

Using Video to Include the Experiences of People with Dementia in Research

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Abstract

There is a need to develop more inclusive approaches to researching the experiences of older people with dementia if research is to counter the marginalisation and exclusion they face. This paper outlines findings from a study using video to research the communicative experiences of older people with dementia. Video was found to be a useful tool, enabling the inclusion of this group's experiences in research and their involvement in the research process. The implications of these findings for video research and the involvement of people with dementia in research are discussed.

Introduction

The aim of this paper is to examine critically the usefulness of video as a research tool for both researching the experiences of older people with dementia in a residential care home and for facilitating their involvement in the research process. The use of video as a research tool is reviewed and the methods used to collect the data for the study outlined. Findings from the study are presented concerning the usefulness of video for researching the experiences of people with dementia and involving them in the research process. Finally the paper reflects on the meanings of involvement for both the person with dementia and the researcher.

Involving People with Dementia in Research

The marginalised status of older people with dementia in society has consequences for researchers wishing to study this population (Wilkinson, 2002). Seemingly objective research findings and representations can lead to the 'othering' of people with dementia, exacerbating their marginalisation and disempowerment (Fine, 1994). There is, however, a growing body of research working to counter these processes, seeking to understand the perspectives and experiences of people with dementia themselves (Clarke and Keady, 2002). In particular, the perspectives and experiences of people with dementia have been sought in relation to the services they receive (Allan, 2001; Barnett, 2000; Dabbs, 1999; Pratt, 2002; Reid et al, 2001); and their experiences of dementia (Cheston and Bender, 2000; Sabat 2001; Snyder, 1999). This research has tended to focus on people with moderate and mild dementia, and little attention has been paid to non-verbal aspects of the experience of people with dementia.

This body of research, however, constitutes only a small step towards addressing the exclusion and marginalisation of people with dementia. Writing from the field of disability, Oliver (1993) argues that for research to foster positive change in the status of marginalised populations, researchers need to work in 'joint enterprise' with marginalised people. Emancipatory and participatory approaches to research, widely used in the fields of disability and feminism, provide models for a new kind of dementia research which allows people with dementia themselves to determine research priorities and methods (e.g. Millen, 1997; Walmsley, 2001). In this way, people with dementia may actively participate in moves to challenge their 'othering' and marginalisation.

These approaches to research have started to permeate the field of dementia research (Corner, 2002). Where once people with dementia were treated exclusively as the objects of research, now their consent is routinely sought for participation (Dewing, 2002; Hubbard et al, 2002). Moves to a more participatory, or even emancipatory approach to research with people with dementia, however are slow. Expertise in consulting with and working with people with dementia is growing (see Wilkinson, 2002 for a collection of chapters), however very few people with dementia are actively involved in shaping research. Those that have been involved have highlighted the many benefits to them, particularly in terms of increased self-worth, confidence and optimism (McKillop, 2002; Robinson, 2002). However, many barriers still exist to involving people with more advanced dementia and those who are not familiar with research practices. There is an urgent need to develop new methodologies to allow the inclusion of all people with dementia in research.

Video as a Research Tool

Video is a relatively under-used tool in social science research (Prosser, 1998). Video recordings of social life allow non-verbal aspects of experience to be captured and create a permanent record of the experience that may be subjected to micro-level analysis time and time again (Rosenstein, 2002). Furthermore, video enables those involved in the interaction recorded to reflect and comment on their behaviour (Caris-Verhallen et al, 2000; Sanders and Dabbs, 1992). In the field of dementia, video has been used successfully in both these ways to examine the responses of people with very advanced dementia and the perspectives of staff during caring interactions (Athlin et al, 1990; Kihlgren et al, 1996; Norberg et al, 1986; Phillips and Van Ort, 1993).

A key issue identified by many researchers who have used video to examine social life is the extent to which the recording is a true and representative depiction of 'real life' (Prosser, 1998). The potential distorting influence of the video camera on the behaviour of the research participants has been widely reported (Heacock et al, 1996; Lomax and Casey 1998; Rosenstein, 2002). Furthermore, the influence of the person using the camera on the data collected has been highlighted (Roberts et al, 1996; Rosenstein, 2002). Thus, the resulting recording can be seen to be both a social and technical construction. Post-modern and ethnographic approaches to research, however, question the extent to which a true and representative depiction of 'real life' is possible in any research (Denzin and Lincoln, 1994). These approaches embrace the influence of subjective aspects of the research relationship and situation on the data collected, and reflect on this in their analysis (e.g. Agar, 1996; Hockey, 1992; Sanger, 1996). In this context, the distorting influence of the video camera becomes merely one more aspect of the research situation to reflect on. Indeed Lomax and Casey (1998) demonstrate the possibilities for using the video recorded data itself to reflect on the influence of the camera in the construction of the research data.

Video and Involving People with Dementia in Research

The ubiquity of video in society makes it an ideal tool for involving people in research who are unfamiliar with traditional social science methods. Video has been used to disseminate the findings of a participatory project involving older women (Warren and Maltby, 2002) and as a medium for older people with dementia to document their life stories (Rose, 2000). Furthermore, the use of video enables researchers to reflect critically on the research process, which is essential to the development of new inclusive methodologies for people with dementia. In the field of midwifery, Lomax and Casey (1998) highlighted new mothers' perceptions of the video recordings as being the research proper, and revealed the ways in which they used the camera to differentiate what they considered to be midwifery business from social aspects of the visit. There has, however, been no critical reflection on the use of video in research in the field of dementia. Research from a nursing perspective has highlighted the ethical issues of preserving anonymity and consent (Heacock, 1996; Latvala et al, 2000; Roberts et al, 1996); however, so far, these issues have been ignored by dementia researchers using video.

The following sections will outline the use of video in this study to research the communicative experiences of older people with dementia. The success of this approach in both gathering data and in enabling the inclusion of the participants in the research will be considered. The implications of this for both video as a method and the inclusion of people with dementia in research will be discussed.

Research Aims and Design

The research presented in this paper forms part of a PhD study, examining the communicative experiences of older people with dementia in a residential care setting. The ethnographic methods of participant observation and informal interviewing were used to gather data in one residential care home over the space of six months. Both pen and paper and a video camera were used to record the residents' experiences, and the video recordings were played back to the participants to

elicit their perspectives on the data. Consent was sought from all residents for their participation in the research and opportunities for their involvement in the research were maximised.

Methods

The data for this study was collected in one local authority residential care home in Central Scotland, home to 46 older residents, approximately half of whom had dementia. Having negotiated access with the social work department, the university ethics committee and the manager and staff of the residential care home, consent was sought from the residents themselves.

Consent was negotiated both formally in a one-to-one interview and on an ongoing informal basis. The first few visits to the home were spent getting to know the residents and chatting to them about the research. The residents were then approached individually and, using an information sheet and a notebook and video camera as props, the research was explained to them. At this point the residents were asked if they were willing to be observed and for notes to be taken about their behaviour. Residents who agreed were then asked if in principle they were willing to be video recorded and informed that they would always be asked for consent before the video camera was turned on in their presence. Relative consent was also sought for residents who the manager identified as being unlikely to be able to remember the presence of the video recording for its duration, three years. (For further discussion of the access and consent process and ethical issues arising in the research see Cook, 2002).

Having obtained formal consent from all the residents I spent two months visiting the home twice a week as a participant observer. In this time I chatted to the residents and joined in the activities in the home, taking notes using pen and paper. Verbal consent was renegotiated with the residents on every visit and I took every opportunity available to remind them I was a researcher and to ask their perspectives on the activities I was observing. Posters were displayed round the home with my picture and a brief description of the project to reinforce my role as a researcher in the home.

After two months of getting to know both the people and the regime in the home, I started to use the video recorder to record the residents' experiences in both naturally occurring interactions and those that focused around the activity of being recorded itself. The video camera was used to facilitate the residents' involvement in the research in two ways: to develop their understanding of the research and to involve them in the data collection and analysis process. Before recording the residents, I explained the research to them, showing them the camera and encouraging them to hold it. On several occasions I asked the residents what they would like me to record and encouraged them to use the camera themselves to film what they were interested in. Many of these recordings were then played back to the residents who had featured in them to elicit their interpretations of the communication recorded and their feelings on the video and being recorded. Play-back sessions occurred either immediately after they had been recorded, by plugging the camera into the back of a television or on my next visit to the home. Detailed field notes were taken immediately after the video recording sessions to contextualise the interactions and activities filmed.

The video recordings were transcribed, including four layers of information: the context to the recording (from the field notes); the action recorded, including the residents' verbal and non-verbal behaviours; the participants' interpretations and perspectives on the recording; and my own interpretations of the data. These transcriptions were analysed qualitatively using Nvivo, a computer analysis software package (Richards, 1999).

Findings

Researching experience

This study employed both pen and paper and video recorded participant observation to research the experiences of older residents with and without dementia in the context of an ethnographic and inclusive methodology. This approach proved highly successful in accessing the experiences and perspectives of the residents regardless of their cognitive abilities, and highlighted the agency of the residents in the home.

Pen and paper participant observation proved a useful method to gather data, allowing for many interactions in the home to be detailed along with notes about the wider context. This approach did not allow for the inclusion of more subtle aspects of interaction, in particular non-verbal behaviours, as I was unable to write fast enough to record this detail. Interactions in which I was involved proved particularly difficult to record and were generally written up from memory later.

The introduction of the video camera enabled not only the verbal aspects of behaviour to be transcribed accurately, but also non-verbal aspects of the interaction. The permanent nature of the video record meant that recordings could be played back over and over again allowing the detection of the smallest details in the interaction. Recordings were replayed time and time again, allowing them to be reanalysed in light of my developing research ideas. In this way the experiences of the participants guided the framing of the research and I was not bound to the interpretations and recordings made at the time of the observation.

Analysis of the recordings revealed the agency of the residents with and without dementia and their sophisticated use of both verbal and non-verbal communicative behaviours. The following example from a recording in the home at supper time shows a female resident with advanced dementia both using and interpreting verbal and non-verbal behaviours in her attempt to resist being moved to the dining table:

Male carer approaches the female resident, who is sat in her chair, leans over and takes her hand ready to help her out of the chair.

Carer: Your tea's ready!

Resident: (looks up) Is it?

C: (still holding her hand) We have some food here, some scrambled eggs and you'll get a cup of tea with it.

R: Just a cup of tea, tea, tea.

C: (takes her other hand ready to pull her up) Come on trouble!

R: (sits back and resists, trying to cross her arms) I am trouble, come over.

C: (still holding her hands) Aye.

R: (looks away from the carer) I'm stay, com, comfortable.

Facilitating Understanding of the Research

The use of video enabled the older residents with dementia to be involved in the research process by facilitating their understanding of and engagement in the research. Many residents found it hard to comprehend that my spending time in the setting, chatting and taking notes constituted research. Introduction of the video camera, however, immediately crystallised the research process, creating an activity that they could understand. Although the experience of being recorded was novel for the residents, they were all very familiar with video as a medium and the camera provided an immediate reminder that they were being filmed and that these films would be watched. Residents responded to this in very stereotypical ways as the following clip shows:

Beatrice looks up and sees the camera with me behind it and smiles, then Jean looks up

Jean: Are you taking our picture?

Researcher: I am.

Bea: will we smile?

J: Take a shot of my scarf.

(Beatrice laughs)

Both residents in this clip responded to the camera as something to show off to, with Beatrice later joking that I should send the clip to Hollywood to see if they would 'give us a rise'.

The novelty of the video camera and the activity of being recorded challenged residents to engage with the research and sparked interest in a way my presence as a participant observer never did. The following clip highlights this and features a conversation recorded whilst I was out of the room by a female resident, Maria, who is discussing the experience of being recorded with a fellow resident:

'You see it's very strange I don't myself understand. You understand about this girl, she wants to put me in the machine. You understand? If I can understand, it will be the first time I have, we will see if I like or not, it depends. If I understand I will like very much but if I don't understand why, I will be here.'

The clip clearly demonstrates the difficulties many

of the residents with dementia faced trying to understand the research. In the case of Maria, however, the special nature of being ‘put in the machine’ made it worth the struggle.

The increased understanding and awareness of the research fostered by the use of the video camera helped in the negotiation of ongoing consent with the residents. Not only was the camera meaningful to the residents, but it also provided a physical prompt, reminding them they were part of the research. This enabled more meaningful ongoing consent to be negotiated, residents changed their minds from day to day and even during recordings as to their willingness to be involved, as the following clip shows:

Two residents, Elsie and Ginny, had been chatting together for some time when I asked if I could record them. They both agreed and I had been standing directly in front of them recording for five minutes before Elsie remarked to Ginny...

E: this girl’s standing here with that stupid..., will she no sit down? There’s a seat there.

A: I can’t see you if I’m sat down, Elsie.

G: She can’t see if she sits down, she wants to take a photograph of you.

Elsie puts her head down and shakes it

G: *(looks at Elsie)* No?

A: Would you rather I stopped?

G: I think so.

A: OK *(and I turn off the camera)*

Although use of the video camera encouraged residents to engage in the research and made the research process more meaningful, the camera did not overcome residents’ difficulties in understanding the research aims. Analysis of the residents’ responses to the video revealed that they reached many different understandings of the research, not all of them coinciding with mine. A common misinterpretation of the research was that it was about the residents’ life stories, as the following clip shows.

Whilst recording three residents chatting in the foyer, one of them, Jean, calls out to Ella who is passing...

Jean: Where you going?

Ella: I dinae ken (laughs). I’m walking but I didnae ken where I’m going

J: Tell this young lady the story of your life.

E: The story of my life (looks questioningly at Jean) I’ve nae life, I’ve nae life, I’ve been working too hard!

(Ella laughs bitterly and sits down. Jean turns to me and says)

J: ask Ella a question, like where she used to live.

Researcher: So where did you used to live Ella?

This clip shows Jean clearly involved in the research, however operating with a very different conception of the project to my own. In one sense, this misinterpretation has few consequences for the study: Jean’s question generated interesting data. However, this recording is evidence that Jean’s consent to participate in the study is misinformed, which is problematic for any research, not least that which seeks to avoid disempowering the research participants. The response of a resident with more advanced dementia, in the following clip highlights this problem more starkly still:

I approach three residents sat in the foyer and ask if they are willing to be video recorded, explaining that it’s for my study at the university on older people’s communication. They all agree, however the first thing recorded when the camera is turned on:

Anne: What’s it for, the paper?

Jean: It’s not for the paper, *(to the researcher, joking)* the News of the World is that where you’re from?

Researcher: It’s for my project.

A: What?

R: My project

J: *(to the researcher)* She doesn’t ken what a project is.

R: My university studies.

A: I didn’t know what you said *(looking at me)*

R: Right *(pause)* you can watch the video when it’s done.

Therefore Anne, although clearly engaged with the research, cannot be said to have given informed consent for participation, raising a question as to

whether I should include this data in the research. This issue will be considered in more detail in the discussion section of the paper.

Involving Residents in Data Collection and Analysis

To involve the residents in the data collection and analysis of the findings, residents were encouraged to use the camera themselves and were shown the findings and asked to comment on them. Neither method proved very successful.

Many of the participants in the study readily handled the video camera and recorded with it, however none of the residents in the home were able to see through the viewfinder. This meant that they had no control over what was filmed, rendering them unable to contribute to the data collection process in this way. Residents were, however, able to be involved in determining the data collection in different ways. The video camera provided a physical frame to the research, which residents were able to manipulate, giving them control over the data collection process. Residents commonly responded to this frame by 'voting with their feet' moving in and out of the research as they chose. One resident in particular, however, acted as a director, calling people in and out of the frame of recording and ensuring she was seen in a good light:

Two residents are sat in the lounge as I ask if I could record them chatting.

Marg: You can get that big handsome fella in, (then calls out to the passing man) come over here and get your picture took! (Anne turns round to look as does Marg, who then sees Lena)

M: Lena you going to get your picture taken?

L: Eh? (as she slowly approaches)

M: You can get a seat up here, (pointing to a chair) you can get a seat round that way, you're getting your picture taken.

L: Am I?

It is important to note, however, that Marg's active role in the research had implications for Lena who, through Marg's actions unwittingly participated in the research without giving consent to be recorded

on this occasion.

Involving residents in the data analysis was also problematic. For the most part residents enjoyed watching the video recordings after they had been taken, however it was hard to elicit their perspectives on the research in this way. Residents were readily able to reflect on their experiences of being recorded and on the feel of the recordings. They were less able to answer specific questions about the communication in the recordings, particularly if they had forgotten being recorded. Playing the videos back immediately after the event helped in this regard, but was not always possible depending on the availability of an appropriate television. Instead, residents laughed at the recordings, commenting on their own and others' hair and clothes. Although this method was not successful in eliciting the perspectives of the residents on the research, these sessions did make the research more meaningful for the residents, thereby facilitating their involvement in the day-to-day data collection for the study.

Reflections

Meanings of involvement

The findings raise many questions about what it means to involve people with dementia in research. Analysis of the recordings show that, through the use of an inclusive methodology, residents with dementia were clearly engaged in the research and interpreted meaning from it. Despite all my best efforts, however, the residents' understandings of the research, and in particular of the broader research aims, did not always correspond with my own. In many cases residents clearly consented to research they did not understand. Given both the cognitive impairments experienced by people with dementia, and in general their lack of experience of being involved in research, this situation is inevitable, and poses a challenge for the future involvement of people with dementia in research.

Current conceptualisations of participatory and emancipatory approaches to research and medical and social science ethical guidelines all place participant informed consent at the centre of ethical research practice (Dewing, 2002). However, findings from the study highlight the incongruity of imposing such a cognitively driven and abstract conceptualisation of good practice on people with

dementia, going against all the principles of person-centred-care. In this study, restricting the research to involving only those who gave informed consent would not only have prevented the recording of the experiences of many people with more advanced dementia, but would have precluded their involvement in the research process, leaving the participants disempowered either way. This is not to deny the importance of informed consent in research, but merely to highlight the problems inherent in this approach and the need to find new ways of conceptualising research if, as a field, we are committed to the involvement of people with dementia.

Table 1. Meanings of involvement for the researcher and the research participant.

Nature of involvement	Meaning for Researcher	Meaning for Research Participant
Awareness that being researched	Avoids disempowerment and 'othering' of participants	Provides opportunity to show 'best side' to the camera
Understanding of research process and aims	Enables informed consent	Gives status and sense of satisfaction / achievement
Informed consent to research	Meet requirements of ethical committees	Provides opportunity to exercise choice and self-determination
Participation in data collection and analysis	Avoids disempowerment and othering	Provides opportunity to show 'best side' to the camera.

A first step to finding a new way of conceptualising research that might ethically and meaningfully include people with dementia is to examine the meanings of involvement to them. Analysis of the video recordings and field notes enabled interpretation of a number of meanings for the residents of being involved in research. These are summarised in Table 1, alongside the meanings for me, the researcher, in involving residents in the research. Comparison of the two columns highlights the abstract concerns of the researcher

on the left as opposed to the very personal concerns of the participants on the right. As a researcher, I was motivated by theoretical and ethical understandings of research and the requirement of research ethics committees; however, involvement afforded the older residents with dementia, choice, status and some determination in the ways in which they were represented. Indeed, this finding is supported by the experiences of James McKillop and Elaine Robertson, whose chapters on the benefits of being involved in research highlight the importance of value, respect and relationship with the researcher and made no mention of ethics or guidelines (McKillop, 2002; Robinson, 2002).

Discussion

The findings show that in the context of an appropriate methodology, video is a useful tool for involving people with dementia in research. The older residents with dementia in this study found the activity of being video recorded both meaningful and interesting. Furthermore, the presence of the video camera provided the residents with a physical reminder that they were being recorded and were part of research. Thus the use of video, as opposed to pen and paper participant observation, made the research process transparent, facilitating the residents' involvement. Access to more appropriate technology would have facilitated the residents' involvement further. Use of a video camera with a screen on the side, would have enabled at least some of the residents to see what they were recording, enabling them to play a more active role in the data collection. Furthermore, ready access to a television with a scart socket¹ would have enabled the videos to be played back to the participants immediately, making it easier for them to comment on the recordings.

These findings also have implications for the field of video research more generally. In this study, the socially and technically constructed nature of the recordings, so frequently highlighted as problematic (Heacock et al, 1996; Prosser, 1998; Rosenstein, 2002), became an advantage. The overt use of the camera in the context of an inclusive methodology served to remind the participants they were part of the research and enabled them to control the data collected.

Analysis of these recordings enabled reflection on both the extent to which the research processes were empowering and their influence on the data collected.

Finally the findings have implications for our understanding of what it means to include people with dementia in research. The use of the video camera provided a permanent record of both my successes and failures in including the residents with dementia in the research process. Analysis of this data reveals that being involved in research is a meaningful experience for the residents, and that these meanings were of a very different nature to those of the researcher. The challenge for researchers working in this area is to develop inclusive methodologies that embrace both sets of meanings. Video is clearly a useful research tool to this end.

1. A scart socket enables the video camera to be plugged into the back of the television, allowing the recording to be viewed on the television.

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