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Participatory video and well-being in long-term care

Film-making is an effective way of engaging people with dementia and improving their well-being. **Andrea Capstick** and colleagues explain how 'participatory video' gave one group an opportunity to tell their own story in film

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*Participants' real names have not been used.

When people living with dementia are involved in film-making projects, the subject of the film is often limited to their own 'illness experience' following diagnosis. But what would people with dementia themselves decide to make films about, given complete freedom of choice? And what impact would making such films have on their social participation and well-being?

These are the questions we set out to answer in our recent research study on participatory video in long-term dementia care. Over 18 months in 2012-2014 ten people with dementia took part (eight women and two men, with an average age of 87 years) all of whom were living in the same long-term care facility in the north of England. Each of these participants worked with us to co-construct a short film, using simple digital storytelling software to join individual still images together to form a slideshow. The participants' own voices – speaking or singing – form part of the soundtrack, and we also edited in sound effects and music to accompany the images they chose. This article explains how the study was carried out, what the participants chose to make films about, and what we discovered in the process about the impact of film-making for our participants.

Participatory video

Participatory video (PV) is an approach to film-making which aims to give people who are socially marginalised or excluded an opportunity to tell their own story in film (Milne *et al* 2012). It has been used worldwide with many groups of people who struggle to have a voice, such as homeless people or those living in socially-deprived communities. Prior to a pilot study we (Andrea and John) carried out in 2011, however, it had not been used with people with dementia. The pilot study was carried out with people attending a day centre for those with young-onset dementia, and it seemed to enhance self-esteem and social confidence for those who took part (Capstick 2011). People living in long-term care are, of course, particularly prone to social exclusion, and that is why we decided to see if the findings would also apply in this kind of care environment.

In PV it is of paramount importance that control of the process, including decisions about what to include and what to leave out, is handed over to

the participants, who become – in effect – the film directors. In the case of people with dementia this involves making adaptations which enable each person to take part in line with his or her abilities and preferences (Capstick 2012).

Participants were selected on the basis that staff or relatives had concerns about their current levels of well-being or social participation. We looked out for people who seemed to be on the margins of activities that already took place, or did not seem to be getting the opportunity to make full use of their abilities. We did not exclude anyone on the basis of cognitive difficulty. Three of the ten participants had capacity to consent for themselves, and in line with Section 30-33 of the Mental Capacity Act 2005 'consultees' were approached to give an opinion on whether each of the remaining seven would have wished to take part at a time when he or she had capacity. All consultees felt this would have been the case. We also used process consent (Dewing 2007) as we went along to ensure that all participants were happy with each stage of the project.

Film-making process

We started out using a process known as 'photo-elicitation' (Harper 2002). We presented participants with a series of images from online image libraries with a Creative Commons licence (eg Flickr). To begin with we used generic images, for example, animals, flowers, actors, political figures and archive images of the local area. Sometimes these were downloaded and printed as hard copies, and sometimes they were shown on a tablet device. As we came to know participants better, we were able to develop an increasingly



individualised sequence of images for each of them.

Henry*, for example, told us the name of a village he had been evacuated to during the war, and showing him pictures of this village elicited more information about his time there, including how he had helped the local blacksmith in his forge. A new set of images of blacksmiths and the tools of their trade was then identified in order to tailor Henry's film to his precise memories. Many of the films also incorporate family photographs that we scanned in order to create an electronic copy.

The next stage was to put the sequence of images into a storyboard, or album, mapping out possible content of the film. This was flexible and could be added to, or put in a different order, during the six weeks that each film took to complete. When the films were finished, participants could also keep the hard copy album, and we used any left over images to make collages which participants could put on the wall to remind them of the process.

The films were made using free digital storytelling software called Photo Story (version 3) to upload the saved electronic images in the desired order. Sound tracks were added to create an audio-visual slideshow. The simplest way of doing this is to use music tracks within the Photo Story package itself; for example Hope's father was a keen pianist, so her soundtrack includes piano music from this internal menu. We also audio-recorded participants talking about the images they had chosen.

We edited the pictures and words together using another free download called Audacity. Some participants liked to sing. Lily's film incorporates her own rendition of several songs she told us her husband used to sing to her. In other cases we used music downloads; for example, Henry particularly wanted *I'm looking over a four-leaf clover* on his soundtrack.

We used software called Freesound to add the sound of crashing waves to accompany a seashore image, or birdsong for a countryside scene. All participants were asked if they wanted to give a title to their films, and several did so. In other cases, titles were taken from interesting things the person said during the film-making process. Rita's film is titled *Down where all our roads end*, because that was how she described the area of terraced housing, since demolished, where she grew up.

The subjects of the 10 films are listed below. Consistent with findings about the 'remembrance

Subjects of participants' films

Name*	Age	Subject
Henry	85	The fenland village where he was evacuated during WWII
Florence	88	The area on Merseyside where she grew up in the 1930s
Eileen	76	A children's home in the north of England
Joyce	92	A maternity hospital where she worked as a young woman
Nora	87	The NE coastal town where she lived as a young girl
Lily	86	A close-knit area in the Yorkshire city of her childhood
Rita	81	WWII bombing and evacuation to the Lincolnshire countryside
Rose	99	Her home as a newlywed and the department store where she worked
Frank	92	His school in Ireland, and work for the Employment Exchange
Hope	81	A specific road in the Yorkshire city where she grew up

bump' in autobiographical memory (Thomsen & Berntsen 2008), they are all linked with memories from the period between approximately five and 30 years of age, and with emotional events and specific places from those years.

Social participation and well-being

Before the film-making activity started, we observed each participant, during a period of time when he or she was taking part in another activity provided at the care facility, using the behaviour category codes (BCC) coding frame from Dementia Care Mapping (University of Bradford 2005) and the Bradford Well-being Profile (University of Bradford 2008). Many of the activities the 10 participants were involved in at this baseline point had high potential for well-being (eg art group, music group, table-top games) but we found that for nearly a third of the time (31%) participants were either not taking part in the intended activity at all, or were doing so only passively. Although there were numerous indicators of well-being such as showing affection, displaying creativity, and expressing humour, all participants exhibited some negative indicators such as boredom, anxiety or listlessness.

When we repeated the same measures during film-making (sometimes one-to-one, sometimes in small groups) we found that given a free choice of how to spend the time, a full 59% was spent in reminiscence, with most of the remainder spent in general conversation (29%) or creative self-expression (9%). None of the time at this mid-point data collection was spent in disengaged or passive states. There were observable improvements on baseline during the PV intervention, with very high levels of well-being for some participants while making and watching their films. Nine of the 10 participants had ▶

Photographs

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Social citizenship for Eileen

Eileen's interests were predominantly sporting ones, particularly running, swimming and cycling. Many trophies and keepsakes were on display in her room. On occasions, Eileen had been swimming with a member of the staff, but within the care environment her interests were not drawn on when planning activities.

The baseline measures were completed when Eileen was taking part in a large music group, during which she seemed bored and listless. When there was no scheduled activity taking place, Eileen often provided care to other residents, listening to their problems, and giving advice. Occasionally she would find these demands distressing, and try to find a member of staff to take over the responsibility. Once a week a group of students from a local school came to visit, play bingo, and give manicures to the residents. Although Eileen is very articulate and has interests that the students would be likely to share, she was only passively involved in these visits.

Eileen's film has a strong narrative, telling the story of how she used her sporting interests to deal with difficult feelings about growing up in care. She describes cycling, in particular, as a route to escape and independence. Initially, Eileen was apprehensive about whether people would like her film, but when they did she became very proud of it, and asked for copies for all her relatives. She was particularly keen for her film to be viewed widely, to ensure that what she had experienced as a child in care did not happen again. She also contributed to an article about the study in the care organisation's newsletter.

When a play was staged at a local theatre about a former cycling colleague of Eileen's, the manager booked tickets for the two of them to go and see it together. The theatre arranged for Eileen to go backstage and meet the cast, and she was presented with a signed copy of the script.

► significantly increased positive well-being scores ($p < 0.05$) between baseline and mid-point observation (ie comparing 'activity as normal' with PV). All 10 participants showed a significant decrease in negative indicators between baseline and mid-point ($p < 0.05$).

After the six-week intervention we observed each participant again during an activity provided independently by staff, in order to assess whether the study had any impact on the kinds of activities on offer. The overall range of activities had increased slightly, and disengagement during activities decreased from around a third (31%) to a fifth (21%) of total time. Active self-expression more than doubled from 8% to 17%.

Reminiscence, which was not observed at baseline, did now feature, although still accounting for just 5% of the time by comparison with 59% during the film-making process. When participants were watching their own films, at

least one week after the intervention had ended, well-being did not decrease significantly, suggesting that PV had benefits that were independent of the general social interaction with the researchers that accompanied it.

The number of participants here was small for purposes of statistical testing but the findings are strong, and consistent within the sample. It should be noted, however, that in one instance a participant who had greatly enjoyed watching a film which included images of relatives who had died, later become upset because she could not find them. It may be that she would have been reassured by watching the film again had time allowed, but it must be acknowledged that this kind of distress is a possibility in any form of reminiscence work.

Because people living in long-term care tend to be cut off from the wider community, we also wanted to find out whether PV might have potential to enhance community engagement. To assess this we used an adapted form of Arnstein's 'Ladder of Citizen Participation' (above left).

Published in 1971, Arnstein's ladder is still regarded as a touchstone for service user involvement. The lowest rung of the ladder, 'Manipulation', represents forms of involvement that are coercive or personally inappropriate. For example, the person with dementia may be involved in activity that is not in keeping with his or her own wishes, and there may be a degree of coercion to take part. The highest rung, 'Citizen power', indicates genuine influence beyond the confines of the care environment itself; here the person with dementia decides on the nature of the activity and its intended outcomes. In between are varying degrees of choice and engagement, from activities undertaken solely with the aim of 'making the person better' ('Therapy' – rung 2) to more authentic and negotiated partnership working around rungs 6 and 7.

Eileen in her cycling club days (her own photo)



We found that participants' potential for social citizenship was higher, on average, by around three rungs than it appeared at the outset of the study. Among other activities, the participants were able to co-construct films which have been hosted by local history websites and screened at film festivals, to attend dissemination events, and to join a service user panel of 'experts by experience'. The case study example (see box, left) outlines in more detail how this worked for Eileen.

Additional findings

All 10 participants were able to complete a film that was meaningful to them, and enjoyable for them to watch either alone or with others. In several cases this was in spite of significant problems with short-term memory and language. Although each film was unique, there were some common themes, in that all participants wanted to make a film that was autobiographical and located in a specific place. Making and watching films together proved important, and had potential for breaking down barriers between people with and without dementia. Group viewing validated the lived experiences and achievements of the participants.

The content of the films also helps us to understand more about the intersections between social and national history and the lives of people with dementia. Henry and Rita both talked about experiences of being evacuated during the war, and Frank talked about leaving Northern Ireland during the Troubles. We suspected that living in a care environment was sometimes reactivating memories from much earlier in life, of having to leave a familiar place for one that was relatively strange and unknown (Capstick & Ludwin 2015).

On a lighter note, all participants spoke frequently about local cultural traditions and leisure pursuits, such as fairs and sports days, dance halls and cinemas, and the neighbourliness of local communities. These findings tell us a lot about what people with dementia may value and enjoy doing, and show that a little local history research on the part of care staff can be invaluable.

We found that the use of visual images often appeared to enhance vocabulary and fluency of speech. Nora – a former secretary – was one of the participants assessed not to have capacity to consent for herself to take part. In general conversation her ability to produce spontaneous speech was quite limited. In the following transcript Nora is looking at pictures of typewriters and shorthand notebooks. She not only remembers the word 'shorthand', but also reads a word in shorthand before the researcher manages to decipher it.

Nora: Oh, look it's in shorthand, as well! Have you done it?

Researcher: I have; I learned to do shorthand when I left school, and it was just like that. I can still do it a bit, but not much.

N: Oh well then, you do it a bit, go on!

Researcher demonstrates shorthand outlines for "This is..."

N: (Laughing) I can't do it you see; but that's gorgeous!

R: (Reading the extract from the shorthand notebook) I think that says, "In many...";

N: "Branch?"

R: "Branches of..."

N: "In many branches of" – is that it?

R: I think so!

Conclusion

We set out to discover whether PV improved social participation and well-being for people with dementia living in long-term care. Using BCC, the Bradford Well-being Profile, and Arnstein's Ladder of Citizen Participation we found positive outcomes for all 10 participants individually, and for the group as a whole. Notable additional benefits were the potential for watching films together to enhance relationships between people with and without dementia, and for visual images, when used as prompts, to facilitate conversation and improve recall, vocabulary and verbal fluency.

Although each film was unique, there were some distinct recurring themes. All films were autobiographical and related to childhood or early adulthood. All were also firmly grounded in a specific location, or locations, and connected with emotional memories from that period in the person's life. The findings add further weight to the body of research on reminiscence, with the majority of time spent in this type of activity when participants had a choice. As with all reminiscence-based activity, there was potential for participants to become upset when talking about unhappy events or people who had died. In our study there was one instance of such memories causing significant distress later. This must be balanced against the evident enjoyment the participant had gained from watching her film at the time.

Staff at the care facility where our study was carried out took part in an end-of-study focus group where they identified a number of potential uses for PV. These included: creating slideshows with photos taken during outings and activities to play in the lounge, showing films to local schoolchildren to increase intergenerational and local history awareness, and using autobiographical film in the induction process for new staff.

In the autumn of 2014 we held a workshop on how to carry out PV with people living with dementia as part of the Bradford Science Festival. We are now keen to repeat this in other venues. As part of the funding from NIHR-SSCR we have also produced an information pack, including a copy of the dissemination DVD from our study, and a step-by-step 'How to conduct your own PV project' guide. ■

• **To receive a copy** of the participatory video (PV) information pack, please send your name, postal address and brief explanation of how you will use it to a.j.capstick@bradford.ac.uk. Copies are available free to the first 100 eligible people (clinicians, practitioners, researchers, students or artists conducting relevant projects) to contact us.

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