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CHAPTER SEVENTEEN

Participatory Video and Situated Ethics: Avoiding Disablism

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This chapter considers the adaptations which may need to be made to participatory video in order for it to be accessible to people whose marginalized status stems from a label of “disability,” whether this is physical, sensory or cognitive. To date there has been an ill fit between the emancipatory principles of participatory video, and the technical rationality (Schön, 1996) and hypercognitivity (Post, 2000) of its methods. Because participatory video is intended to enable marginalized, socially excluded and unheard groups of people to make films which reflect their own interests and concerns (Robertson & Shaw, 1997), adaptations to allow people with disabilities to take part would appear vital from an ethical point of view. Yet ethical issues in general do not appear to have been given sufficient consideration in the participatory video literature to date, and there is little evidence of engagement with emergent areas of debate such as the ethics of visual research (Prosser, 2008) and the importance of working in solidarity with people with reduced or fluctuating mental capacity (Nuffield Council for Bioethics, 2009).

Precisely because so many currently unheard voices belong to people who have disabilities of various kinds, it is vital that technical skills in filmmaking are not given precedence over the broader social and psychological benefits of participation. If participatory video assumes a participant who is able-bodied and without cognitive problems, there is a danger that it may unwittingly exclude many voices. Participatory video thus needs to be inclusive in its methods as well as its principles. It can achieve this by making adaptations that allow participants who are unable to see or hear, for example, or who have physical disabilities such as cerebral palsy or arthritis, or who are unable to remember a sequence of actions due to a cognitive disability, to take part on an equal footing with the rest of society.

In this chapter these issues are highlighted through a case study of my own experience of implementing participatory video in a UK day centre for people with early-onset dementia, and discussed in the context of “situated ethics” (Simons & Usher, 2000). The findings from this pilot project suggest that participatory video has considerable potential for building self-esteem and improving social inclusion for people with disabilities. Successful adaptations *can* be made to participatory video, but in order for this to happen the participatory video community will need to be explicit and transparent about strategies for including people with disabilities.

The Problem with Technical Rationality: Ethical Principles for Participatory Video

Definitions of participatory video tend to place emphasis on two main characteristics of the approach. First are the underpinning principles of agency and empowerment; here the literature stresses the potential for those involved in participatory video projects to “take a more active part in decisions that impact upon them” and “to tell their own stories” (Robertson & Shaw, 1997, p. 1). This is clearly vital for people with disabilities. Second is

“video as tool use.” In this respect I would argue that, even though there is no conscious intention to omit people with disabilities, the language used in mainstream descriptions of participatory video is exclusionary. For example, Robertson and Shaw’s 1997 text (at the time definitive) claimed that “active participation is an *essential* component. Group members *operate the equipment for themselves from the very start... Through hands on use of the equipment... participants can develop confidence [italics added]*” (1997, p. 1) This tool- and technique-based definition of participatory video is still frequently reproduced or glossed without critical analysis in more recent sources. For example, Lunch and Lunch (2006) identify the “First step in the participatory video process” as follows: “Participants (men, women and youth) *rapidly learn to use video equipment* through games and exercises [italics added]” (p. 12). The case study I present later in this chapter suggests that the rapid, hands-on learning of video equipment use stressed in these definitions of participatory video is, in fact, much less important than making adaptations to the process which allow each person to take part on his or her own terms.

Schön (1996) defines technical rationality as “the heritage of positivism, the powerful philosophical doctrine that grew up in the nineteenth century as an account of the rise of science and technology, and as a social movement aimed at applying the achievements of science and technology to the wellbeing of mankind” (p. 12). In Schön’s view, technical rationality, or the “Technological Programme” as he also described it, results in human problems being reduced to technical ones, the solution then being to choose the right kind of technology to solve the problem. By implying that it is the acquisition of technical skills, and competence in the use of technology, that empowers people, it might be argued that participatory video comes dangerously close to a technical-rational approach.

The technical-rational frame of reference in the Western world is also characterized by what Post (2000) has described as “hypercognitivity,” a conviction that it is the cognitive

domain of rational thought and knowledge acquisition which defines the nature of being human. Correspondingly, those who lack cognitive capacity are denied full human status: “The hypercognitivist value system... is merely an example of how our culture’s criteria of rationality and productivity blind us to other ways of thinking about the meanings of our humanity and the nature of humane care” (Post, 1998, p. 72). Post further draws attention to the ways in which a hypercognitivist society fails to maintain and enhance the emotional and sensory domains of experience which are shared by all human beings regardless of their cognitive capacity.

Post is a moral ethicist, and the principlist view of ethics is a good starting point for discussing some of the ethical issues that arise in participatory video work. Principlism attempts to provide a consistent framework for ethical reasoning and decision making using four criteria which, it suggests, should always apply when making decisions about the best interests of human beings (Beauchamp and Childress, 2001). These are:

- non-maleficence (doing no harm);
- beneficence (attempting to do good);
- autonomy (ensuring that people can make informed choices); and
- justice (treating people fairly).

Applying these four principles to the inclusion of people with disabilities in a participatory video project, it becomes apparent that a requirement for rapid learning of equipment use may, in fact, be maleficent, because it might cause some people physical pain or emotional distress. For other people, even if it is not positively harmful, it may have no benefits if they do not enjoy it or cannot later remember how to do it. Such a requirement may also override the personal choices or preferences of some people and therefore fail to meet the principles of autonomy and justice. It is important to note here that, for a principlist,

justice does not mean treating everyone as though they are the same; it means treating each person fairly, in accordance with his or her individual needs and abilities.

The principlist approach informs many professional codes of ethics (for example, those used in nursing, social work, and education). It does not, however, necessarily always equip researchers well for the kind of moment-by-moment, provisional, on-the-spot decision making that must often be done in fieldwork situations. Schön (1996) contrasts the “technical-rational high ground” with the “swampy lowlands” in which much real-world decision making must always take place. To guide us through these swampy lowlands, then, participatory video practitioners need to adopt the more “situated” ethics, described by Simons and Usher (2000) as “the inescapable necessity of making ethical decisions, and the difficulty and complexity of such decision-making, in situations where recourse cannot be had to indubitable foundations and incontrovertible principles” (p. 3).

The Situated Ethics of Visual Research

Ethical issues common to all research include those of consent, capacity and confidentiality. Consent should, of course, be fully informed and this presents challenges in any case in which the participant may be considered to have a reduced capacity to understand the conditions of his or her involvement, the true purposes of the project, or who will have access to the findings. The literature on participatory video to date has paid little attention to the question of capacity to consent to the use of visual images, particularly when these are likely to be disseminated beyond the immediate environment in which the study takes place. Here it must also be acknowledged, however, that the ethics of visual research is itself a still emergent area of debate which has developed rapidly in recent years alongside new media mobilities and digital culture. The increasing ease of recording and malleability of visual images gives rise to new ethical concerns about issues such as the ownership of such images,

rights to their dissemination and reproduction, and consent to their use in varying contexts and for different audiences. Many of the ethical issues that arise in participatory video are thus shared with other forms of visual research or practice. (See, for example, the series of working papers on visual research ethics produced by the UK Economic and Social Research Council's National Centre for Research Methods.)

There is, to my knowledge, no ethical body which regulates participatory video projects, so unless a project is classed as research and therefore comes under the auspices of a formal research ethics committee it will not be subjected to ethics approval before it begins or to monitoring or evaluation during the fieldwork process. It might be argued, then, that an ethical code of practice for participatory video is overdue. This would act as a catalyst for more open discussion about the best interests of all participants, and help in the development of active and transparent inclusion and diversity strategies.

Ethics is undoubtedly a two-edged sword and this is all the more reason why participatory video practitioners need to be well informed about such debates, particularly if their projects involve children, people who may be deemed to lack capacity to consent to the dissemination of their films, people with mental health problems, or those who have a particularly dependent relationship with the researcher or fieldworkers. Participatory video projects tend, in reality, to be characterized by significant power imbalances between researchers and participants, and this is something which needs to be acknowledged and debated openly.

Prosser (2000) suggests that “what is important is that practitioners of visual research reflect on and report back their experiences in order to ground their situated ethics in reality” (p. 132). In line with this guidance, I have used the next section of this chapter to report back on the ethical challenges that arose from carrying out my first participatory video project in a UK day centre for people with early-onset dementia (under 65 years of age). In the constantly

changing and unpredictable environment that was the normal life of the day centre, rapid decision making and creative thinking were necessary in order to find solutions to the ethical challenges as they presented themselves, and I discuss how situated, contextual solutions were found in line with each of the four moral principles identified by Beauchamp and Childress (2001): non-maleficence, beneficence, autonomy and justice.

Solutions were, in fact, found for most of the ethical challenges and practical difficulties which arose, so that the people with dementia were able to take part in a way that was meaningful and enjoyable for them, and that was also in keeping with the principles, if not always the standard techniques, of participatory video.

A Case Study Using Participatory Video in a Day Centre for People with Early-Onset Dementia: Situated Ethics in Action

The reasons for my original interest in participatory video were twofold. First, I had been involved in an advisory role in developing the script of a short fiction film about the experience of a woman with dementia in a care home (Bays & Appignanesi, 2006). This film was introduced into the curriculum of the degree program in Dementia Studies for which I am a module leader, and I conducted a fairly extensive evaluation of its use with students and other practitioners (Capstick, 2007; Capstick, 2009). Following this, I became interested in extending the use of film to involve people with dementia themselves, rather than having actors play their roles. I wanted to use film creatively in teaching students, but also in ways in which people with dementia had a direct part. I was interested in using film to capture conversations and activities that came about spontaneously, in order to provide students with examples of the day-to-day experiences and interests of people with dementia.

The second reason was that, as providers of courses for healthcare practitioners, we are required by the Patient and Public Involvement initiative (PPI) introduced in 2003 by the

UK's National Health Service, to involve service users and carers in the design, delivery, assessment, and evaluation of our Dementia Studies curriculum. While 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 (Hope, Pulsford, Thompson, Capstick & Heyward, 2007; Thompson, Capstick, Heyward, Pulsford & Hope, 2007). Projects which do involve people with dementia directly in a service user role often put undue emphasis on the experience of dementia itself, from diagnosis onwards, rather than taking the approach that the person's life as a whole is of interest (Bartlett & O'Connor, 2010). It is still common for service user involvement work in the field of dementia to refer to the "voice" of people with dementia in the singular (e.g. Goldsmith, 1996; Cantley, Woodhouse & Smith, 2005) rather than recognizing that people with dementia are a heterogeneous and polyvocal group. By contrast, Katz, Conant, Inui, Baron and Bor (2000) advocate the active involvement of older people, including those with cognitive problems, in healthcare education through a Council of Elders who are recognized as "experts by experience" (Katz et al., 2000, p. 852). This is the model that has informed my own work on service user involvement in practitioner education.

People with dementia are particularly prone to social exclusion and stigma, and this can lead to depression and a loss of self-esteem (Burgener & Berger, 2008). The Nuffield Council for Bioethics stresses the importance of working in solidarity with people who have dementia in order to combat stigma and promote inclusion. Baldwin (2006) describes the factors that work against people with dementia being able to tell their own story as a form of "narrative dispossession" (p. 101). On the face of things, then, participatory video seemed the ideal way of addressing the situation I have described here. Its emphasis on allowing participants to tell their own story in particular seemed well suited to a project designed to involve people with dementia. I was, however, concerned about the implications of trying to

teach the use of video equipment to people affected by the short-term memory loss, spatial disorientation, and problems with language and concentration which are typical of this condition.

Kitwood (1997) identifies “outpacing,” that is “providing information, presenting choices etc. at a rate too fast for a person to understand; putting them under pressure to do things more rapidly than they can bear” (p. 46) as one of 17 types of “personal detraction” in dementia care. He suggests that it is personal detractions of this nature—not just an underlying disease process—which cause much of the deterioration in people with dementia. In this view, outpacing participants with dementia in the process of attempting to teach participatory video skills could cause them harm (in the form of frustration, embarrassment or anxiety) due, for example, to difficulties in retaining complex information, or inability to recognize objects.

The day centre where my project was carried out is housed in a pleasant nineteenth-century villa, originally built as a private residence, which stands in its own grounds. It is open every weekday, and generally has around twelve people with dementia (“members” as they choose to be known) attending at any one time. The extent and nature of their disability varies, but all experience problems with short-term memory, information processing and concentration. Several also experience difficulties with verbal communication, object recognition and spatial/temporal awareness. In the course of the project, ten members of the day centre were involved in some way in the creation of film and photographic data. The way they contributed was determined by their own level of interest, choice of involvement and, in some cases, evidence of enjoyment that I could deduce from non-verbal communication.

Although this was a pilot project, it was carried out under research conditions, including a full ethical process for gaining consent and—where appropriate—protecting participant confidentiality. In England and Wales the Mental Capacity Act (MCA)

(Department of Constitutional Affairs, 2005) states that there must be a presumption of capacity in the case of people with dementia and other forms of cognitive disability. Prior to the MCA coming into force in April 2007, there was a presumption of *incapacity*, and people with dementia were often included in research without their explicit consent, or excluded from research on the grounds that they could not give informed consent. Obtaining proxy consent from relatives was common practice. Several years prior to the introduction of the MCA, for example, Bond and Corner (2001) pointed out that “older people with dementia have usually been excluded from or marginalized in studies about dementia because of traditional assumptions about their ability or appropriateness as participants or respondents” (p.95). Now, at least in law, the decisions made by a person with dementia must be taken into account unless it has been demonstrated by formal assessment that the person in question permanently (rather than only transiently) lacks capacity to make decisions on his or her own behalf. Professionals and researchers are also under a clear obligation to act in the best interests of the person with dementia. Some of the participants in this project, for example, clearly stated that they wanted their own first names to be used in the films they made and anything that was written about them. Since it seems unlikely that this could harm their interests in any way, I have respected that decision.

I made audio-recorded field notes as soon as possible after each visit in order to keep a record of what happened, and this included the various snags I encountered along the way. At first it was rarely apparent to me that these were actually emerging ethical problems, but this became much more obvious over time. I have drawn on these field notes at points in the discussion below.

Non-Maleficence and Beneficence: Avoiding Harm and Doing Good

In the event, I made no attempt to carry out a standard participatory video teaching session in the day centre. Instead, the project was introduced gradually, without pressure, one step at a time. We started out by taking photographs before moving on to film. A series of photographs taken by the participants was used to introduce the idea of making a film that would join the pictures together. Rather than using complex, “high tech” cameras and equipment, I used the simplest hand-held mini-camcorders I could find. These are no larger than a digital camera and have a very simple mechanism, consisting only of on, off, record, and play buttons. Muir (2008) notes that participants in his study became noticeably more enthusiastic about using a similar mini-camcorder when they realized that it was much easier to use than they had anticipated. This was also my experience. Over time, three of the day centre members were able to produce films more or less independently using the camcorder, and another was happy to walk with me telling me what she would like to film as we went, provided I did the actual camerawork.

I gained ongoing, negotiated process consent at each visit (Dewing, 2007), and also within visits whenever a new activity was introduced, by reminding each person what I was doing, and ensuring that each participant was happy to be involved. At each visit I showed the members the films or images from the last time I was there, and reminded them what we had been doing. All the participants were able to demonstrate whether they consented to the process of image capture or not, either verbally or non-verbally. Gaining informed consent to the dissemination of images is, however, more complex. This involves a degree of abstract reasoning about a future situation that may be difficult for someone with cognitive difficulties. The same may also be true of dissemination by way of conferences and publications, since these are concepts which may be unfamiliar to participants for reasons of education and social background as much as of disability. In a study involving older people without dementia, Davies (2008, Negotiating different levels of consent, para. 2) found that complex,

multi-purpose consent forms were “confusing, potentially worrying and off-putting” to participants. As far as possible, then, each purpose was explained verbally using language that the participants were likely to understand, for example, “Can I use your film to show people when I am doing my teaching?”. Full information about the project was also provided for the participants to take home and discuss with family members.

Several members of the day centre indicated either verbally or non-verbally that they were happy to appear on film and this was taken as consent to the process. One participant, for example, replied with a “thumbs up” sign, and by saying “No problemo”. In some cases, however, including those where the person’s capacity to give informed consent was in question, I avoided filming faces, tending to focus on people’s hands while recording their voices. Hands are not only less identifiable than faces, but they can also be extremely expressive, and this enabled me to capture images of people engaged in some form of activity such as painting or playing dominoes. Other people, equally clearly, gave non-verbal signs that they did not want to be included even in a passive role, and these were respected. In addition, in a relatively small environment it was sometimes difficult to avoid inadvertent capture of brief clips of people who had not consented. For all these reasons a process of consent by editing was used.

Consent by editing involved the following steps: First, it was agreed from the outset that no images would be seen outside the day centre unless the participants were happy with them. There was a group screening of the rough-cut film at the day centre. At this stage the participants were reminded that any scenes they didn’t like for any reason could be cut. Although, in principle, participants who withdrew their consent could be edited out at this point, nobody asked to be excluded. Two participants asked for minor edits to scenes in which they were unhappy with the way they appeared, while John, who had been ambivalent about whether he wanted to take part, gave retrospective consent to the inclusion of scenes

involving him. Interestingly, once he was able to see the finished product he took considerable pride in these scenes. Editing film in this way until the participants approve the final product takes longer, but helps to ensure that in addition to being happy with it themselves, participants will also be less likely to object to other people seeing it. Asking the question “Is there anyone you would *not* want to see this?” was a useful additional check at this stage. Gaining informed consent in this way is a more valid approach for people with cognitive difficulties, because it means they are responding to something visible and concrete, rather than the abstract concept of a film which was all that was available to them at the beginning of the project.

Autonomy and Justice: Respecting Choice and Treating People Fairly

This next section explains adaptations I made in order to involve two women, Pam and Carol, who for various reasons would not have been able to take part in self-directed film-making. As a bridge to their involvement in producing a film, I wove into the project two additional participatory visual methods—photo elicitation and digital storytelling. Photo elicitation is a technique that has been used in visual sociology research to stimulate responses to interview questions (e.g. Harper, 2002). People with dementia often find it difficult to sustain a conversation, and this can be one of the main factors leading to their social exclusion. I used photo elicitation techniques initially to promote topics of conversation. First, I audio-recorded the responses of Pam and Carol to an inventory of likes and dislikes devised by Jones (2002). This includes, for example, the respondent’s favorite color, piece of music, actor, singer, flower, holiday spot, animal and food. I then used this information to search online for matching images which were covered by a creative commons license. I looked for pictures that were as bright and attractive as possible, and put them into an A4 booklet. These booklets proved very popular in themselves; both Pam and Carol asked

if they could take a copy home to keep, and Pam told me quite some time later, “I still look at my book that you made me every day.”

I then audio-recorded Pam and Carol’s responses to the images in each of their books in order to be able to edit together the verbal commentary and digital images. This method of combining pictures and words spoken in response to them is known as digital storytelling (see, for example, the UK’s Patient Voices project). It was noticeable when using photo elicitation and digital storytelling techniques that Pam and Carol’s could find words and recollect events significantly better than in general conversation, or in interview-type situations using merely verbal prompts. For example, Pam mentioned Elizabeth Taylor as one of her favorite actors, but didn’t initially offer any further comments. When I showed Pam a photograph of Taylor as a young woman, however, she remarked spontaneously, “She was a beauty... she was married ever so many times, sometimes to the same man... Richard Taylor, no, Richard Burton.” On a subsequent visit, an image of Taylor and Burton together generated further discussion about the couple’s glamorous Hollywood lifestyle. Techniques such as photo elicitation and digital storytelling, clearly have potential for adding to the enjoyment of the participatory process and can enable people with less interest in the technological aspects of participatory video to take part.

Carol had problems with spatial awareness that made it very difficult for her to line up a camera shot while she was moving. She struggled visibly to accommodate the image on the viewfinder with the image she could see with her naked eye. Although she never seemed to be upset by this and showed signs of enjoying the collaborative aspects of being a film-maker, she was never particularly interested in the products of the exercise. An extract from my field notes records that

At one point when Carol was moving around with the camera, one of the staff asked her if she wanted a cup of tea, and she said “Wait a minute, we’re filming.” That was

a good expression of autonomy on her part, because she's not normally very assertive. So even though she wasn't producing "useable film" [I was referring here to film useable for teaching students], the fact that she said this was really quite enlightening about how she feels about the process.

A further extract from my field notes relates to a tension between competing priorities. In this project, capturing film footage and maintaining relationships of trust with members were sometimes in conflict. This is a situation that is likely to arise quite frequently in participatory video work with people who have physical disabilities or mobility problems.

Diane, Shirley, Kath and Norma went out on a shopping trip. I was unsure whether to go with them or not, and decided not to, because neither Pam nor Carol were taking part in the trip. Because I think they look forward to me going now, and have an expectation that I spend time with them, I didn't want to upset them by seeming to leave them behind. Pam also had quite a nasty infection in her leg, and had to sit with it up on a stool. Carol didn't want to go without Pam, so I felt I should stay with them.

The ethical concern identified in this field note led, in fact, to a new asynchronous method for including Pam and Carol in a film. I decided to visit a local market in my own time and film clips of a variety of different stalls which I then took back to the day centre for Pam and Carol to watch. I recorded their responses as they watched the visual images, and edited in the things they said as voice-over commentary. In response to an image of a fruit stall, for example, Pam and Carol can be heard in the finished film discussing the different types of fruit and their respective merits, for example, "Apples... Pink Ladies... [my husband's] favorites... lately they're not so nice"; "pears... too hard". The two women now emerge as discerning shoppers, able to spot a bargain (for a fuller discussion see Capstick, 2011).

Although the approach described here involved Pam and Carol in a relatively low-tech aspect of filmmaking, they were extremely proud of their film, and when it was shown in the day centre it was clear that both their own self-esteem and their standing with the rest of the group had increased as a result. Pam and Carol were able to display their local knowledge and expertise to other members of the day centre. These findings suggest strongly to me that the process of being involved in filmmaking in a way that values the person's opinions and lived experience is most important. For those who are not able to engage with the technical complexities of filmmaking due to some form of disability, true participation lies in being included, listened to and having their views valued and respected.

Conclusion: Toward an Ethics of Inclusion

As I hope the case study has demonstrated, there is considerable potential for using participatory video with people who have a disability such as dementia, and much reason to believe that this can have real benefits for those who take part. Adaptations need to be made, however, so that there is less emphasis on active use of technology by each person, and more focus on individualized support and facilitation. The challenge for participatory video now is not only to adapt its methods, but also to open up some of its underlying assumptions to discussion. While ethical debates will not solve existing problems, and may well introduce some new ones, they may at least help to make important issues more evident. In the end, the case of people with disabilities serves to illustrate central issues for participatory video wherever and with whomever it is practiced. For all participants, beneficence, autonomy, and social justice rely on individual, situated decision making.

Finally, there is a need for reflexivity. To date the emancipatory gaze of participatory video has largely been turned outwards, with an admirable zest for doing good in the world. But this needs always to be matched by a corresponding reflection back: on how participatory

video might be made more inclusive, accessible and ethical, and on how it might become more critically aware of its own unspoken assumptions and practices.

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