

Using Participatory Video to Understand Diversity Among People With Dementia in Long-Term Care

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Within care organizations, “people with dementia” are often labeled as a homogenous group with little differentiating them from each other. This can mark them out as separate from and less capable than those without dementia. When individuals with dementia are described, understood, and related to in terms of their diagnosis, individuality may get lost. In this article, we seek to unsettle the socially constructed boundary between “people with dementia” and people without dementia. This is explored in the context of fieldwork we undertook as part of a Participatory Video project where we worked alongside people with a dementia diagnosis to co-create short films about their interests and concerns. In the process of this work, we found that alternative unities emerged between ourselves and people with dementia, as the dementia label faded into the background and the person, with all his or her diverse interests and life experiences, came to the fore. We found ourselves building rapport and making connections with our research participants, a diverse group of individuals whose life experiences, outlooks, and experiences were simultaneously unique to them but also shared in many ways between themselves, and with us. As we spent time with participants in the communal lounge, in the adjoining day center, walking the hallways, out in the garden, or in individual apartments when invited, we found that people shared a wealth of information with us: about how they were feeling, things they liked, things they had done, instances of trauma, as well as some of their happiest times.

This article explores encounters that took place in the course of fieldwork we undertook as part of an exploratory Participatory Video study in which we worked alongside people with dementia living in long-term care. Participatory Video (Milne, Mitchell, & de Lange, 2012) is a filmmaking approach that has been used for many years to enable harder-to-reach groups, and those whose voices are char-

acteristically marginalized in society to tell their stories. In the context of this study, Participatory Video was used to co-produce films with participants about their lives, interests, and concerns. The project aimed to find out whether being involved in this kind of intervention makes a difference to participants’ well-being and social participation.

The discussion in this article focuses on what the co-produced films indicate about

diversity among the population in question. Our concerns had been activated because, in the course of previous care home research, we had noted that activities provided for people with dementia often failed to take account of their individual abilities, interests, or choices. Group activities were often based on the assumption that all participants would enjoy the same things and benefit equally from them. Claims about the success of such activities were often based on enthusiastic responses from a small number of participants, while the voices of those who were not able to take part, or did not want to, were less often heard. The purpose of the study discussed here was therefore to explore the potential for a more personalized approach to facilitate these voices to be heard.

In this article, we explore some of the findings from this study through a focus on encounters that took place during the fieldwork process between ourselves (second author, principal investigator; and first author, research assistant) and our research co-participants. Each filmmaking intervention spanned approximately six weeks, and by the time this process began, we had already spent a significant period of time with participants in order to build rapport and learn about their interests. For over a year we visited the same fieldwork site weekly for a full day.

In the course of our encounters, we quickly found that some of the commonly held ideas about dementia were unsettled. While there have been significant public information campaigns aimed at challenging stigma related to dementia, it is still not uncommon to find ideas about an “empty shell of a person” or “the loss of self” underpinning dominant discourses about dementia in popular culture (Johnstone, 2013). As Van Gorp and Ver-cruysse (2012, p. 1274) have noted, dementia tends to be stigmatized as “one of the most dreaded dis-

eases in western society,” and it is this stigmatization, as much as or more than the actual symptoms of dementia, that has major repercussions for both social inclusion and quality of life.

Consequently, “people with dementia” are often viewed as separate from, and less capable than, those without dementia and continue to face significant social stigma. When individuals with a dementia diagnosis are predominantly described, understood, and related to in terms of that diagnosis (i.e., “person with dementia”), personhood comes under threat. In this way, “people with dementia” are set apart from, and seen as less capable than, those “without dementia.” A sense of individual identity can easily get lost as a lifetime of experience, knowledge, and skill are replaced by a diagnosis that pathologizes the person and reduces him or her to a homogenizing label. This is often reflected in activities that are based on assumptions about what “older people” are interested in (such as reminiscing about the queen’s coronation or playing Bingo) rather than taking individual interests and choices into account. People with a dementia diagnosis report feeling segregated from the rest of society (Bryden, 2005), which may partly be due to preconceptions and social stigma surrounding the condition. While the symptoms of dementia do tend to become more pronounced over time, failure to take individuality into account, social isolation, and stigma may exacerbate symptoms and hasten deterioration (Hancock, Woods, Challis, & Orrell, 2005). The assumption that people with dementia are a homogenized group can lead to excess disability and inappropriate care interventions.

In the course of our fieldwork, we found ourselves building rapport and making connections with our research participants, a diverse group of individuals whose life experiences, outlooks, and experiences were simultaneously unique to them

but also shared in many ways between themselves and with us. This supports the view that social inclusion for people with dementia needs to be based on accurate assessment of diversity within this population.

The article first outlines the methodology used to generate data, before going on to discuss how diversity within the population of people with dementia emerged as we conducted fieldwork. This is then explored in relation to one participant, Florence, as a way to illustrate the points we make and draw out the significance of individuality in this context. The article concludes by outlining the implications for practice in this area.

Methods

Participatory Video (PV) provided a way to explore diversity in the care environment.¹ This approach gives people who are socially marginalized or excluded an opportunity to tell their story. The choice of subject and content is participant driven. Given some of the possible cognitive impacts of dementia, ensuring that participants with dementia are enabled to take an active role in producing films based on their concerns and interests requires some adjustments to the PV process (Capstick, 2011), and in the context of this study, PV was adapted to be as inclusive as possible. The participatory aspect of this work necessitates a responsive, flexible, and adapted approach according to ability and interest. Before beginning the filmmaking, we spent several months making regular visits to the care home in order to build relationships and gain trust from both residents and staff. This approach to rapport building proved effective, and we were eventually accepted as a familiar presence. Participants did not always remember who we were (although they sometimes did), but over time there was a sense of familiarity

and warmth that comes with having preestablished relationships, supporting the viewpoint that people with dementia have an emotional memory.

We were influenced in this work by the reflexive turn in feminist sociology (Coffey, 2002; Shacklock & Smyth, 1998; Stanley & Wise, 1993) and constantly reflected on our inevitable presence in the research, our preconceptions and biases, and how these dynamics might be impacting on the research encounters. In research methods literature, we find a lot about the importance of reflecting on these aspects of fieldwork but less about the positive uses of intersubjectivity in research encounters. More than needing to be mediated, managed, and accounted for as an inevitable “problem,” the researchers place “in” the research process may actually hold positive benefits for participants by creating a sense of reciprocity and shared understanding.

The ten participants (two men and eight women) had an age range of 76 to 99 years. Their speaking (and sometimes singing) voices—representing a range of regional accents from the North and South of England and Ireland—provide the film soundtracks. The films were predominantly made using Photostory 3, a free piece of software that strings still images together² to create a film. Images used in the films were personal photographs provided by participants and their families, archive images from local history websites, or photographs of objects that fit with narrative themes the participants chose to talk about. One woman’s film, for example, includes photographs of the cycling jersey and trophies from her days as a member of a local cycling club.

Each filmmaking intervention lasted approximately six weeks, during which time we spent at least an hour each week with participants. Sessions usually involved one-to-one work between researcher and participant, although on a few

occasions family members joined in with the agreement of the participant, and sometimes there were group sessions where we worked with more than one participant at a time. These group sessions were unplanned and occurred organically.

As we spent time with participants in the communal lounge, in the adjoining day center, walking the hallways, out in the garden, or in individual apartments when invited, we found that people shared a wealth of information with us: about how they were feeling, things they liked, things they had done, and instances of trauma, as well as some of their happiest times. This is an especially intense dynamic in the course of ethnographic fieldwork where relationships are established over time (Coffey, 1999). The process of fieldwork, particularly this type of ethnographic work, means that our interactions are not just about the research agenda as it is laid out, but that the process inevitably, necessarily, and ethically becomes a very porous, human interaction. Here, the encounters took on a reciprocal quality, as (often in response to questions from participants) we shared aspects of our own lives and experiences with participants. Considering the ethics of good research to include reciprocity in terms of “the extent to which the research relationship becomes reciprocal rather than hierarchical” (Guba & Lincoln, 2005, p. 209), sharing information about ourselves may have helped in several ways—by taking pressure off of participants and keeping the exchange going when participants might have felt worried because they couldn’t remember something, and providing an opportunity for them to offer their own opinions, thoughts, and advice on what we said. For example, the following is an excerpt from the second author’s field notes:

I had to leave early from this site visit to go to the dentist. When I explained this to

the participants sitting in the lounge, several of them made sympathetic comments, such as “Have you got a sore one?” and “It isn’t coming loose, is it?” I said, “No, just a check-up,” and they wished me well with it.

This excerpt illustrates how, sometimes, a nurturing, caregiving dynamic arose, where people we worked with were seeking to encourage and support us in our endeavors. This counters the all-too-often held assumption that equates dementia with incapacity to relate to other people and their needs and a consequent inability to create intersubjective meanings.

Findings: “People With Dementia” – A Diverse Population

The PV process was successfully adapted with 10 out of 15 participants. Where it was not possible to complete a film, this was due to practical and ethical considerations rather than problems with the PV process itself. The impact of the PV intervention was found to be significant both for participants’ well-being and their social participation, and was maintained after the study when they were watching their own films and each other’s. A mixed-methods approach was employed to assess this, comparing pre-, during, and post-intervention measures based on ethnographic field notes, behavior category coding frames from Dementia Care Mapping, and the Bradford Well-Being Profile (Bradford Dementia Group, 2005). Our focus here, as explored in the following section, relates to the qualitative aspects of the study and draws on our ethnographic experiences and notes.

The ten films resulting from the study range in length from around 4 to 12 minutes. None of the participants chose to produce films that were overtly focused on their memory problems

or current living situation. All chose a narrative format based on their own early life and its most meaningful events. Often, the stories intersected with events in local, social, and national history. The main subjects of each film are listed below:

- Henry (85) The Fenland village in the English countryside where he was evacuated during WWII
- Florence (87) Moving to one of the first social housing estates in Liverpool in the 1930s
- Sheila (76) Growing up in a children's home
- Jean (92) Working at the local maternity hospital
- Nellie (87) Growing up on the northeast coast and her love of the sea
- Lily (86) The close-knit area where she grew up and her family values
- Rita (81) The bombing of her school and evacuation to the country
- Rose (99) Working in a local department store
- Frank (92) His schooldays in Ireland and early working life as a civil servant
- Hope (81) Landmarks in the local area where she and her brother and sister grew up

While people with a dementia diagnosis are often understood and related to in terms of that diagnosis, issues around memory were thus far outweighed by conversations and interactions focused on other issues and topics, and this dynamic is reflected in the films that were produced. The dementia label faded into the background and the person with diverse interests and life experiences came to the fore. It can be seen that there were some repeated themes in the films, for example, experiences of wartime bombing and evacuation, being a "good neighbor," and working life. Many stories were also ones of adversity overcome, sug-

gesting that the participants drew on these stories to give them strength in their present circumstances. Popular music, dance halls, and cinemas were frequent themes of a more lighthearted nature that were woven into the stories of most participants, and helped to generate spontaneous conversation between them as time went on.

The eventual films are co-constructed between ourselves and the participants in the study, both in terms of content choice and the ways in which that content is organized, and this process relies on ability to create intersubjective meaning. Sharing information about ourselves, and creating a bilateral exchange of information, also meant that the interactions we were engaged in took the recognizable shape of a conversation rather than a traditional interview, which a person with dementia might well mistake for a memory assessment test, such as the Mini Mental State Examination.³

The following section presents a more detailed case study of our work with Florence. We have chosen Florence's film because, as well as drawing out some of the dynamics already discussed, it raises issues related to perceived capacity, and the importance of spending time with people in order to get a sense of who they really are as individuals. Florence was assessed not to have capacity to consent to taking part in the study for herself, and her son was appointed as her personal nominee under the U.K. Mental Capacity Act (Department of Constitutional Affairs, 2005). Florence's son agreed that she would have wished to take part in the study at a time when she did have capacity to consent, meaning that it was possible for us to recruit her to the study. We then went on to find that Florence's abilities were far beyond initial appearances.

Florence: A Case Study

Florence (a pseudonym), aged 88, had lived at the care facility with her husband prior to his death.

She was the quieter, more retiring partner in the marriage, and staff commented that, now widowed, she was vulnerable to becoming lonely and disengaged. Some of the other residents said they found it difficult to understand Florence or help her when she tried to do housework in the main lounge. When not engaged in activity, Florence could often be heard to repeat, "I want to go home" in a quiet monotone. We did not, initially, have high hopes of being able to make a film with Florence. Once we started working with her, however, she surprised us. She had far more capacity to tell her story than we had thought. She has a wry sense of humor, a wide vocabulary, and is very caring and polite. She was always very concerned to offer us a cup of tea and something to eat. She likes to sing, particularly the song "Happy Days Are Here Again," which features in her film. At one point in the film, Florence answers a question from a (postdecimal) researcher about how many shillings there were in an old pound, by saying "Is it twenty?" and when this is confirmed, "Oh, I got something right!"

Florence's story is interesting from a social history perspective because her family moved from a slum clearance area to one of the first social housing estates in the 1930s. She talked a lot about the benefits of the new house, with its increased living space (she came from a family of seven), the garden where her dad could grow tomatoes in the greenhouse, and the indoor bathroom by comparison with the previous outdoor toilet. At the same time, however, there was the loss of community spirit, and something of a family rift as her mother had wanted to stay put in the old neighborhood where her family still lived.

Over the course of our encounters with participants like Florence, we found that boundaries shifted as we moved away from being "people without dementia" interacting with "people with

dementia." Alternative unities emerged between participants and researchers based on shared interests, experiences, and outlooks:

... when I told Florence that my grandmother, like hers, kept a shop, she asked me what the shop sold, and was amused when I said, "Ladies' corsets, among other things." (She echoed the phrase back later by saying that her grandma's shop sold sweets "among other things.") (second author, field notes)

While in some instances we found ourselves communing over similarities and shared knowledge, at other times we took on an active learning role in relation to the participants we were working with, who, beyond being "experts by experience" of dementia (Katz, Conant, Inui, Baron, & Bor, 2000), are experts on their own lives, histories, and interests. Here, the assumption that dementia renders those with a diagnosis less capable, knowledgeable, and insightful is also challenged in the process of co-creation, as in the course of our encounters we found ourselves continually educated by participants about a myriad of things.

From our participants we learned a great deal about social history. This was particularly so in relation to geographical place and how that connected into a broader sociopolitical context. In Florence's case, it related to the sociopolitical milieu of daily life in a working-class neighborhood in Liverpool during the 1920s and 1930s. The core of Florence's narrative focused on a particular bridge that appeared to be a crossroads leading in one direction to the family home, and in another to the row of shops she went to as a girl with her mother. Florence also told us about the excitement she and her four brothers used to feel on the occasions when, as children, they had a day out in New Brighton, which involved taking a ferry across the

River Mersey. “We couldn’t get there fast enough!” she would often say.

As the second author and Florence looked through photographs related to the area where Florence grew up, Florence explained the layout of the neighborhood, asking, “Are you enjoying this?” in a tone of voice that suggested a sense of satisfaction in sharing her story and having it heard, and the second author replied, “I am, yes, you know a lot about it.” It appears to have been significant and affirming for Florence that somebody was actively interested, over a series of meetings, in learning about her life and hearing the stories and thoughts she wanted to share.

Florence described one shop in particular—Anakin’s—that sold potatoes. Initially, we wondered if she meant a greengrocer’s, since we were not familiar with the idea of a shop that sold only potatoes. But she said no, that wasn’t right, it was definitely a shop that sold potatoes and not much else. After some research, we discovered that Florence was right. There was a shop on that street that did primarily sell potatoes. In fact, at its height, Anakin’s Potato Store had 27 branches across Liverpool (Discover Liverpool, 2013). As well as learning something new, in instances like these we are pressed to reflect on our own preconceptions.

Through working with Florence, we built up a sense of her true capacity, and this unfolded as being greater than we had first anticipated. Similarly, when we showed Florence’s film to the care staff, they were more impressed by it than they had been by films made with some of the more outgoing residents.

Conclusion

The content of participants’ films and their foregrounded memories varied considerably, reflecting the diversity of social backgrounds and lived

experiences present in this population. This works to counter the view that sees people with dementia as a homogenous group defined by their diagnoses and nothing else. At the same time, there were frequent echoes and resonances within the film data related to wartime experiences, social upheavals, and shared leisure pursuits.

As Florence’s case illustrates, our encounters suggest that this kind of immersive ethnographic work has great potential for use in dementia research more broadly as a way to highlight the diversity present within this population. This approach was effective both as a way to establish rapport and understanding with participants and as a strategy to move away from understanding people with dementia purely in relation to their dementia diagnosis and toward a more holistic understanding of a whole person with varied interests and a history of experiences.

These findings have clear implications for practice development and practitioner education. They indicate, for example, that social inclusion for people with dementia needs to be based on accurate assessments of diversity within this population. While individualized, one-to-one work provides an important route to effective engagement with people with dementia, this can often happen best during routine care interventions and day-to-day conversation and need not be unduly time intensive. Practitioner education needs to draw on commonalities between people with dementia and caregivers, rather than on differences. These commonalities may lie in the domains of gender, social class, occupation, shared interests, parenthood, or having lived or grown up in a similar neighborhood. Confidence in carrying out and communicating individualized life history research and social history research therefore need to be seen as core skills in the education of dementia practitioners. Above all, the current tendency

toward a one-size-fits-all culture within organizations providing dementia care needs to shift toward a true recognition of the uniqueness of each person.

Notes

1. The study was carried out at a care facility where the principal investigator and co-investigator had good preexisting relationships, based on previous pilot work they had undertaken in the day care center. The day center population was mixed in terms of race, ethnicity, and national origin. In the residential unit where the study reported here took place, however, the population was almost entirely White British. Dimensions of diversity among the participants in this study were primarily those of gender, age, and socioeconomic status. All names are pseudonyms.
2. A key output from this study is to create a flexible template that staff in care environments can follow in order to engage participants in this type of work. It was therefore important that we use free software, keeping the cost down for care homes.
3. The Mini Mental State Examination (MMSE) is a standardized 30-point questionnaire test used by doctors to screen for dementia and estimate the severity of cognitive impairment. People taking it often describe the experience as exhausting.

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