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## **Travels with a Flipcam: bringing the community to people with dementia in a day care setting through visual technology**

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Type of article - Shorter submission: Early report on a study of technology in situ

Abstract: This paper discusses the exploratory process of making a short digital film with two women with early-onset dementia in a day care setting. The film was produced as part of a larger participatory video (PV) pilot project within the day centre. My main subject here is the adaptations to the standard PV process which I made in order for the two women, Pam and Carol\*, to be able to take active part. These adjustments took account of their individual abilities related to cognition, physical mobility and social confidence. I discuss the development of an asynchronous approach, which involved my going out into the local community to capture images of Leeds City Market using a mini-camcorder (Flipcam) and the subsequent addition, at the day centre, of voice-over commentary by the two women in response to the visual images they saw on screen. Extracts from their film narrative presented here suggest that participation in the film-making process helped to reconstruct their sense of cultural identity and social engagement. The resulting short film is now being disseminated to Dementia Studies degree students by way of their social networking site.

Key words: Dementia; digital film; participatory video; social inclusion.

### *\*A note on ethics:*

Under the terms of the Mental Capacity Act (DoH, 2005) people with dementia are deemed to have the capacity to give informed consent unless it has been demonstrated by formal assessment that this is not the case. The approach followed in this project was to gain ongoing, negotiated process consent at each visit and within visits whenever a new activity was introduced (cf Hellstrom et al 2007). The participants have also been able to select which of the films including their voice or image they wanted to be made public, a form of 'consent by editing'. Written consent was obtained

for dissemination to a wider audience at the end of the project. Pam and Carol, the two women who provided the voiceover for the film about Leeds Market did not wish to be anonymised, and their real names are used with permission.

Brief biography:

Andrea Capstick is a lecturer in Dementia Studies at the School of Health Studies, University of Bradford, UK. She is currently course leader for the MSc Dementia Studies programme. Her research interests include participatory visual methods, arts-based education, and social history narrative.

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*Background:*

My interest in involving people with dementia in making film is closely tied to the strategy for involving people with dementia in the delivery of the Dementia Studies degree programme on which I am a course leader. As providers of courses for health care practitioners, we are required by the NHS, as part of its Patient and Public Involvement initiative (PPI) to involve service users and carers in the design, delivery, assessment and evaluation of the curriculum. Whilst considerable progress has been made in recent years in service user initiatives with people with mental health problems and learning difficulties, very little has so far been done to involve people with dementia in such work (Katz, 2000; Hope et al 2007).

The nature of dementia makes service user involvement a challenge because the condition typically involves problems with short term memory, concentration, and language. More significantly, however, dementia is still frequently portrayed by the media as a condition that leaves no trace of the former person intact, as 'the death that leaves the body behind', so the idea that people with dementia might be able to contribute in a meaningful way to the education of those providing services for them strikes many as an unrealistic one. It is well established that people with

dementia are subject both to exclusionary practices, including 'narrative dispossession' (Baldwin et al 2006) and social disenfranchisement (Beard and Fox 2008). As Bartlett and O'Connor (2010) point out, even when projects do involve people with dementia in a service user role, undue emphasis is often placed on their experience *as* patients from the point of diagnosis, rather than taking a 'whole life' approach.

In order to challenge social attitudes such as these, and involve people with dementia in a way that goes beyond mere tokenism, over the last three years we have developed a three phase approach (Thompson et al 2007). Phase 1 involves people with mild cognitive problems taking part in teaching, assessment and course management; Phase 2 involves outreach work in the local community working with people who have moderate dementia to create learning resources for students. Phase 3 (to begin in 2010) will involve ethnodrama based on observations of people with severe dementia in long-term care (cf Kontos and Naglie 2004).

This paper relates to Phase 2 of the strategy, in which a 9-month participatory video project was carried out in a local day centre, producing in total over 50 film clips designed to introduce service users' perspectives into the curriculum. Here, however, I will focus on just one film created with two women at the day centre. It may be helpful first, however, to explain why PV was chosen in preference to simply filming *in* the day centre.

### *Participatory video*

I decided to pilot the use of PV in the day centre because this method of film-making is based on a model of community engagement in which groups of people who are at risk of social exclusion or marginalisation become involved in making *their own* films about matters that are of concern to them (Robertson and Shaw 1997). This fits well with the current shift away from the construct of 'service users' as passive recipients of care, to 'experts by experience' who are acknowledged as

having an educator role (McLaughlin 2009). Important here is the view of people who have dementia as active agents in the creation of film, rather than passive recipients of care or 'therapy'.

PV has previously been used with older people (HelpAge International 2002), but as far as I have been able to discover, this approach has not previously been used explicitly with people who have dementia. The benefits of using visual images in promoting conversation with people with dementia have been widely noted (eg Allan 2001) but projects in this field have generally been limited to a 'photo elicitation' approach, in which images are used to stimulate a response either in research or for therapeutic purposes. For example the Circa conversation aid uses themed, randomly-selected, images on a computer display to prompt memories and facilitate communication between people with dementia and caregivers (Alm et al 2004). However, PV differs from projects such as these in a number of ways. First, the intention in PV is that the participants are actively involved in the film-making process; this includes deciding on a subject, capturing images, and editing. Second, the subjects and images are personal to the individual, rather than generic. As a result, PV seems on the face of things to be more suited to the context of user involvement contexts where the person with dementia is seen as an active commentator on services, rather than a passive recipient of them.

Whilst PV is widely promoted as a way of involving groups of people who may be socially marginalised (Lunch and Lunch 2006) there is, however, a danger that without adaptation it may itself exclude those with disabilities of various kinds. PV does not appear to take into account that among such groups there are likely to be higher than average rates of cognitive, sensory or physical disability, each of which presents different challenges to involvement.

In the following section I discuss the adaptations made to the standard PV process in work with Pam and Carol. I would suggest that these adaptations are fundamentally issues of practical or 'situated ethics' (Simons and Usher 2000) since they seek to maximise beneficence ('doing good') in the context of routine decision-making.

*Situated ethics: adapting Participatory Video*

I visited the day centre 12 times between June and November 2009. On each occasion I decided beforehand on one or two 'mini-projects' to carry out with the members based on what I had been able to find out about their interests, preferences and abilities. Because the equipment needed to be easy to operate, lightweight and portable, I decided to use a mini-camcorder (Flipcam) in preference to the more complex equipment that would usually be used in a PV project. The Flipcam is the size of a digital camera, simple and easy to use, with one button for record/stop and another for play.

Pam and Carol were always keen and interested in taking part; however, I soon realised that the standard approach that I had been taught during my own PV training would need adaptations in order to allow them to be fully involved. PV training places a lot of emphasis on engagement with film-making equipment and technique. Pam and Carol were more enthused by the idea of being in films than they were in the technicalities of film-making. Carol had difficulties with spatial awareness that made it difficult for her to line up a camera shot, for example, but she enjoyed watching film clips of the day centre played back and commenting on them.

On some visits we used Flickr, Google and YouTube to find images and film clips of things that interested people from the wider world outside the day centre. Local landmarks, historical buildings and images of familiar sights in the past were a keen source of interest. Both women were interested, for example, in looking at on-line images of their favourite holiday destinations. Both also liked to look at images of Leeds city centre in the past and present. I was surprised that both of them recognised a brightly coloured image of a café in Leeds City Market and that this triggered a chain of reminiscences about shopping.

Filming inside the day centre had obvious limitations, since the space was quite confined and background noise (from TV and Bingo calling, for example) could be intrusive. Whilst I had intended at the outset to make films during trips and outings away from the day centre, the practicalities of my schedule were such that it was only rarely that my visits coincided with such events. Of those trips that did take place, Pam did not take part in any, and Carol in only one. In the audio-recorded field notes made after each visit, on one occasion I had noted

Neither Pam nor Carol took part in the shopping trip this afternoon. Pam has a bad inflammation of her right leg and had to keep it up, resting on a stool. Carol didn't want to go without her.

My loyalties were always divided on these occasions, because although taking part in the outing would offer better opportunities for capturing interesting footage, it was people like Pam and Carol who actually had most to gain from being included in the project. At this point I had to do some creative thinking about how to capture images that were visually interesting, and still involve people with dementia who were less keen or able to go out.

Simultaneously, my thinking about potential ways of using moving image was becoming more ambitious. When I first started to use a camcorder I tended to make what one man in the day centre astutely described as 'long photographs'; that is, filming from a static position a scene in which there was some form of inherent movement - a bus slowly trundling over a bridge, for example, or my dog running round the garden; this merely replicates life as usual within a limited field of vision, and it can make for very dull viewing. Now, increasingly, I began to experiment with more creative uses of the camera such as those outlined by Benjamin (1936) in his classic text *The work of art in the age of mass production*

by focusing on the hidden details of familiar objects, by exploring commonplace milieus under the ingenious guidance of the camera, the film on the one hand extends our comprehension of the necessities which rule our lives: on the other it manages to assure us of an immense and unexpected field of action....' (Benjamin 1936: 15)

This growing awareness of ways to use a camera more creatively ultimately suggested a solution to the problem of how to involve people who didn't leave the day centre. I decided to capture images of Leeds City market in the form of short film clips of stalls selling different goods, and to take them back to the day centre for Pam and Carol to watch. I then recorded their comments, in response to the images and edited the two together in the form of a short film. Pam and Carol thus took on an active role in the film as its narrators, and are credited as such whenever it is shown to an audience. Extracts from the voice-over commentary on the finished film, and some findings from the process are discussed below.

### *Film-making and social inclusion: the importance of place*

Seeing comes before words...it is seeing which establishes our place in the surrounding world (Berger: 1972: 7)

As Harper (2002) points out images of 'collective or institutional pasts...or images depicting events that occurred earlier in the lifetimes of the subjects...may connect an individual to experiences or eras'. I quickly found that the films I made had to be personally meaningful to the day centre participants. One of my own favourite film clips - made through the rain-spotted window of a double-decker bus going through a city centre at night - may have been strong on artistic merit, but it failed to engage the interest of people at the day centre, because it had no content that was personally meaningful for them. Leeds City market, which first opened in 1857, is on the other hand a building immediately recognisable to local people, with its ornate Victorian entrance and arched

glass roof. Now surrounded by department stores which make the streets of any major city indistinguishable from one another, it is a continuing reminder of the city's history and culture.

(Insert Fig 1 around here)

I spent time in the market, sometimes filming whilst walking, stopping frequently to move the camera slowly over the surface of a particular stall's contents whenever something interesting took my eye, and adding interest to the shots by introducing different perspectives and camera angles. The resulting film thus juxtaposes the static and dynamic, and includes a wide variety of goods, with different textures, colours and forms of display.

The film begins at the entrance to the market (see Figure 1). When I showed it to Pam and Carol, their initial responses were subdued. Both clearly recognised the place, but seemed unsure what connection it had to them. They showed few signs of engagement, and the voiceover comments on the early sections of the film are murmured and perfunctory.

Sweet stall 1 - Pam: Sweets, is it?

Increasingly, though, as the film moves from stall to stall, Pam and Carol begin to link the goods for sale with their own experiences. Initially, there is a slightly sad tone to the comments, a sense of things not being as they used to be.

(Insert Fig 2 around here)

Fruit stall -Carol: Pink Ladies (apples)...

Pam: I used to love them ...

Carol: Lately they're not so nice...

Pam: Pears too... all hard

As the camera continues its journey, however, there begins to be a more palpable sense of identification and engagement; interestingly, though, in the passage quoted below it is noticeable that there are still two separate narratives taking place

Shoe stall - Carol : Trainers... I've got some that colour (pink)....and I've got them and all.

A.C: Would you wear those, Pam ? (spike-heeled fashion shoes)

Pam: Oh no, oh no, no....No, no. I wouldn't wear them at all. I

wouldn't get into them (laughing)

Carol: I've got some right lovely ones at home, upstairs. They only come out for  
weddings and funerals (sad)

(Insert Figure 3 around here)

The difference between sweet stall 1 (above) and sweet stall 2 (which follows) is particularly striking; the narrative is now animated, and interwoven into a seamless dialogue between the two women. They now use each other's names for the first time, and show a greater sense of agency and humour. The comments suggest that through the medium of digital film they have now entered a different spatio-temporal zone: the responses indicate that they are actually *in* the market and able to make decisions about what to buy

Sweet stall 2: Carol: (animated) Oooh, what are we having? All that bottom row....

Pam: ...All that bottom row, *and* all that top row (laughing)

Carol: (to A.C) and we'll let you have one, won't we, Pammy?

Pam: Oh yes we will, yes we will, Carol

Carol: If you want one, you can have a word with us!

(Insert Figure 4 around here)

At the pet stall, Pam demonstrates her knowledge of local history (the market *was* damaged by fire in 1975) and both participants assert their dislike of cats. Pam also asks me a question, which reciprocates the one I asked her earlier at the shoe stall.

Pet stall: Pam: What are they, Andrea? (A.C: guinea pigs).....oh yes, so they are? The market got burnt a long time ago, about 20 years ago, didn't it? All the animals got burned. Somebody set off a wire, or something, and everything got burned. That was a long time ago. What's that, a cat? Do you like cats, Andrea? I don't like cats at all I'd rather have a dog.

Carol: I don't like cats; they pee on your flowers! (both laugh)

At the final stall, where cosmetic goods are on display, the verdict on the market contrasts markedly with the disconsolate tone at the beginning of the film; now there seems to be more of a sense that good things (and times) are still to be had.

Cosmetics stall: Carol: Actually (note of surprise), to say it's just a small village sort of thing, you get some good stuff.

Pam: Oh you do, yes you do.

The film-making process here suggests first, that people with dementia can take part in participatory video projects if adjustments appropriate to their individual needs and preferences are made. The process used here also appeared to go some way towards reconstructing a sense of cultural identity for Pam and Carol, as they increasingly took on the role of 'critical consumers' within a recognised urban terrain which they associated with previous life roles. Beyond this, the film is also helpful for demonstrating to existing practitioners and student-practitioners that people with dementia respond to sustained interaction, even if their initial responses are limited. Since the project ended

the film of Leeds City Market narrated by Pam and Carol has been made available to Dementia Studies students – including overseas students - through their social networking site for the module *Practice Development and Organisational Change*. The themes of shopping and markets are multi-cultural and intergenerational, and the film has generated considerable interest, with two comments particularly relevant to the theme of this special issue

Student 1: It really felt as though they [Pam and Carol] were in the market with you.

Student 2: And as though we were in the market with them!

### *Conclusion*

This paper describes the process of involving two women with early onset dementia in the production of a short film about Leeds City Market. The film-making process was intended to be participatory ; however, it was necessary to make adaptations to the standard PV process advocated by Lurch and Lurch (2006), taking into account the needs and abilities of each of the two women. These adaptations are, however, in keeping with the principles of PV, since the intention is to involve two women who would otherwise not have been able to take part. PV adapted in this way has potential to reverse the traditional power differentials inherent in research and practice development involving people with dementia (Proctor 2001). Moreover, as Lewandowski (2008) notes, visual images are ‘anamnestic’; they work against forgetting. In the context of dementia, where short term memory, in particular, is compromised, films such as this also provide a permanent record that a person with dementia can watch again in order to be reminded of a particular place or time. They also have significant potential for educational use, including the modelling of inclusive and participatory approaches to working with people who have dementia. Above all, this was a project in which the ability of new media mobilities (Urry 2007) to compensate for physical loss of ability and social agency was clearly demonstrated.

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