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SAGE Research Methods Case Health Submission for Consideration

Case Title

Ethnography in Dementia Care Research: observations on ability and capacity

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Contributor Biographies

Katherine Ludwin is a researcher in Dementia Studies at the University of Bradford. She has a PhD in Sociology and Politics from Birkbeck College, University of London, which was located in gender studies and explored expectations related to family norms. She has worked on several dementia research projects and is interested in creative methods and the significance of identity and difference in the lived-experience of dementia.

Andrea Capstick is a Senior Lecturer in Dementia Studies at the University of Bradford. She holds a Doctorate in Education (EdD) for her work on the use of film and narrative biography in teaching dementia studies, and has published on a variety of subjects including service user involvement in dementia care education; arts based approaches to teaching and learning, and the ethics of visual research. In 2012 – together with Dr John Chatwin – she was awarded funding by the National Institute for Health Research's School for Social Care Research to study the impact of participatory film-making on social participation and well-being for people with dementia living in long-term care.

Published Articles

Capstick A and Chatwin J (2016) The carnival is not over: cultural resistance in dementia care environments. *Pragmatics and Society*, 7 (2): 169-195.

Capstick, A. and Ludwin, K. (2015) Place memory and dementia: findings from participatory film-making in long-term care. *Health and Place* 34: 157-163.

Capstick A, Ludwin K, Chatwin J, and Walters E R (2016) Participatory video and well-being in long-term care. *Journal of dementia care*, 24 (1), pp. 26-29.

Ludwin, K. and Capstick, A. (2015) Using participatory video to understand diversity among people with dementia in long-term care. *Journal of Psychological Issues in Organisational Culture*, 5 (4), pp. 30–38.

Abstract

This case outlines the rationale and methods used when carrying out ethnographic fieldwork in a care home environment with research participants who were living with a dementia diagnosis. Although concerns had been raised at ethics approval about the use of such methods – visual ethnography in particular – we found that there were ethical benefits for the participants whose capacity for research participation, and for social participation generally, was, in every case, higher than anticipated at the outset. By comparison we found that formal methods for assessing ability to give informed consent often appeared to create excess disability, and to exacerbate ill-being for people with dementia. The case draws on specific examples to show how issues related to methods and to ethical conduct of research are frequently intertwined, and should be considered together rather than in isolation.

Learning Outcomes

By the end of the case, students should:

1. Have a fuller understanding of the nuanced nature of mental capacity assessments.
2. Be able to think creatively about exploring an individual's ability and capacity.
3. Reflect on the ways that a researcher might be viewed or perceived in the context of ethnographic work.
4. Be able to identify examples of situated ethical dilemmas arising in research with people with dementia or other seldom-heard groups.

Case Study

Introduction

From 2012-2014 we carried out a participatory video research study that involved co-producing films alongside ten people living with a diagnosis of dementia (first author Research Assistant, second author Principal Investigator) in a care home in a Northern UK city. Participatory Video (Milne et al, 2012) is a film making approach that has a history of being used to enable those who are socially marginalised to tell their stories and have their voices heard. In our study, the individual short films focused on the lives, interests, and experiences of the participants, and their content was participant- driven. The study aimed to work with people who might, for a variety of reasons, be particularly isolated in a care context, and to find out if taking part in this kind of work made a difference to their well-being and social participation. All of the people who took part in the study were living in the same long-term social care facility and, prior to beginning the film- making intervention, we spent several months immersed in the care environment as a way to ascertain who the

potential participants might be and to build relationships with them. During this process we were looking out for people who might, for example, be less able to take part in formal group activities, or those who were often on the margins of conversations, or had few visitors.

The active part of the film-making intervention - which technically lasted around two months for each participant- was therefore embedded in a broader context of ethnographic engagement and took place within the context of established rapport. Our weekly visits continued throughout the eighteen months of the project as we spent roughly a full day each week at the care centre, getting to know to people, paying attention to what was going on, and undertaking the film-making work.

Ethnography, a research approach rooted in anthropological traditions, has no single definition and is variously understood depending on epistemological position and disciplinary location. However, broadly speaking, ethnography can be understood as “the study of social interactions, behaviours, and perceptions that occur within groups, teams, organisations, and communities” (Reeves et al, 2008: 337). Researchers typically immerse themselves in the social context being studied, over lengthy periods of time, in order to generate detailed, descriptive accounts. Because of the persistent levels of stigma and social isolation experienced by people living with dementia, we have been guided by a school of thought that draws on critical theory as a model for ethnography, which begins with “the attempt to understand and document the culture of the oppressed” (Hammersley, 1992: 100).

As ethnographers have long realised, the kind of research practice Clifford Geertz (1973) describes as ‘thick description’ is not primarily about understanding individuals and their ‘behaviours’ in a vacuum. Rather, it is about contextualising human actions and ways of responding within their cultural context. This can be particularly important in the field of dementia care, where the dominant discourse is often a biomedical one, which attributes

everything done and said by people who have dementia living in a formal care environment to their diagnosis, rather than recognising it as a response to the prevailing organisational culture.

Ethnographic work is becoming less possible in the current socio-political climate as research is driven by the agendas of funding bodies with a quick turn around on results and a heavy bent toward a positivistic research paradigm which increasingly requires measurable outcomes. Whilst our overall study did use mixed methods for these reasons, it seemed to us that working collaboratively with people with dementia as co-producers of their films also required a sustained period of relationship building and meaningful engagement. We believed it would help us to understand the people we were working with more fully if we understood something about the community in which they now lived. Likewise, spending time with people enabled us to understand something about their backgrounds, life stories, and what was important to them. These are all important aspects of establishing genuine relationships with people for any research purpose, but in this case they also helped us to begin to develop a sense of what each participant might want his or her film to be about. As Rachael Litherland and Andrea Capstick (2014) have pointed out, if we are not able directly to elicit the views and lived experiences of people with dementia there is a danger of misrepresenting them, and of failing to acknowledge the extremes of social and cultural diversity among those who are affected. The kind of ethnographic research practice we aspired to was therefore one which shed light on otherwise hidden or unseen dynamics, including group dynamics, and regarded people with dementia as a heterogeneous group, rather than assuming similarity on the basis of shared diagnosis.

Negotiating the field

It was our belief, based on our understanding of research dynamics, and our own practical research experiences prior to working together on this study, that investing a sustained period of time in relationship building was ethically and practically the best strategy for achieving strong working partnerships with our research co-participants. The more we knew about and understood our research-partners, the better able we were to adapt the participatory video work in order to maximise involvement in the process (Capstick, 2012). Spending a large amount of lead-in time at the site meant we were known, seen, and familiar. When we initially started to visit we ‘stood out’ visually as unfamiliar faces, but over time we found that, although participants rarely remembered our names, they began to recognise us when they saw us, often acknowledging this by saying, for example: ‘Oh, you’re back again’; ‘Haven’t we met before?’ Or ‘I know I know your face.’ This indicated that establishing rapport over time was not only possible, but that immersive ethnographic research can be a good way of building on emotional memory, which often remains undamaged for much longer in people who have dementia, than do short-term or semantic memory.

The kind of immersive work described here can, as documented by previous ethnographers, be challenging. It is often emotionally intense, and can be tiring, and upsetting, particularly in contexts where participants are already socially marginalised, excluded or unheard. It can therefore present researchers with a range of ethical, emotional, and practical quandaries. Michael Parker (2007) suggests, for example, that the negotiation of consent in ethnographic research is only possible when engagement between researchers and participants is based on principles of respect, recognition, dignity and justice. Working in a care-setting may present some particular challenges related to residents’ well-being and safeguarding, particularly when the observed quality of care is capable of improvement as is currently the case in many

formal dementia care environments. One of our potential participants became seriously ill during the early part of the study, and we had serious concerns about the quality of her care. As these concerns lay outwith the focus of the study itself, and were not covered by ethics approval, we realised that we could not include them as data; however, we were bound by professional ethics to feed back our concerns both to a research mentor within our University, and to one of the more receptive managers at the site, who did in fact act upon them.

Negotiating staff perceptions

Other dilemmas arise from the differing ways in which the presence of researchers in a care environment can be constructed by those who live and work there. As Martyn Hammersley and Paul Atkinson (2007: 63) point out, “people in the field will seek to place or locate the ethnographer within the social landscape, defined by their experience”. We had several meetings with the on-site and regional managers in the early months of the study and these were eased by AC and a co-researcher having carried out previous research in the day care wing of the same site.

Some months into the fieldwork, the centre manager gave us key fobs to enter the building freely which we took as a sign of acceptance and trust. We found, however, that with a few exceptions, front line care staff were wary of us in ways that neither the residents of the home nor the managers appeared to be. Reflecting on this, we thought about how we might be ‘placed’ or ‘located’ by these different groups. The residents often thought we were members of staff, nurses, or people who had been brought in to put on a show as part of the entertainment schedule. One of the centre managers was on our study advisory group, so had an in-depth knowledge of the study. The on-site manager, with whom we had minimal direct contact, was usually working in her office when we visited. As a result she perhaps did not experience the same concerns about being observed as the direct care staff, whom, we felt,

continued to interpret our presence in various ways, despite the regular briefing and feedback sessions we provided. It seems likely that

- They felt vulnerable to negative interpretations of the care they provided within the current media discourse about inadequacies in care settings, which are often attributed to low-paid and poorly prepared direct care staff.
- They were worried that we were there to evaluate their practice or put them under surveillance; acting in a ‘spy role’ and reporting back to the centre management about what we were seeing.
- We may have resembled or been associated with inspectors who visit care homes in order to monitor standards; or as other outside officials who observe what is going on.

Typical responses to these interpretations were twofold. First, there was a tendency for direct care staff to avoid coming into a room when we were there, including the communal lounge where many of the residents spent most of their time. Rather than spending time there, the care staff tended to congregate in the staff office; this meant we may have formed an inaccurate view of how they interacted with the residents when we were not there. It seemed that activities were being staged for our behalf, precisely as a display of ‘what usually goes on here’. This is in keeping with the well-known Hawthorne effect (Landsberger, 1958); the tendency for participants who know they are being observed to make a deliberate attempt to impress. As has been pointed out previously, however, when practitioners make an extra effort in order to impress researchers, they can only do so within the constraints of their current understanding of what constitutes good care practice (McCambridge et al 2014, for example). As a result, many of the activities we felt were staged for our benefit, took the form of quizzes, word games, board games, or other activities that either required intact

cognitive skills, or assumed that all people with dementia enjoy doing the same things. In one case we arrived to find that an activity coordinator had set up what appeared to be a game of dominoes with a group of people we knew enjoyed playing the game. Initially this looked like good progress, until we realised that s/he was asking the participants to add the spots on the dominoes together, rather than actually playing the game as intended. In the process some quite skilled dominoes players were subjected to disempowerment, whilst others had simply withdrawn from the game.

Reflecting on our suppositions

On several occasions, we were sharply reminded of how we are marked by presuppositions and stereotypical assumptions. Florence was one of the participants whom the staff felt would not be able to make a film with us, and indeed AC who worked with her on a one-to-one basis in order to do so, also initially had doubts about this. Not only was Florence able to work with us to make a film, however, we also learned from her in the process things which we had previously been unaware of.

Florence told us about a shop called Anakin's that did not sell anything but potatoes. As we had not heard of a shop that sold only potatoes, we first thought she meant a greengrocer's. She told us that was not the case – Anakin's was definitely a shop that sold potatoes and very little else. A little research told us that Florence was right. There was a shop at the location she had been talking about that primarily sold potatoes. At one point Anakin's Potato Store had 27 branches in Liverpool (Discover Liverpool, 2013). Not only did we learn something new, in cases like these we were also pushed to be reflexive about our own preconceptions.

During 2013 when the gay marriage debate was underway, before the legislation was introduced [first author] was in the lounge with a group of 4 or 5 residents. It was a quiet morning, with not much on. The following is an extract from the first author's fieldnotes:

We were chatting on and off, with interludes of silence. During one of these interludes, Frank came into the lounge and joined the circle, (he is one of the study participants, in his early 90s). He broke the silence, telling us that he had been listening to the radio and they were covering the news about gay marriage. 'Oh no', I thought, 'here we go' and I readied myself for a group conversation about how terrible this was etc. Instead, Frank said 'I can't see what the problem is... I was happily married to my wife for over 40 years and I can't see why they shouldn't be able to do the same'. I will really have to go away and think about my (ageist?) assumptions.

Ethnographic practice

An ethnographic approach allowed us to build up a sense of the community in which our co-creators were living. Our practice was to write very detailed accounts of each visit as soon as possible afterwards, focusing not on a research agenda decided in advance, but on the dominant sensory impressions the visit had left with us. This involved recording the minutiae of events and interactions: our own with the participants; the participants with each other, or other residents; and the participants with staff. When both of us visited on the same day we often shared our field-notes and discussed them as a way of debriefing. In this way, we were not only getting to know each potential participant as an individual with various interests and outlooks but also beginning to understand more about the cultural context in which that person's day-to-day experience was being played out. To use Sabat et al's (2004) term, we

were learning about how that individual was ‘socially positioned’ by others within the organisational culture, and his or her reactions to that positioning.

This kind of immersive work creates space for dynamics to emerge in the field that the researcher is not necessarily expecting or anticipating. When we came to write up our field-notes we often found that the dominant impressions we had been left with had little connection with the intended purpose of our visit. At the same time, however, these unexpected insights were often the most enlightening ones. Among other things we came to understand more fully that capacity was context-specific and that the procedures for assessing capacity and best interests in people with dementia often, in themselves, exacerbate the problems with memory and language typically experienced by people with a dementia diagnosis, creating what has been termed by Rogers et al (2000) and others as ‘excess disability’ in people who have such a diagnosis. The following extract from field-notes, for example, relates to a visit during which [second author] assessed the capacity of one potential participant using the lengthy information sheet and consent process which had been approved by the research ethics committee (REC) for gaining informed consent from participants.

Rita meets the inclusion criteria because she expresses a sense of loss of personal freedom and independence, which constitutes social exclusion in a broader sense. She talks to Eileen [another participant in the research] about things that don’t actually happen very often, eg ‘We like to keep active... we go out to the shops, don’t we?’ She attributes her memory problems to advancing age and seems relaxed about this (‘As you get older you just forget things’). She likes to adopt a caring role (eg toward Joyce, another participant). It’s noticeable that staff don’t interact with Rita, even briefly, in the way that they do with some of the more obvious ‘characters’. She can provide a fluent

and engaging account of her life story, and it seems likely that she would enjoy taking part.

I [...] had a discussion with Rita to assess her capacity to consent to taking part in the research. Although she enjoyed the conversation and didn't show any anxiety about the idea of making a film or taking part in research, she didn't retain the information for long enough to make an informed decision about taking part. She understands the concept of a University and commented that she left school at 14 and never had the opportunity to go, but thought it was nice that I did. She can also personalise the information, in the sense of talking about things that she would like to include if making a film like Eileen's, but the conversation then tends to turn into a general discussion about her life and experiences rather than about taking part in research. (second author field-notes)

We were, by this point in the study well able to judge the likely wishes of our participants, and how they characteristically expressed their individual wishes, from our ethnographic work. Here we can see, however, that conducting the upfront assessment of capacity with Rita is, in itself, at risk of excluding her from participating in the film-making process which she has clearly demonstrated she would like to take part in. Using ongoing process consent as advocated by experienced dementia researchers such as Dewing (2008) reduces these risks and is, we would argue, a more socially inclusive way of involving people who may lack capacity in research carried out under the terms of Sections 30-33 of the Mental Capacity Act (2005). In England and Wales, these sections of the Act relate specifically to the conduct of research with people who may lack capacity and therefore be deemed unable to give informed consent for themselves to participating in the research. The Act requires that alternative means are used to facilitate the consent process wherever possible. In order to be able to consent for themselves, participants need to be able to understand the information

they are given, apply that information in their own case, retain it for at least a brief period of time, and make a decision. A person who does not meet all four criteria will be deemed to lack capacity to consent for him or herself and appointed a consultee who can advise on his or her likely wishes. This is discussed in more detail in the next section.

The participatory video study came under Sections 30-33 of the Mental Capacity Act (2005) which states that people who lack capacity may still take part in research if there is evidence that they wish to do so, and if – in the opinion of a consultee - they would have wished to do so at a point where they still had capacity. The research ethics committee (REC) set a number of conditions, these included:

- Each participant must complete a full informed consent process at the outset; process consent alone was not considered sufficient.
- Participants must not appear, as they currently are, in any of the short films made by them. This included the three participants deemed at the outset of the study to have capacity to consent for themselves, as the REC ruled that they might lose capacity during the study.
- Film footage recorded at the research site during the study (eg to record participants' responses to their own films) could only be seen by the research team, not by anyone else.

Revisiting capacity

In the course of our ethnographic immersion in this environment, as already discussed, we made some interesting discoveries about the abilities of participants, particularly those considered at the outset, using the formal information giving process, not to have capacity to consent for themselves to taking part. It appeared, then, that the ethnographic approach had

great potential to humanize people beyond their diagnostic label and give a different view in terms of their individual ability and capacity. As time went on it often became apparent that people often had a great deal more ability than we – and others - had initially assumed. Moreover, people had a wide range of different abilities, many of which were not amenable to being assessed by a test of mental capacity. None of the following participants was considered – using the formal process – to have capacity to consent for themselves, however:

- Hope displayed constant care and empathy towards her friend, Ann, who was physically frail.
- Nora had a much wider vocabulary than we previously thought. This became apparent when we were looking at pictures together; she described a budgie in one image as ‘autocratic’, for example.
- Lily liked to sing as a main way of communicating, and knew the words of a wide range of popular ballads from the 40s and 50s.
- Rita displayed high levels of procedural or ‘embodied’ memory; she had never forgotten the right way to hold a baby.
- Joyce had a particularly mischievous sense of humour and liked to tell stories.
- Rose had a lot of local knowledge, and liked to talk about influential people she knew; we hadn’t heard of one couple she mentioned but later learned that the local University had a building named after them.

Knowing somebody over a prolonged period of time left a different impression than a single visit might have done. This has significant implications for how dementia researchers approach the issue of capacity, who ends up excluded from research in the process, and how

the practice might be more inclusive. Here there is a significant challenge to received wisdom about how capacity assessments should be undertaken in the context of dementia research, where judgements are often made on the basis of a single, often quite short, visit. There may also be implications here for capacity assessments in a more general sense, as research indicates that the MCA principles for undertaking an assessment are not fully understood or applied in practice (Poole et al, 2014; Williams et al, 2012).

The lengthy up-front information process the REC required resulted in a four-page document which it was necessary to go through with each person in order to establish whether s/he had capacity to consent for him/herself. This led, we believe, to assessments of incapacity in people who would have been able to give (and withhold) ongoing process consent that had ongoing implications in the field-notes. When Florence, for example, was originally asked informally whether she wanted to take part in making a film, she was very enthusiastic about it, saying, 'That's for me'. When told – as part of the information process – that it was a piece of research, however, she said, quite reasonably that she would like to discuss it with her husband as, 'That's a bit more serious'. Unfortunately Florence's husband had died some time earlier, a memory which she did not retain. As a result of her not being able to express a decision to consent for herself, Florence was appointed a personal consultee, her son, who confirmed it was the sort of thing she would have wanted to do, and expressed no reservations about any aspect of her involvement. Later in the study, however, Florence withheld her consent from one part of the process in a way that neither the REC, we, nor her son had anticipated. We arrived intending to film in her flat, and it became evident that she was not comfortable with the (male) film-maker being there, referring repeatedly to needing to wait 'until Alf [her husband] came back'. We understood from this that Florence did not want her husband to think she had had another man in the flat while he wasn't there. The

film-maker accordingly withdrew, the interaction was recorded on audio only, and Florence was happy to continue on that basis. What this demonstrates very clearly, though, is that Florence did have capacity to make at least some decisions for herself, and that in this instance her son had not anticipated her likely wishes about all parts of the research process. In fact Alf's opinions continued to be very important to Florence, as her responses throughout both consent and research consistently show.

Eileen and Frank, both of whom did have capacity to consent for themselves at the outset and retained this throughout the study wanted, against the REC decision, to appear in their own films. It was extremely difficult to explain to them why this was not possible, and in the end different versions of their films were made for private and public viewing. It is interesting to reflect that in this case the REC decision would imply that no-one at all can take part in a film for public viewing, since anyone who did so could subsequently lose his or her capacity to consent to its screening.

The ruling that film of the participants could only be seen by the research team had significant methodological implications, as well as ethical ones. First, it meant that as researchers we were not able to show publicly the film data recorded when participants were viewing of their own films. Some of this data showed very positive responses, and a degree of well-being and ability to communicate personal information that the participants much less rarely demonstrated during other activities. This has implications for the evidence-base available to other researchers who might consider using participatory film-making or co-production techniques more generally in future. Because such approaches are time-consuming and demanding on researchers' interpersonal skills, strong justification is needed for their use. Unfortunately, whilst such visual evidence did emerge from our study we are not able to share it with other researchers and would-be researchers, and have had to rely on

verbal descriptions of this material. Second, it once more deprives those people with dementia who communicate largely through non-verbal means of a 'voice'.

Here, the ethics committee ironically required research practice that disregarded the decision-specific capacity of some participants and may even be considered to have contravened the original intentions of the MCA. Similar tensions have been documented by other researchers working in a dementia research context where ethics committees have impeded, rather than enhanced the inclusion and involvement of people with dementia in research (see, for example, Ward and Campbell, 2013; Capstick and Middleton-Green, 2016).

Conclusions and recommendations

- There is a fundamental case for the importance of relationship-building as an integral part of fully understanding individual capacity and ability. This is particularly important when working with groups of people whose voices are less often heard, or who are readily constructed as lacking capacity.
- A long lead-in time and acceptance within the environment in question are both important for this kind of immersive approach. This means that it is preferable to carry out research with people and groups already well known to you, or where there is a natural route in.
- Spending time immersed in an environment – even one you think you are already familiar with - offers a vantage point on issues related to capacity that goes beyond formal, text-book understandings of how capacity assessments might work.
- The situated ethical issues arising in fieldwork are rarely the same issues that are anticipated by RECs – or researchers – no matter how time consuming and adversarial the ethics approval process. There is a strong case for building case law about real-world ethical dilemmas arising in research and making this widely available.

- Using a combination of critical ethnography and situated ethics, it is possible both to understand more about the concept of excess disability, and to bolster the capacity of people with dementia and other cognitive problems to take part in social research.
 - In the process we will often find that the abilities of those previously constructed as lacking capacity are greater than we expected, and we will become more able to develop reflexively as researchers and learn from our co-participants as a result.
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Exercises and Discussion Questions

1. In the paper we talk about the challenges we faced when building rapport with front-line care staff. Imagine you are a front-line staff member in this setting. In addition to those mentioned, what strategies could the researchers employ in this situation to put you at ease and build better relationships?
2. In the paper we talk about the lengthy information and consent sheets that we were mandated to use as a result of the ethics committee decisions. Can you think of any alternative ways in which information about the study could be conveyed, and consent be recorded?
3. We have not addressed the politics associated with leaving a research-site after such a long involved process where close relationships are established. What issues could arise here and what strategies might a researcher employ to leave in the most ethical way possible?
4. We have discussed some of the limitations of a conventional capacity assessment process. Who might this process exclude and what might be the implications of this (e.g. in terms of how research informs practice)?

Further Readings

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Web Resources

None

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