

Introduction

Worldwide, 35.6 million people have dementia (Wortmann, 2012). It is a condition which requires both societal and medical responses. Nearly two thirds of people with dementia who live alone feel isolated (Alzheimers society, 2013). People with dementia without supportive social networks report lower wellbeing (Cooper, Bebbington, and Livingston, 2011), but are least likely to be able to access activities, including cultural activities. This is concerning as observing and participating in cultural activities improves mental and physical wellbeing in population studies (Cuyper, Krokstad, Holmen, Knudsen, Bygren, and Holmen, 2012). Alzheimer's Disease International advocates creating 'Dementia Friendly Communities' by adjusting local services, support networks, and broader social structures to create environments where people with dementia can live well (Wortmann, 2012).

There is a growing body of research exploring the use of the arts in treatment and care for people with dementia. Recent work (e.g. Backhaus (2011) and Kilick's *Dementia Positive* (2012)) has explored this trend. Kitwood's work on 'personhood' and on defining a 'person centred' approach to dementia care has been extremely influential, and has facilitated the embedding of arts and health based approaches to dementia care in mainstream health policy discussions (Kitwood, 1997). As Ryan and Martin (2013, p. 196) suggest, 'it is increasingly apparent that arts-based therapies such as visual art, music, drama, poetry, horticulture, dance and storytelling can be important vehicles for patients to express their thoughts, emotions, and ideas in symbolic fashion'. Recent work by Beard (2013), de Medeiros and Basting (2013), and Zelig, Killick and Fox (2014) has systematically reviewed arts and health interventions for people with dementia. Participating in arts-based cultural activities has been shown to improve wellbeing of people with dementia, and even those with more severe illness can derive enjoyment from and commit to appropriately tailored activities. Positive effects on observer-rated wellbeing, have, for example, been reported with abstract art-making sessions delivered by student volunteers (Sauer, Fopma-Law, Kinney and Lokon, 2014), museum object handling (Johnson, Culverwell, Hulbert, Robertson

and Camic, 2015), and art gallery visits together with family carers (Camic, Tischler and Pearman, 2014). People with dementia have also demonstrated commitment to and derived satisfaction from artistic education workshops in a day centre (Ullan, Belver, Badia, Moreno, Garrido, Gomez-Isla, Gonzalez-Ingelmo and Tejedor, 2013).

In 2013 the Bloomsbury Festival (London, UK) team sought to extend festival's year-round programme of community engagement activities and create a 'Festival in a Box', a 'cultural meals on wheels' (Mager 2013) that would take the festival to the homes of local residents with dementia who were unable to attend the event itself. Working with the Bloomsbury Festival team to develop this idea, our study aimed to trial the first intervention to bring cultural activities led by professional artists to isolated people with mild and moderate dementia in their own homes. We aimed to test, in a qualitative study, whether and how they engaged in the project. We used interviews with participating artists and dementia 'befrienders' to triangulate the perspectives of people with dementia engaging with the 'Festival in a Box'.

Methods

Ethics

We obtained study approval from the University of London School of Advanced Study ethics committee.

Recruitment

We first recruited befrienders from a local Age UK Camden 'Dementia Befriending Service', a volunteer service that specifically supports people with dementia who have no regular carer and are unable to access support services outside the home such as day centres. All befrienders were told about the study at a team meeting and invited to discuss it further if they thought any of their clients might be interested. Participating befrienders then invited their befriending clients to take part if they met the following inclusion criteria: diagnosis of

mild or moderate dementia and capacity to give informed consent to take part, as assessed by the befriender.

To ensure a person-centred approach, participating people with dementia filled in a simple questionnaire with their befrienders to provide background on their current or past cultural interests. Artists skilled in these activities were recruited from the Bloomsbury Festival's collaborative community of artists and allocated to participants based on their preferences for activities. The artists represented a number of disciplinary backgrounds, and included a ceramicist, poets, a filmmaker, a photographer, and singers. Artists received introductory training in working with people with dementia from an Age UK Camden representative and the project team. This comprised half a day of training: a brief, didactic session on dementia followed by a group discussion on how to manage communication difficulties in dementia such as speech and hearing loss or problems with memory or understanding. The study team were available throughout the project to discuss any concerns between visits, and an artist representative on the steering group relayed more general concerns of the artists to the group.

'Festival in a Box' development

Development process

Using the 2013 Bloomsbury Festival programme as a starting point, a panel comprising the authors, two professional artists, a befriender, a festival organiser and a local architect developed the framework of the 'Festival in a Box' outreach programme. We decided to build a single, portable, layered box that the artists would take with them to each session, with space for materials for the main activity selected by the participant and befriender. The box also included additional materials for other activities if the person did not engage with the selected activity, for example photographs of the local area to guide reminiscence. Finally there was space to add artistic materials from the session that the participants wanted to

contribute to the 'Festival in a Box' archive. The architect designed and made the box (Figure 1).

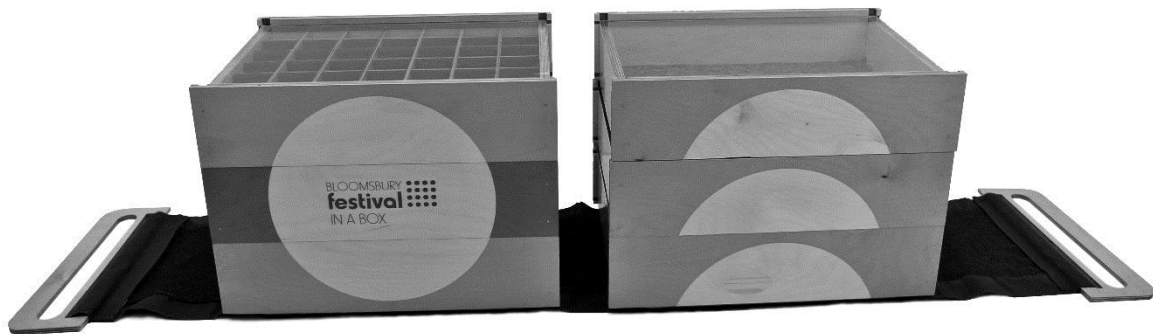


Figure 1 – The box.

The 'archive' component of the box was conceived as creating a two-way interaction between festival and people with dementia. Embedding an archive within the box meant that the engagement process was documented, and a resource was created that could inform the evaluation process, and (where suitable) be displayed to the public. In the heart of Bloomsbury, an area famous for its libraries and collections of international importance, our project sought to assemble a small archive formed collaboratively by all the 'Festival in a Box' project participants.

Attendees of the 2013 Bloomsbury Festival were also encouraged to suggest ideas and experiences from the festival to include in the project. At the festival a stall, manned by the study team, presented an exhibition of designs for the 'Festival in a Box' and invited festival

attendees to collect objects and write down their impressions of the festival. These were discussed by the study team at their meetings and offered to participating artists for inspiration in shaping their activities. For example, leaves collected during the festival were incorporated into a tile-making workshop led by the ceramicist.

Visits

The 'Festival in a Box' outreach programme comprised weekly home visits by an artist who delivered cultural activities to participants in their own homes. The activities (which included music, poetry, pottery, ceramic tile and wrapping paper making, and photography) were selected in advance, using a checklist prepared by the study team and completed by the befriender with the person with dementia.

Artists visited with the befriender and the researcher. Sessions lasted about an hour, including the artistic activity and qualitative interview as these were carried out in parallel, to minimise recall bias. Sessions were planned by the artists who adapted their usual professional performances or workshops to the situation, drawing on the training session they attended as part of the study, resources collected during the 2013 Bloomsbury Festival, and their professional and personal skills. As the activities were selected by the client and session content responded to the artist-client interaction, each session was unique, but followed a standard structure: (1) the researcher discussed the study with participants and obtained written, informed consent; (2) the artist introduced the activity planned; (3) participants were engaged in the activity; (4) discussion of art works produced.

Participants were also encouraged to tell stories about memories evoked by the activity, and reminisce about the local area, with local photographs from the box used as prompts where appropriate. Clients were engaged, where possible, in developing materials—drawings, writing, photographs or a verbal response to the existing material. These materials were

sometimes kept by the participants, and some were added to the box at the participants' discretion. In this way, a weekly 'archive of engagement' for each participant was developed.

Each participant was visited 3-4 times, with the number of visits decided by whether data saturation for a participant was reached or new information was still emerging. In some instances artist availability affected the planned activity for visits.

Assessment

Qualitative interviews were carried out by experienced researchers with all participants with dementia. We also collected socio-demographic information using a standardised questionnaire. The interview topic guide included the following questions: "How long have you lived in this area? What did you do today? How did it make you feel? Have you done anything like this before? Please tell us about it. Did it make you think about/remember anything about your life in this area?" Questions were kept deliberately simple, and were repeated for each visit. Open-ended questions were used to encourage storytelling. The interviews were in the participant's home and carried out during the cultural activity and immediately after it. The befriender and artist were present.

Befrienders and artists who took part in sessions were also interviewed separately, after all the sessions were complete. The topic guide for these interviews included questions about how they thought the person with dementia had engaged with and felt about the activities, how the interviewee had felt during the sessions and what memories it may have evoked for them. Artists were also asked whether and how participation in the project had changed their views about dementia or their professional artistic practice. Interviews were conducted in the presence of the 'Festival in a Box' archive section for each participant, which was used as a prompt throughout the interview process.

Analysis

We employed thematic analysis. This is essentially a method for identifying and analysing patterns in qualitative data. We digitally audio recorded all visits, including interviews, and transcribed them verbatim, removing all identifying information from transcripts prior to analysis. Transcripts from the people with dementia, covering both the outreach delivery and interview were analysed together. Transcripts from artists and befrienders were analysed separately.

Our analysis plan followed the phases of analysis outlined by Braun and Clarke (2006): familiarisation with the data, coding, searching for, reviewing and naming themes, and writing-up. Three researchers read and re-read the transcripts, thematically coded all data independently to ensure reliability, and identified themes. A group reading was then conducted by the project steering committee, comprising the authors, an artist, a befriender and a festival representative. All members of the group read the transcripts separately and then the three project researchers presented their proposed themes. Other group members suggested additional themes, and disagreements were resolved by group consensus. The contents of participants' 'Festival in a Box' archives were also presented at group readings to prompt discussion. Artefacts from the box and photographs from visits facilitated discussion. Together the group finalised a coding frame, which was used to code the interviews. This process was repeated for the befriender and artist narratives.

Results

Six individuals with dementia participated. Four lived in their own homes and two in sheltered accommodation. A seventh participant withdrew due to ill-health before the start of the visits, while the others were visited 3-4 times. Activities selected by the people with dementia and their befrienders included music (listening, singing, jamming), poetry, pottery, ceramic tile and wrapping paper design, and photography.



Figure 2 - Tile making on Festival in a Box visits.



Figure 3 - Ceramics workshop on Festival in a Box visits.

In total, seven artists undertook weekly visits as part of the project, of whom four responded to a follow-on request to be interviewed. All three befrienders who took part were interviewed.

Table 1 describes the participants and the visits. Themes identified across the transcripts are discussed below.

Individuals with dementia

Understanding and engagement

All but one participant responded to the sessions in ways that indicated they engaged well and enjoyed them.

“When she sings I remember the words. I remember the words and I know the song” (P3)

“Gosh I didn’t realise I could do anything like that [...] I’m a genius!!” (P1)

“Yes, yes, yes, because you’ve got imagination and apart from this chap here, [befriender] I never meet anyone with imagination” (P4)

One participant (P6) was confused by activities including poetry and ceramic tile decorating and was only engaged by more general reminiscence of her life in the local area.

“I’m now completely confused, one, two, three people, who...” (P6)

Reflections on other cultural activities

Some participants reminisced about their cultural activities before dementia onset.

“I was never frightened of standing up and projecting when most people were embarrassed” (P4)

“I didn’t perform as showman. I didn’t perform but I played guitar” (P3)

“I was [shy] at first but from being in a drama group you get to open out. That’s a good thing. If you know a good drama group, you join” (P2)

In other cases, the visits provided an opportunity to reflect upon the loss of cultural activity and other losses related to illness or old age. For one participant (P3) the visits evoked frustration about speech problems resulting from vascular dementia:

“I’ve always scribbled one way or the other [...] I think this is the only time I haven’t, now” (P5)

“It’s been a long time since I did anything like that [...] But I used to love it” (P2)

“there are times that I feel that I’m in prison for a crime that I haven’t committed. I still feel that” (P4)

Voice, Agency & Participation

Participants often discussed their right to be heard and their capacity to participate fully in the activities. The importance of *voice* and of being heard emerged as a dominant theme across the sample. In some instances this was contrasted with previous life experiences of being silenced, particularly in childhood. We were challenged as a team to use the correct language and questions to facilitate speech:

“I had a very strict school. We didn’t talk much” (P2)

“You’re asking the question, let me finish it” (P4)

“You see I’m not like most of your patients who are incapable. I’m capable of doing absolutely everything” (P6)

Themes of voice and voicelessness were encountered most strongly in participant 3. Loss of speech and memory, and resulting frustrations, were very apparent in this narrative, which was marked by a strong desire to talk:

“I want to read my poems [aloud]. I can’t read them. I start to read them. I’m trying to read them” (P3)

“I would tell you a lot more, but I can’t tell you anymore” (P3)

Community engagement/ isolation

Memories of lives lived in central London were often set against participants' perception of their current community, neighbourhood, and social environment in a modern, international city. Themes of anxiety and precariousness were detected, but also reflections on the importance of community support networks that participants continued to draw on.

"Well will I still be brave enough to go out there?" (P1)

"I've been here a long time, but I don't know a lot of people" (P2)

"[London is] an international transit camp with pieces all over the place" (P4)

"All my children learnt to walk in the British Museum on that lovely floor... There's a room with highly polished floor and they loved it because they slithered, that's how my children learnt to walk, in the King's Library" (P6)

"Everybody in Sainsbury's. I go in and I say... I've got my milk and my bread and they say you were here half an hour ago and bought that! ... They are really nice, the people in Sainsbury's" (P1)

Befrienders' Perspectives

Befriender characteristics are detailed in Table 2. Befrienders reflected on how their perceptions of what participants could do despite dementia had changed and how they might incorporate the activities in future sessions.

"I think giving poetry, writing poetry, all that stuff. I mean I think that's good for him. Getting his attention, really challenging him to do a lot of things. I think I will try and do that more" (B1)

"I didn't think he could do that [play notes on the piano] with his dexterity and everything. So that was really nice. Even with the poetry I didn't think he had such strong passion for it. Such determination to get it done. Like I think that's the most determined I've ever seen him do something" (B2)

"She was also trying to get him... doing things which would get him to... story-tell and he told a bit about his own life and it's a form of story" (B3)

"I think she definitely went into more depth than I'd known her to when I've been on my own with her. Definitely more" (B4)

Artists' Perspectives

For the artists interviewed, working on the project helped to de-mystify dementia, countering negative stereotypes and challenging their preconceptions of the condition.

"I suppose I feel more humane towards it [dementia], because before it was kind of like a clinical...it's person with dementia [...]. In my general life I don't integrate with people with dementia and I don't...So it's kind of like... It's just more about the person, I suppose" (A1)

"I had the fear it was going to be really depressing and I would come out crying my eyes out [laughing]! But of course it wasn't. It was absolute joy" (A2)

Several artists noted that the project had changed their perspectives on their own practice.

In some cases this resulted in new work being created, whilst others found it had influenced their subsequent creative work.

"I think it strengthens your practice, it is good experience and it pushes you to really think about what you're doing in a different way" (A4)

"A lot of the work I do is all about story telling—and it made me get right down to the nitty-gritty and break it down to what is this actually about [...]. It made me ask myself questions about what my story was that I wouldn't have done necessarily otherwise" (A3)

Cross-Project Theme: connections and meaningful encounters

Across participants, artists and befrienders, interviewees spoke of the unexpected synergies and moments of meaningful encounter that had been created by the 'Festival in a Box' project:

"[Did you enjoy today's visit?] Yes, yes, yes, because you've got imagination and apart from this chap here, [befriender] I never meet anyone with imagination" (P5)

"[The best part was] meeting people, hearing stories. People that have lived in Camden...I've lived in Camden my whole life, so meeting people that have lived in Camden for 30 years, 40 years and hearing their experience of it. [...] you don't hear the stories of people that have lived there for 40 years. You know what I mean? You don't really get that" (A3)

"That's one of the things I get from the Bloomsbury thing. Like when you think about these artists, you know, you, me, [participant's name], really unlikely people to come together and share something amazing. So, yeah, that gives me a lot of hope and, yeah, I think I would take that away from it" (B2)

Discussion

Participants with dementia, artists and befrienders enjoyed and engaged with the 'Festival in a Box' visits, through active participation in arts and music, humour, and through sharing memories about places and events. The project allowed people with dementia freedom to tell their stories, prompted by engagement with cultural activities. It also allowed participants, artists, and befrienders to discover unexpected affinities and points in common. The main themes from people with dementia's interviews were: engagement, reflection on value of previous cultural activities, current feelings of precariousness and isolation and the importance of having a voice and being heard. Artists engaging with people with dementia for the first time gained new perspectives on the condition, which challenged preconceived perceptions, stigmas and apprehensions. Some also developed new work or spoke of new perspectives gained on their creative practice. Befrienders with established relationships with participants gained insight into their clients, their life histories, and their narratives of self. All of those involved in the project, participants, befrienders and artists, described unexpected moments of connection and meaningful encounters.

By working with an established befriending service, we successfully engaged isolated people with dementia. By engaging befrienders and the people with dementia to choose the cultural experiences, we enabled them to retain control over their session, and we think this helped engagement. We are not aware of previous intervention trials that have included people with dementia living in their own homes without identified family carers. Through interviewing participants during the visits, we explored how the participants felt at that time, as most would not have been able to accurately report their feelings about the project after the event due to memory impairment. Because of this unstructured, flexible approach we cannot fully manualise the project. It provides a structure through which professional artists can bring their performances to isolated people with dementia, but the intervention will vary with the artist's skills and abilities to communicate.

This was a small-scale, exploratory outreach programme. As such, the 'Festival in a Box' project raises a number of questions which may need to be addressed by a research on a larger scale and with a more controlled sample group. One issue that warrants further study is how much of the enjoyment and engagement we reported may have been due to companionship of the visits rather than the specifically arts-focused activity of the 'Festival in a Box'. Recent work by Johnson et al. (2015) has offered compelling evidence of the unique effectiveness of a museum object handling activity in direct comparison with straightforward social activity. However we did not include such a control in the 'Festival in a Box' visits, as this was not a controlled study.

Our analysis suggests that the combination of art activity and the social nature of the visits—a combination used effectively in 'social prescribing' initiatives (Stickley and Hui, 2012), (Stickley and Eades, 2013), for example—improved the subjective wellbeing of all those involved in the project. This was demonstrated across the 'temporary community' achieved in the triangulation of perspectives offered by dementia befrienders, artists and people with dementia involved in the study.

Beard (2013) notes that art therapy with people with dementia can 'empower participants and stimulate conversation, interaction, and meaningful activity' (p.7). Zelig et al. (2014) note that, 'arts projects can produce internal connection and also friendships [they] create a space that outside the demands of daily life and [foster] the ability of people with dementia to engage reciprocally' (p.26). Our results suggest that 'Festival in a Box' activities empowered people to tell their stories and interact, which in turn created meaningful moments of social interaction for all of those involved in the project. Just as the 'Festival in a Box' outreach created a miniature and peripatetic 'festival', it can also be seen to have created a temporary space for shared meaningful experiences among the project community, with the box itself acting as an 'archive' of these moments of interactions.

The 'Festival in a Box' programme is now a regular part of Bloomsbury Festival, so that local isolated people with dementia continue to be included in the event year-round. Moreover, selected materials from the 'Festival in a Box' have been on public display in arts spaces across the UK and we hope this will advocate for inclusion of arts in dementia care and people with dementia as involved citizens in community arts festivals. We continue to explore the possibility of a future larger-scale pilot study of the programme, which could explore in greater detail the complexities of methodology in measuring the impact of arts and health activities for people with dementia.

The UK *Prime Minister's Challenge on Dementia* notes that, '62% of people living with dementia living alone are lonely and [...] people with dementia find it hard to access services which may help them overcome this isolation' (p.22). 'Put simply', it suggests, 'our society is not geared up to ensure people with dementia can live well in the community' (Department of Health, 2013, p.13). Our small-scale 'Festival in a Box' project (project website: www.festivalinabox.blogs.sas.ac.uk) successfully engaged and enthused people with dementia, artists and befrienders in this intervention development study. If larger scale studies are also positive, the project could provide a format for inclusion of people with dementia in festivals and public events, so that 'dementia friendly' festivals and events can contribute to our collective vision of 'dementia friendly communities'.

Table 1: Participants with dementia characteristics and visit summary

ID	Demographics	Visit summary
P1	Woman in her seventies has lived in local area for 40 years.	Ceramic tile making and wrapping paper design. Great enthusiasm for the activities leading to reflection upon earlier life. Articulation of fears and anxieties in regard to family, money and dependence.
P2	Woman in her early nineties has lived in local area for over 40 years.	Opera singing and poetry. Visits allowed reconnection with previous cultural experiences as a performer and demonstration of skills in an environment that allowed for mobility and memory problems.
P3	Man in his seventies, originally from Barbados but a long-term resident in UK.	Photography, music and poetry. Due to severe speech problems, from a previous stroke, he expressed frustration during the visits about the communication difficulties linked with memory problems
P4	Man in his late seventies.	Reminiscence and poetry. Other artistic activities were more problematic as he tended to narrate 'signature stories'
P5	Man in his eighties. Lived in London for much of his adult life, originally from Ireland.	Poetry and storytelling. Conversation did not flow easily during these visits with him preferring to observe and listen. However memories emerged and humour played an important role
P6	Woman in her late nineties has lived in Bloomsbury for over 60 years.	Reminiscence and ceramic tile making. She has links with a Bloomsbury Festival from 1970's. She challenged the use of reminiscence; changing the activity was more successful in getting her to talk about her previous experiences.

Table 2: Befriender characteristics

ID	Demographics	Years befriending
B1	30 – 40 years old	2.5 years, 2 years with current person with dementia
B2	18 – 30 years old	4 years, 6 months with current person with dementia
B3	65 – 75 years old	5 years, all with current person with dementia

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