of play and playfulness, providing a 'magic circle' (Huizinga, 1955) that fosters the required conditions for a co-creative, co-design space. This aims to encourage social interaction between people with dementia, to stimulate imagination and creativity; and engage even the most reticent, less confident members. Our observations, however, suggest that the exact notion and nature of co-design within the context of working with people with dementia is unclear. We critically explore whether such participatory creative practices that engage people with dementia can be considered as purely co-design. In conclusion, we argue that such interaction is better described as co-creation and that this definition can still embrace considerable contribution and involvement by people with dementia in a co-design process.

Corresponding author: Emmanuel Tseklevs, Lancaster Institute of Contemporary Arts, Lancaster University, Lancaster LA1 4YW, UK. Email: e.tseklevs@lancaster.ac.uk

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Introduction

Engaging and involving people with dementia in participatory, creative group activities is an important contribution towards reducing social isolation and depression for those with dementia and their family and carers (Hanneman, 2006). Social isolation, in particular, is increasingly acknowledged as a major problem for people with dementia and their carers in the UK (Alzheimer's Research UK 2018) (Schreiner, Yamamoto & Shiotani, 2005). Research conducted by Alzheimer's Society (2013) found that 35% people with dementia only go out once a week and 28% have stopped going out of the house altogether; 23% have had to give up doing their own shopping and 9% say they have given up doing everything. Of these respondents, 35% wanted more support and 14% wanted to access activities, but they explained that lack of confidence was one of the biggest barriers to going out. They were found to be afraid of becoming confused in public and getting lost, or becoming a burden to their family or carers. These feelings can leave them isolated and depressed.

In the UK alone, there are 850,000 people living with dementia, estimated to rise to over one million by 2021 (Alzheimer's Research UK, 2018). Although the term dementia is often used to refer to Alzheimer's Disease or to vascular dementia, there are more than 200 subtypes of dementia identified and defined and each has different pathways and processes (Zeilig, Killick, & Fox, 2014). However, dementia as a condition, of whichever type, results in progressive cognitive impairment and decline, with a profound effect on memory and the ability to maintain independence, which subsequently increases social isolation and depression. This has a considerable impact on those with dementia and the thousands of families and carers involved in supporting them. There is a wide research literature reporting on the social needs in dementia, from earlier work by Kitwood and Bredin (1992), to more recent reports such as Vogt et al. (2012). Much of this literature focuses on designing interventions to support people with dementia and their caregivers (Span, Hettinga, Vernooij-Dassen, Eefsting, & Smits, 2013). For instance, how to facilitate reminiscing to enhance a sense of personhood (Wallace et al., 2013; Siriaraya & Ang, 2014; Kuwahara et al., 2006) or to address the safety and autonomy of people with dementia in order to better deal with wandering (Lindsay, Brittain, et al., 2012; Holbo et al., 2013) or to support daily living (e.g. cooking or improving sleep) (Ikeda et al., 2011; Ehleringer and Kim Si, 2013; Hoey et al., 2011). However, despite a number of recent exceptions (see for example, Killick & Kenning, 2015; Rodgers, 2015, 2017; Rogerson, Treadaway, Lorimer, Billington, & Fyfe, 2013; Treadaway & Kenning, 2016), there has tended to be less focus on examining how to effectively stimulate and facilitate engagement, imagination, and social interaction of people with dementia, through participatory playful approaches and activities.

Given the value of group activities for people with dementia (Luja'n Escalante, Tseklevs, Bingley, & Gradinar, 2017), it is timely to explore the ways participatory approaches may be designed to support this population. Broadly, there appear to be two different types of approach to providing group activities. One scenario assumes people with dementia have limited capacity to actively engage with a participatory activity. In this case, at whatever degree of capacity, carers or support workers are required to provide entertainment, choose the input for the activity and in this way encourage interaction (Hendriks, Truyen, & Duval, 2013). The second scenario presupposes there is often a great deal more capacity to engage than may be apparent, even with people who need more or less continual supportive care. In this scenario, there is assumed to be the means to co-create, for instance, in an arts work- shop and even actively to co-design an activity (Robinson, Brittain, Lindsay, Jackson, & Olivier, 2009; Rodgers, 2015; Treadaway & Kenning, 2016).

In this paper, drawing on observations from our Ageing Playfully project (see Luja'n Escalante et al., 2017), we examine the potential benefits and challenges of facilitating activities for people with dementia that draw on either co-creation and/or co-design of playful activities specific to their own needs. In particular, drawing on current debates in the arts and dementia (see Hendriks, Slegers, & Duysburgh, 2015), we discuss the process described as co-design or co-creation, and the differences between these kinds of activity. Finally, we discuss how to harness the benefits of co-creation or co-design when designing a model for workshops that can be used by carers and support workers for people with dementia.

Co-design or co-creation?

The challenges and benefits of including people with dementia in ethnographic (Hubbard, Downs, & Tester, 2003) and participatory research (Hendriks, Huybrechts, Wilkinson, & Slegers, 2014) has been already explored and documented in the literature. More precisely, involving people with dementia as co-designers of assistive information technology (IT) applications is increasingly becoming a popular approach (Branco, Quental, & Ribeiro, 2015; Hanson et al., 2007; Lindsay, Brittain, et al., 2012; Mayer & Zach, 2013; Robinson et al., 2009; Rodgers, 2015, 2017; Treadaway & Kenning, 2016).

Despite these assertions about the value of participatory activities, there is still a degree of dissonance in the literature about the exact nature of the engagement of people with dementia in research, and how best to involve them in the activities. Those researchers working with people with dementia arguably seem to conflate co-design with co-creation (Sanders & Stappers, 2008). This raises a number of questions, examined in this paper, such as to what extent can participatory design research approaches realistically engage people with dementia in research? If so, are these participants called upon to co-design in the activities (thus having an equal part in the discussion about designing a piece of artwork or artefact); or are the participants, in fact, simply joining in as co-creators in a

design that the workshop team/ research team have already partially developed or previously outlined in design?

According to Sanders and Stappers (2008) the terms co-design and co-creation are often used interchangeably, thus they propose a clearer definition of the different processes involved. Co-design accordingly, 'refers to the creativity of designers and people not trained in design working together in the design development process' (p. 7), whereas co-creation, 'refers to any act of collective creativity, i.e., creativity that is shared by two or more people' (p. 7). Central to the concept of co-creation is the belief that all people are creative and seek outlets for creativity in their lives (Sanders & Simons, 2009). Co-design presents a fundamental shift in the traditional designer-user relationship. The co-design approach enables a wide range of people to make a creative contribution in the solution but critically also in the formulation of a problem, a task that has been predominantly led by designers. This process goes beyond consultation, building and deepening equal collaboration between users and designers as they resolve a particular challenge. A key element of co-design is that users, as 'domain experts' of their own needs and experience (Sleeswijk Visser, Stappers, van der Lugt, & Sanders, 2005), become central to the design process. In the process, the designer's role shifts from that of a translator (of user experiences/needs) to that of a facilitator (Sanders & Stappers, 2008) providing ways for people to engage with each other as well as providing ways to communicate, be creative, share insights and test out new ideas.

However, within this context a disparity is found amongst researchers working with people with dementia employing a co-design approach. Although several authors present co-design as a most beneficial and appropriate approach when working with people with dementia, others argue that a different more individualised co-design approach is required. More precisely, Robinson et al. (2009), argue that involving people with dementia in the process of participatory design is feasible and could lead to devices being developed that are more acceptable and relevant to their needs. Rodgers (2015), for instance, demonstrates how participatory design can work for people living with dementia, and his work suggests that this can potentially improve social inclusion through participation, and creativity. Likewise, Treadaway and Kenning (2016) conclude that co-design is a valuable method of addressing the complex needs of people with dementia by involving them in the development of appropriate designs to support their wellbeing. In contrast, Hendriks et al. (2013) note that to collaboratively design with people with dementia in a co-design process is very challenging. Having looked at several case studies that employed a co-design approach whilst working with people with dementia, they developed 33 guidelines as a starting point for researchers and designers who were setting up participatory projects (Hendriks et al., 2013). Their more recent work, which included a workshop held with other researchers active in the field, led them to advocate a highly individual approach sensitive to individual participants, that adapts the co-design techniques to accommodate their needs (Hendriks et al., 2015).

Therefore, based on the existing literature on co-design the following core elements, especially from the user's perspective, are seen as important: (a) making a creative contribution to an identified problem and considering a solution; (b) building and deepening equal collaboration between users and designers; (c) engaging with each other, communicating and sharing insights during the co-design process; (d) as co-designers sharing ownership and agency both in the process and in the resulting artwork, model or artefact. In response to the question whether participatory research, as presented in the literature in this way is co-design or co-creation, we argue that there is a need to examine more carefully the extent to which the core elements of co-design can be applied when working with people with dementia.

Playful approaches for people with dementia

Play is defined by Van Vleet and Feeney (2015, p. 640) as having, 'the goal of amusement and fun . . . [and] . . . 'is highly interactive among play partners. . . ' Similarly, Barnett (2007) in her study of playfulness in young adults, note the element of amusement and concludes that playfulness can be defined as, 'the pre-disposition to frame (or reframe) a situation in such a way as to provide one-self (and possibly others) with amusement, humour, and/or entertainment.' (Barnett, 2007, p. 955). Play and playfulness can add joy to life, relieve stress, supercharge learning, stimulate the mind, boost creativity and connect us to others and the world around us (Gordon, 2014). Play has the potential to foster greater motivation by satisfying three fundamental human needs: the need for competence, autonomy and relatedness (Tieben, Sturm, Bekker, & Schouten, 2014).

Growing evidence from research reveals that playfulness could serve to promote physical and emotional health, and subjective wellbeing (Rogerson et al., 2013; Waldman-Levi, Erez, & Katz, 2015), as well as greater levels of physical activity in later life (Fozard, Bouma, Franco, & Van Bronswijk, 2009; Proyer, 2014; Staempfli, 2007; Van Vleet & Feeney, 2015), Salah, Schouten, Goebel & Arnrich, 2014). Play and playfulness also show promise in stimulating, engaging and enhancing social interaction for people with dementia. Yet, although it has been a subject of research in how to better support health and wellbeing in general (see also Bekker, Sturm, & Eggen, 2010; Ferrara, 2012; Proyer, 2014; Tonkin & Whitaker, 2016), it has not been specifically explored as widely in the area of dementia. Though even the relatively small amount of research in this area, suggests that the use of playful activities as a strategy when caring for people with dementia is becoming more widely accepted (Killick, 2013). For instance, Anderiesen, Scherder, Goossens, Visch, and Eggermont (2015), in looking at the kinds of play experiences that are appropriate for people across the different stages of Alzheimer's Disease, developed guidelines for the experience of play in this situation. Dunn et al. (2013), Treadaway, Kenning, and Coleman (2015) and Tseklevs, Bingley, Escalante, and Gradinar (2015) have found that fun and playful activities are important ways of working with people with dementia, and this can enhance positive emotions, and promote social

inclusion.

There are some interesting playful approaches reported in the literature, Treadaway and Kenning (2016), investigated the use of ludic (playful) artefacts by developing sensory textiles with embedded electronics, for use in activities designed to support the wellbeing of people with late stage dementia in residential care. They co-created various items with the participants, such as a textile collage in the shape of a favourite dog, like that previously owned by the person with dementia, who could press the nose of the 'dog', which then barked a recorded same breed of dog. Another textile model had various items (logos and a football, etc.) associated with the person's favourite football team, which when pressed played a recorded song or a tune. The researchers found these artefacts were highly beneficial for the person with dementia; soothing, distracting, comforting and facilitating 'in the moment' conversational bridges with family members and caregivers. Other researchers, such as van Rijn, van Hoof, and Stappers (2010) and Branco et al. (2015), designed leisure games based on insights from the literature and advice from professional carers, with the aim of stimulating social interaction among people with dementia. Initial feedback from these projects has shown promise in encouraging engagement and participation in the playful activity.

The Ageing Playfully project

In discussing the issues of co-design and co-creation, we draw on our own research project 'Ageing Playfully', in which we explored the process of how to engage people with dementia as co-designers in playful and creative activities within a small group. When designing the research, we embraced the concept of playing as an inherently human activity that stimulates wellbeing (McGonigal, 2011). Through playful, participatory art sessions with people with dementia and their carers, by imagining, creating, and embodying artefacts, we aimed to create what is known as a 'magic circle' (Huizinga, 1955), in which players can feel safe, resourceful and empowered within that moment and space of the game (Salen & Zimmerman, 2003).

As described in Luján Escalante et al. (2017) we ran four workshops with twelve people with dementia, their carers and two support workers, recruited via an Age UK, Lancashire 'circle of support' group. Although participants were at different stages of the condition everyone was fairly mobile and people were still living at home, some more independently than others. Ethics approval for the project was granted by the Lancaster University Research Ethics Committee. Each participant gave written consent, supported by their carers at the start of the project. Consent was also verbally confirmed at the beginning of each workshop session, as each individual's memory loss often meant they were unlikely to recall consent from each previous session. An introductory session was followed by three workshops run at weekly intervals.

The project followed the co-design concept, as defined by Sanders and Stappers (2008), and the research phase drew on Sanders and Stappers (2014, p. 10) four distinct design

stages: pre-design (the larger context of the process), generative (producing ideas), evaluative (assessing effectiveness) and post-design (how was the design experienced). During the pre-design phase, the research team established trust by joining, participating and observing the activities of the targeted research participant group. In this case, we joined a weekly local group for people with dementia over a period of two months. This provided invaluable insight into the ways different people expressed their experience of dementia (Nygård, 2006). We could identify the various challenges in co-designing with such a unique group in terms of capabilities and needs. The first lesson we learned in this pre-design phase, was to focus on the person rather than on the fact they had a diagnosis of dementia and to concentrate on wellbeing instead of 'ill-being'. We were also able to design a workshop format and plan of activities appropriate for the needs and capacities of participants.

The aim of the workshop sessions was to offer a playful space where participants, carers, support workers and the research team engaged together in an enjoyable and imaginative process of co-design, using a range of arts and tactile materials. As we noted in an earlier article (Lujan Escalante et al., 2017), a key point of discussion for this paper is that when working with people with dementia as co-designers, the process may not be a continuously shared activity for participants. Instead, at different times, depending on the nature and aim of the activity, they are engaged in co-creating rather than co-designing. Therefore, researchers must critically evaluate the extent of the team input versus the need to support participants to realise, wherever possible, their own input in the co-design process.

In the first workshop, the activity was a co-creation of a 'collaborative collage', with four participants per small group plus carers and support workers, using picture postcards and notes of different activities (walking, eating or drinking, gardening, wildlife, reading, etc.). Participants chose from a range of pictures to create a collage of favourite activities. Through this process, participants shared their interests, from which the research team chose the most popular themes to develop into topics for the following workshops. Subsequent workshop activities involved co-designing tactile 3D models based on two themes: gardening and music. The second workshop, focused on gardening. Each group collectively constructed a model of a miniature garden using toy plastic blocks and figures, textiles, coloured card and modelling materials. Music was the focus in the third and fourth workshop. The groups were invited to co-design playful percussion instruments, using textiles, wooden pieces, elastic bands and so on to make a range of sounds. Throughout the modelling process, firstly, the activities tended to facilitate the sharing of stories in the group. Secondly, the creation of models involved an element of non-verbal communication and this, together with the storytelling, not only further stimulated participants' imagination, but also appeared to encourage involvement and engagement even by those participants with less verbal skill.

A range of qualitative data was collected, including observations, audio recordings, pho-

tography and video recordings of each workshop. We also invited the carers and support workers to a post-workshop focus group to reflect on the workshop findings. Participant observation made it possible to include people with dementia of differing levels of verbal skill, where verbal interviewing would be difficult (Hubbard et al., 2003). The recorded observations were analysed thematically (following Graham, 2007) with the various data triangulated across recorded fieldnotes, visual and audio data from the workshops and focus group audio recordings. Themes were identified through the process of coding, indexing and categorisation. Four key themes were identified; engagement, imagination, social interaction and the reclaiming of a sense of self. We examine these themes in relation to the concepts of co-design and co-creation.

Findings

Engagement

Engagement in the activities by all participants with dementia was observed in each workshop. By engagement we refer to whether or not participants were involved in the activities. For example, we noted people were engaged if they joined in verbally and/or they handled and used the materials, such as adding these to a group model of a garden or musical instrument. Some participants sang along if the group were making up tunes or shared stories and ideas with the group about the model. For example, they shared memories of when they sat or worked in their own garden or recalled the enjoyment of sitting in a park garden watching birds or looking at the flowers and other people walking in the park (see Figure 1).

Most participants were involved in choosing favourite activities in the collaborative collage. Even those participants who tended to be withdrawn and quiet were observed to increasingly engage with the activities over the course of the workshops. This appeared to correspond to the type of activity. So, we noted that for the quieter participants there was slightly less engagement in the first two workshops, particularly the first postcard collage, which required more cognitive interaction. In contrast, during the musical workshops, their engagement increased with markedly greater tactile and auditory stimulation. The more engaged they were, the greater their contribution to the co-creation element of the activity. In the music-orientated activity, participants could make suggestions and work more independently making a musical instrument (see Figure 2).

Figure 1. Garden models co-created by participants during one of the Ageing Playfully workshops; these produced rich narratives.



As the following quotes by participants demonstrate, activities, such as the making of musical instruments, engaged entire groups with participants driving and directing part of the activity:

Let's make out a song and try to play it. I used to play a lot of music before, but it's surprising what we can play with these made up instruments, these drums. . .

If you come up with a song we could go round and play it. I used to do a lot of playing and what have you. But it's surprising what people can do, isn't it? if you think about it. It's one of these things that just comes when you start playing. I used to play but have not in the last fifteen years.

Engagement in the co-creation of the models seemed to require less active involvement in the design and direction of the activity and was an aspect that all our participants demonstrated, regardless of their level of dementia.

Imagination

Once engaged in the task of each workshop, we observed how the different activities stimulated participants' imagination. People who engaged more consistently throughout the workshop series were able to contribute more actively to imagine and co-design the group model. This led into creation of rich narratives with real and imaginative as well as fictional elements, as the following group participant description illustrates:

This is a garden that belongs to two surgeons. That's the garage for their BMW. They've got a policewoman that watches the door. And that's a creeper that goes round the garden. They have a little boy and he is playing with his sandpit and he's got a bucket and a spade. When Mummy and Daddy aren't resting they like to play cricket. As you can see we made the cricket bat and ball. And that's Lee the dog, having a snooze. We've got a speciality of balloon trees and we've got flowers and it's a walled garden because it's got to be secure. And we've got the policeman watching out that nobody comes. And it has won garden of the year because they've got a camera man to come and take a photo. That's our garden.

Figure 2. Musical models produce by people with dementia during one of the Ageing Playfully co-creation workshops that provided engagement and social interaction.



However, a key finding was these participatory arts activities involving tactile and auditory materials also had the effect of positively stimulating participants' imagination, as the following participant quote exemplifies:

That's brilliant . . . your imagination runs wild' 'I can see it's still there.

This was apparent throughout the workshop series. The first workshop used visual materials and had less imaginative potential than the subsequent sessions. The final two musical instrument sessions encouraged the most imaginative input, and this arguably gave the most opportunity for participants to co-design not just co-create, as the next participant quote demonstrates:

We've just created about three new instruments, in this table, that I never knew existed. . . how great is that!

Social interaction

The workshop activities, by the nature of the group work, and the way in which the team designed the project, facilitated participants' interaction with each other. An important finding was that usually less communicative participants seemed to exhibit more positive mood and preparedness to interact, even after workshop sessions. The participants' carers and support workers reported:

I've never seen them [referring to the people with dementia in the research workshops] engaged so much before.

They are really looking forward to coming to the workshops . . . they've been asking, 'what are

we making today?

Some participants liked to be sociable and the workshops offered a happy opportunity to talk with others:

What other vegetables did you use to grow?^[SEP] I am very fond of gardening. Actually, I always planted flowers.^[SEP] So, are you really into flowers more than vegetables?^[SEP] Yes, but I don't like what I now have, but I like to choose flowers so that other people can enjoy them as well.

The other aspect of the workshops was the effect of numbers in the group. The warm up activities and feedback sessions, which involved the whole group were a little harder for less communicative participants than when they worked in small groups.

Sense of self in the context of their everyday lives

The aspect of participants' expression of their own ideas and thoughts about activities could arguably reflect an individual's sense of self, as an expression of personhood (Kitwood & Bredin, 1992). During the workshop, we observed this kind of individuality shining through, such as when a participant sang the nursery rhyme, 'Three Blind Mice', whilst she was playing the musical instrument that her group had created:

I don't know where that came from. I used to sing that to my daughter.

In another small group, five participants developed rich narratives as, for example, in the 3D modelling and making of little gardens, with the emphasis of the stories on comfort, safety and security:

This garden is all about growing things. So, we've got a greenhouse and we've put tomatoes and Wendy can tell you about the pond. We've got a pond with goldfish in it. Initially we didn't want a pond, 'cause there's a boy in the garden. But we've got a sandpit for the boy. We've got an apple tree and a bird is eating all the apples. We've got a big veg patch as well. We were growing beans, sweet corn and scarlet runners that John put on . . . some scarlet runners. We've got John sitting on the bench and we had a dog. We didn't call our dog anything. We've got a little boy and a little girl, so the garden is getting very busy, at which point John sat, the policeman came in and said what is going on here on then? Lot's of flowers, lot's of red roses, white roses, marigolds, lavender, violets. Sweetcorn in the corner and a big hedge. So, it's all about flowers and vegetable growing.

Participants also expressed their pride in showcasing their work to the other groups, in the end of session feedback. Thus, the participatory arts co-creation activities in our project were seen to positively facilitate expression of ideas and social interaction. Taking part in the workshops seemed to improve the mood of some participants and this extended beyond the actual workshop session, as reported here by the support workers:

Some have been talking about them [workshops] with their families.

We've had a family member of one of the workshop members call in to say that they've never seen their Mum so uplifted and in such a good mood.

This aspect of the findings would warrant further research to assess the level and extent of this improvement in mood in relation to co-design and co-creation activities, as a particularly interesting potential benefit.

Playful cards and recommendations

In order to harness the benefits of co-creation, we developed a set of practical recommendations in the form of cards for reference by researchers, informal and professional carers when setting up and running co-creation workshops. Being loyal to the playful nature of the research, these recommendations are presented as set of playing cards (see Figure 3). The Ageing Playfully cards provide themes and ask practical questions to consider when developing activities for people with dementia.

The cards, which are freely accessible online via the project website (http://imagination.lancs.ac.uk/outcomes/Ageing_Playfully_Cards) suggest activities for each of the different stages in the workshop development: before, during and after the sessions. Workshop organisers can rehearse possible scenarios, individually or as a group, and by following the cards be encouraged to enter into an experiential co-creative space best experienced through play.



Figure 3. The Ageing Playfully cards provide practical recommendations on running co-creation workshops with playful activities.

Discussion

An important aspect of these workshops is whether the people with dementia who participated can be described as co-designers, or whether it is more accurate to describe their involvement as co-creators. This affects the promotion of the methodology as having potential for co-design. If the workshops are reliant on a team or support workers to input design, it is perhaps more appropriate to describe these kinds of participatory workshops as an opportunity to co-create. Claiming co-design may inadvertently distract from the benefits of co-creative activities, which as we indicated in the findings, were felt to be very supportive.

Although Sanders and Stappers (2008) suggest a precise distinction can be made between co-design and co-creation, in our project, we found this to be blurred. In terms of engagement with the process, we recognised that participants were able to contribute to some, though not all, stages of the design process. For example, participants with dementia had some limited involvement in pre- and post-design, though most were not completely cognisant of the project or necessarily able to recall either the pre-design introductions or recall enough to feed back in the post-design phase. Their carers and support workers did contribute throughout, with advice and information on our research plans at the pre-design stage and with very helpful feedback in a focus group we held at the end of the project. As our findings demonstrate, participants were, however, able to actively contribute in the generative and evaluative phases of co-design. Largely, these stages were accessible because the design and co-creation was in the moment, over a short period of time with a tactile 3D model to examine and share thoughts and comments about in the group during the session. Thus, the whole process was a rich mix of co-design and co-creation.

When examining other co-design research projects, that involve people with dementia making a creative contribution to a co-design process, arguably, the activities are also perhaps more accurately described as a mix of both co-design and co-creation. For example, the co-design research project outlined by Rodgers (2015) limited the involvement of people with dementia in the design stage, after they contributed in the co-creation of alternative designs of a tartan. The actual co-design ‘problem space’, and the solution and design brief were decided previously, before engaging with the people with dementia. Similarly, in the work of Treadaway and Kenning (2016), people with dementia were not included in either the pre-design, scoping stage or the generative design stage. The problem space and solution were explored by designers, caregivers and occupational therapists in a co-creation process described by Treadaway and Kenning (2016) as a co-design ‘make together’ process (p. 81). The people with dementia were mainly involved in the post-design phase of testing the prototypes. In contrast, Robinson et al. (2009) included people with dementia in all stages of the co-design process in defining the problem and designing the solution. They describe their project as collaborative not purely co-design, thus, rather than blurring the border between designer and end-user, the

design team took the lead role, assuming a translator instead of the facilitator role (apropos of Sanders & Stappers, 2008). The input from the participants with dementia was considered invaluable and led to the prototypes not being thought appropriate and thus not employed by the end-users. These examples illustrate both the advantages of embracing the collaborative nature of co-design/co-creation dementia projects, and also the challenge of involving people with dementia in co-design, and importance of researchers taking into account the participants' needs and the limits of their engagement. Mayer and Zach (2013) point out that the challenges are often because people may not want to admit their memory problems, or are not aware of, or cannot communicate, their difficulties and needs in the situation.

As we found in our project, the reality of engaging people with dementia in a co-design process does require an acknowledgment that memory and cognition problems do preclude a truly co-design relationship. Building and deepening equal collaboration between users and designers is often just not possible when working with people with dementia, due to the gulf between their capacity for equal participation and that of the designers (Hendriks et al., 2014). Sharing ownership of the research outcomes, even participating in the dissemination also form key characteristics of co-design. However, in the majority of co-design projects involving people with dementia, there is a struggle to truly share ownership and agency either in the process or the outcome, in part due to fluctuating mental capacity, lapses of memory and other cognitive problems associated with the dementia. To fully share co-design means being a named member of the co-design team. Research ethical processes, by default, mean participants must remain anonymised, unless they choose to acknowledge participation, a choice that requires full mental capacity and autonomy. People with dementia, as noted in our research, tend to have fluctuating capacity for consent (Cubit, 2010) (Dewing, 2007) and rely on their caregivers to support them taking part, so are unlikely to be named co-designers (Slegers, Duysburgh, & Hendriks, 2014). Also, as Mayer and Zach (2013) explain, it is not always possible to build a continuing relationship with study participants due to the progression of their symptoms that lead to their inability to remember new people and retain information. The notion of shared ownership and that of managing a continuity of information are critical to co-design, as are engaging with other co designers, communicating and sharing insights about the process. However, as Lindsay, Jackson, et al. (2012) found, it is possible to engage with participants and develop an empathic relationship that facilitates their understanding of the research and the issues they encounter. Communication can pose an issue for people whose dementia has progressed to the stage where their speech is affected, and they lack the ability to communicate verbally (due to aphasia), or can no longer work with visual media or make abstractions (Hendriks et al., 2014).

Thus, we would argue, that despite participatory dementia research projects being described as co-design, in fact it is seldom possible to actually conduct co-design with this cohort. Co-creation would therefore be a more accurate term when conducting

participatory research with people with dementia.

Conclusion

Given the problem of social isolation and depression facing so many people with dementia, there is a need to offer ideas for activities that may be supportive, and relatively simple for caregivers and support workers to provide. In this paper, drawing on the small literature and on our own observations in a qualitative, co-design project, we have explored notions of co-design and co-creation and the extent and ways people with dementia may be engaged as co-designers and creators. We conclude that for people with dementia, participatory arts activities and co-design are most accessible as collaborative mixes of co-design and co-creation, and that realistically it is not helpful to insist on pure forms of co-design.

We observed considerable benefits in what could be more accurately termed ‘collaborative co-creation’. Similar to reports from other projects (Robinson et al., 2009; Rodgers, 2015; Treadaway & Kenning, 2016), our participants were engaged and energised by the playful activities. They shared ideas together and played with designs and models in a remarkably and unusually interactive way, drawing in even those people who were less verbal or sociable. We argue that collaborative co-design and co-creation, Treadaway and Kenning’s (2016) ‘making together’ has positive potential to support people with dementia and their caregivers.

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Emmanuel Tseklevs is a senior lecturer in design interactions at ImaginationLancaster at Lancaster University. Emmanuel leads research at the intersection of design, health, well-being and technology. He conducts research in the design of health interventions and services, which are co-created with end-users and are aimed at improving the quality of life and wellbeing of people into old age, including people with chronic and non-communicable diseases.

Amanda F Bingley is a lecturer in health research in the Division of Health Research, Faculty of Health and Medicine of Lancaster University. Amanda is involved in work with the Centre for Ageing Research and has an interest in research with older (and younger people) with a focus on health and place. When facilitating research with people of all ages, she works with a range of qualitative approaches including narrative, ethnographic, creative arts and participatory research methods.

Maria A Lujan Escalante is an international lecturer in design. Her research explores cultural implications of digital-physical interactions through participatory and creative methods. She specializes in facilitating creative workshops that foster knowledge exchange in imaginative ways. Maria is currently working in projects that explore ethical dimensions of ICT innovation as creative process.

Adrian Gradinar is a researcher and designer, whose main area of interest focuses on the intersection of the digital world and the physical one. His research explores how design and the practice of research through design are central to creating better experiences for everyone living in and experiencing this hybrid space. Through his own company, Adrian continues to deliver a wide variety of products and services to both academic and industry partners.