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Webb, J. C., Williams, V. J., Gall, M. R. Y., & Dowling, S. (2020). Misfitting the research process: shaping qualitative research 'in the field' to fit people living with dementia. *International Journal of Qualitative Methods*, *19*. https://doi.org/10.1177/1609406919895926

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Article

Misfitting the Research Process: Shaping Qualitative Research "in the Field" to Fit People Living With Dementia

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Abstract

It is increasingly recognized that people living with dementia should be included in qualitative research that foregrounds their voices, but traditional research approaches can leave less room for flexibility than is necessary. This article builds on others who have examined the challenges and rewards of the qualitative research process with people living with dementia. With reference to a specific project on communication and dementia, the research design adaptations needed at each step to turn a "misfit" into a "fit" are examined. Misfitting, as a concept related to social practice theories, is used to argue the need for a coproduced and flexible approach to research design and data collection. Recommendations include being willing to adapt research methods, data collection locations, and aims of the project to fit participants' competencies, preferences, and realities; spending sufficient time getting to get to know staff and potential participants to build relationships; working round care practices and routines to minimize disruption; and using observational/visual methods can help include people living with dementia at each stage. People with dementia require researchers in the field to be creative in their methods, reflexive in their approach, and person-centered in their goals. Those adaptations can fundamentally change the ways in which the social practice of research is shaped.

Keywords

methods in qualitative inquiry, observational research, conversation analysis, community-based research, case study

Introduction

Historically dementia research has been biomedically focused (Bond, 1992; Hubbard, Downs, & Tester, 2003), overlooking the views and experiences of people living with dementia (Dewing, 2002). Despite a growing acknowledgment of the rights of people living with dementia to have their experiences included in research (Downs, 1997; Shakespeare, Zeilig, & Mittler, 2019) and to be active research participants rather than subjects (Hubbard et al., 2003; McKeown, Clarke, Ingleton, & Repper, 2010; Williams, Webb, Read, James, & Davis, in press), people living with dementia are too often excluded from qualitative research (Taylor, DeMers, Vig, & Borson, 2012). Calls highlighting the importance for further qualitative dementia research persist (Carmody, Traynor, & Marchetti, 2015; Sabat, 2018). More than 15 years ago, Sabat (2003) argued that including people living with dementia in research not only leads to enhanced knowledge about dementia itself but helps us to understand how it is experienced and gives value to people. This led to the wider acknowledgment of the importance of understanding the experiences of people living with dementia, so that they can inform and help construct the

services they use (Murphy, Jordan, Hunter, Cooney, & Casey, 2015). UK policy now recognizes the importance of foregrounding the views of people living with dementia (Department of Health, 2015) and attempts to counteract oft-pervasive deficit focused views by focusing on "living well with dementia," while acknowledging that "everyone with dementia is an individual with specific and often differing needs"(p. 7). This shift of focus is echoed in national and international policies through attempts to create societies that are "dementia friendly," "memory friendly," and "dementia capable" (e.g., see overviews of the dementia policies of Scotland, Wales, UK, United States, Finland, and Malta in a review of dementia policy strategies in Lin and Lewis, 2015); all of which require

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an understanding of the vast panoply of experiences of dementia. This necessitates innovations and adaptations in research methods to better fit the population in order to achieve this task (for an overview, see Phillipson & Hammond, 2018). However, relatively little has been written about how researchers and research practice must adapt *in preparation for and during* data collection, so that people living with dementia can be involved in research (see McKeown et al., 2010, for an overview). We will argue here that research practices need to be adapted in situ at each stage to better fit real people with varying needs and competencies.

With that challenge in mind, this article discusses some of the ways that the research process can be reshaped *for and by* people living with dementia. We draw lessons learned from designing, recruiting, and collecting data in a study aiming to capture and analyze naturally occurring video data of interactions with people living with dementia. We use this experience to explore wider issues on qualitative research processes that seek to be inclusive, drawing on Garland-Thomson's (2011) concept of "misfitting." She suggests that *fitting* and *misfitting* denote an encounter "in which two things come together in either harmony or disjunction...a MISFIT...describes an incongruent relationship between two things: a square peg in a round hole" (p. 592). Her arguments about the experience of disability move the debate on from a structural understanding of social oppression and toward an understanding of the particular time/place context and its impact on the person. The value of the concept of "misfitting" is that it denaturalizes material practices and arrangements that have evolved in order to favor bodies and minds that fall within a societal "norm," and this could easily include research practices that academics take for granted. Further, she argues that when people become misfits, they have the potential to challenge and change the system. This concept is a useful way to examine research processes that aim to foreground the voices and experiences of people living with dementia.

To that end, we offer new reflections on dementia research by drawing on our experience to examine the ways that traditional research processes may misfit this population and how they can be reshaped through, in part, working collaboratively with people living with dementia. We draw on participant recruitment strategies in five memory cafes, two activity groups, a day care service, and a gardening group; overall 28 people with dementia were recruited.

Early Stages of Research: Designing (and Redesigning) Qualitative Dementia Research

The Initial Conception of the Research Project

The study, Getting Things Changed, was part of a large UK program of research about understanding and changing disabling practices (Williams et al., 2018). The initial goal of this particular part of the program was to explore how people living with dementia are supported in everyday life rather than clinical settings, by their personal assistants. In the UK, all disabled

people can be eligible for social care funding in the form of personal budgets or can pay for their own support at home (Laybourne et al., 2016). We intended to find out about what kinds of communication practices work and what could be changed to better fit both parties. We aimed to explore this question by using conversation analysis (CA; Sidnell & Stivers, 2012) to analyze natural interactions between people living with dementia and the person/people who are paid to care for or support them. In addition, we intended to conduct initial interviews to find out from participants what facilitated or impeded interaction.

The broader study was conceived as a way of analyzing social practices in order to understand how they may exclude or "misfit" disabled people (Garland-Thomson, 2011, p. 594) and how these practices could be changed to be more inclusive. Social practice theories (Reckwitz, 2002; Schatzki, 2001) remove the emphasis from the strengths or weaknesses of human beings to conceive of practices as the central phenomenon in social life. Schatzki (2001) describes practices as "embodied, materially mediated arrays of human activity centrally organised around shared practical understanding" (p. 11), and we found Shove, Pantzar, and Watson's (2012) tripartite model of social practice elements (material resources, human competencies, and meanings) extremely helpful. Most practices are not "prescriptive" and do not have a set of rules on which they draw, instead depending on gradual changes in technology, or societal values, which create the need for new competencies to develop (Shove, Pantzar, & Watson, 2012; Williams et al., 2018). By contrast, research practices arguably do have to adhere to specific standards and ethical criteria. What we did not foresee was that our *own* research design could become a focus for observing how the social practice of research "misfitted" people living with dementia and required repeated adaptation.

It is not new for disability studies scholars to mount a critique of social research (Oliver, 1992). Research itself is a social practice that can "other" whole groups of individuals (Bhattacharya, 2009), and Oliver (1992) argued that social research is never objective but is often on the side of the establishment, becoming part of the oppression experienced by people living with disability. For those reasons, a new paradigm of "emancipatory research" was founded by disability scholars (Barnes, 2003; Barton, 2005), a movement by which disabled people would take back the research agenda into their own hands. People with cognitive disabilities were, however, largely excluded from this agenda (Walmsley, 2001), and those with dementia have only recently started to be considered as capable of taking on meaningful roles in the process. We have written elsewhere about how inclusive research can be adapted when people with dementia take on active roles as researchers (Williams et al., in press), and we will refer in this article to various ways in which this group, the Forget Me Nots, helped us reshape the research process. Thus, during the course of the project, they developed their role to become in effect "co-researchers," reviewing and helping with data analysis by sharing their own insights, creating training videos based on

the research, and co-authoring papers. In this article, however, the main focus is on the more specific ways in which traditional research protocols are reshaped to fit *participants* with dementia.

Building a Proposal

Most funders in the UK now require that applicants can demonstrate some engagement with the "end users" whom the research concerns, and this research program was firmly grounded in the concerns of disabled people (Williams et al., 2018). However, our experience highlighted that on both ethical and practical grounds, there is a case to be made for a lengthened pre-data collection phase to be built into funding applications for dementia research. Without this, it may not be possible to spend adequate time getting to know participants and to explain the research, discover their preferred means of having the study information communicated to them, or being able to make accurate assessments of their capacity to consent.

A point often not discussed is that securing funding also has wider implications for the involvement of people living with dementia in the research design. The potential benefits of coproduction to add value to research are recognized (Sabat, 2003) and are increasingly used in dementia research (Clarke et al., 2018). However, while academics are expected to write funding bids as part of their job, it is difficult to collaborate with co-researchers in the first instance, as they should not be expected to give their free labor for speculative research bids. While our study was part of a wide program of co-produced research, the disabled people's organization (Disability Rights UK) that collaborated in planning and writing the bid was not used for including people with dementia. This may speak to the extent to which dementia historically has not been included as part of wider disability activism (Shakespeare et al., 2019), which itself can become a misfitting practice for people who may not consider themselves disabled. The second author, as a project applicant, therefore approached and gained approval and support from the Alzheimer's Society, who were able to connect the research team with their extensive network of local groups. However, it was another "empowerment" networking organization that eventually joined our program advisory group at the start of the funded period, and it was through them that we gained the link with the organization where we met the three people who volunteered to help us with our project plans. As the rest of the article attests, we made adjustments every step of the way, some of which were suggested by our "project advisers" with dementia. We should note here that their role in the research, and their input, grew substantially throughout the project until we were equitably collaborating on the data and outputs, with their suggestions leading impact activities. This will be reflected on a little later. Their earlier involvement could have not only saved time but added expertise through lived experience to the research design. We therefore recommend that qualitative dementia research be built from the ground up in collaboration with people living with dementia, either as advisors or more actively as co-researchers. This may

involve applying for small pots of funding to buy time to work together to build robust, nuanced, and informed approaches, something which funding bodies should consider when allocating funding.

The Ethics Process

Ethical considerations are especially important to the research process where "vulnerable" groups are involved, and in England and Wales, researchers need to follow the provisions of the 2005 Mental Capacity Act (MCA) with those who may not have capacity to consent for themselves. The UK in fact has specialist committees that are experienced in assessing proposals involving participants who may lack capacity to consent. However, ethics "processes" can become a key constraint on research practices. For instance, such committees specify the addition of participant information sheets that are adapted for different groups of people. Although we created an "easy read" information sheet with input from people living with dementia, for some potential participants, any text was problematic. For this reason, we went further and created a short film where people living with dementia explained the project in their own words (explored in more depth later). This was not intended to replace the information sheet but to augment it. What we discovered was that time itself was the most important aspect, and in practice, this meant taking time to talk through the information sheet with each participant, spending weeks, and sometimes months, in the same research locations. This is an instance where research is shaped to fit an agenda that does not arise from participants themselves. There is a tension between protecting "vulnerable" groups from research practices and these processes unintentionally excluding them (Bartlett, Milne, & Croucher, 2019).

Research practices, unlike everyday social practices commonly discussed by theorists such as Shove et al. (2012), are thus consciously shaped and constrained by preplanning and by protocol. However, in this project, the ethics board reviewing our work in fact provided a flexible and supportive framework for our changing needs, allowing us to incorporate changes to the research design to fit potential research participant preferences; for instance, our original plan was to recruit participants via congregate settings but to carry out the research itself in people's own homes. However, this strategy did not yield sufficient numbers of people who employed personal assistants or received home support (Laybourne et al., 2016; Priestley et al., 2010). Almost unanimously, they expressed a preference to take part in the settings we met them in rather than in their homes. The ethics committee were happy to approve the change of research setting because the focus of the project remained the same: (a) How can everyday decision making be facilitated in people with dementia? (b) Can workers learn how to improve their practices through video interaction analysis?

Ethics boards exist to safeguard participants from unethical or ill thought out research strategies; however, qualitative research often needs to be adapted to what happens in the field.

It is precisely this disjunct that can lead to a misfit between the preapproved research approach and adapting to experience in the field. Ethical approval is not the end of ethical considerations, rather they should be reflected on throughout all the stages of data collection (Cridland, Phillipson, Brennan-Horley, & Swaffer, 2016; Dewing, 2007). The consequences of ethics processes which shape the research design have moral, cultural, and political consequences (Dewing, 2002). Where they constrain the involvement of people living with dementia in research practices, this limits the possibility of engaging in potentially therapeutic and affirming processes where participants feel their experiences are of value (McKeown et al., 2010; Tanner, 2012). Researchers may need to build time into projects to make ethical amendments arising from unanticipated experiences in the field, fitting the research strategy to participants rather than the other way round.

Navigating Gatekeepers

Accessing participants in the first instance requires identifying "gatekeepers" who would have to endorse the project aims and enable access (McKeown et al., 2010). Gatekeepers are often invisible in accounts of dementia research (Murphy et al., 2015; Pesonen, Remes, & Isola, 2011). However, it is well known that gatekeepers exercise some degree of control by blocking certain lines of inquiry or by shepherding the field-worker in a particular direction (Hammersley & Atkinson, 1995).

Our intention was to access participants through congregate settings. In order to do this, we had to get endorsement from "layers" of gatekeepers (Hellström, Nolan, Nordenfelt, & Lundh, 2007): a national organization providing dementia services, an ethics committee, support from "Evaluation and Impact Programme Managers," then care coordinators, followed by managers of groups, and finally the care staff themselves; all before speaking to potential participants. At each stage, time and resources were needed to explain the research aims and process to each person before we approached people with dementia themselves (another reason for qualitative dementia research necessitating extra time and funding to be done properly). This required a sensitive approach that adapted the research presentation to best suit each party. For example, a "non-academic" summary of the research methods and approach to CA was put together for gatekeepers at each stage, with examples and outcomes from previous studies using this methodology to facilitate a deeper understanding of our approach.

One factor that helped us to receive support from all gatekeepers was that (a) the primary research method (CA) did not require staff or people living with dementia to do anything other than what they were already doing; (b) we were offering people living with dementia and their conversation partner the chance to watch back and learn from their video, thus ensuring that there was a direct benefit and minimal burden (McKeown et al., 2010); and (c) we were very clear that the aim of this research was not to highlight "good" or "bad" practice but to learn about the interactional skills of the participants, as well as any difficulties they may *jointly* encounter.

We agree with Hellström, Nolan, Nordenfelt, and Lundh (2007) that there is no simple solution to the dilemmas in negotiating access to research participants; a balance between protection and potential participation must be struck, which does not always go in the researcher's favour. What we encountered, like others (McMurdo et al., 2011), is an assumption from service providers and professionals that research, while a highly valued practice, would naturally exclude meaningful participation from those whose memory or cognition was in doubt. In other words, there is often a taken-for-granted view that research is "difficult." It was thus incumbent on us to gently push back against these assumptions, but this could only be done through building trust and positive relationships with gatekeepers, which required time and repeated visits. Our relative success in recruitment was a product of both persistence and time for each gatekeeper in the chain, providing accessible project summaries and making sure to meet them in person. This enabled us to work with gatekeepers to formulate plans of how we would meet people, over what time period, at locations/services that were deemed most appropriate, and to meet each service's ethics protocols.

Lastly, our conversations with gatekeepers about the number of researchers who pass through groups to recruit participants made us reflect that there is a tendency in research to recruit from the most willing and/or visible pool; people who visit congregate groups are both numerous and perhaps more outgoing (and therefore likely to take part) than those who avoid these social groups. This could lead to certain groups of people being over-researched, and the unintentional marginalization of other people living with dementia who fall between the cracks of the care system, and so do not appear on the research radar. Qualitative dementia research recruitment strategies should be mindful of this issue to avoid "misfitting" and excluding these voices from the tapestry of dementia experiences.

In the Field: Fitting and Misfitting in the Recruitment Process

The following section outlines the ways in which research plans that look good on paper may "misfit" the reality researchers face in the field and need to be changed to fit participants.

Adapting the Research Focus

Research as a social practice is heavily reliant on researchers setting their goals and drawing up clear research questions at the planning stage. However, as mentioned above, we shifted the focus of the project to include group interactions and toward *collecting* data in the spaces in which we were originally attending to only *recruit* participants. In CA, this is possible since the focus is on the detail of sequences of interaction rather than on the particular context of the talk. This first shift of focus, though, took the planning power away from us as

academic researchers and became the first step in acknowledging the lived reality of participants.

Presentations and Spending Time With Potential Participants

After a cup of tea and meeting people living with dementia informally in groups, we took our cue from the organizer to introduce ourselves to the group and explain our intended research on communication and support. Asking people "what worked" about speaking with their conversation partners usually elicited explanations of what they enjoyed about certain interactions as well as what a "good conversation partner" meant to them. Once the specific topic area had been covered, we would emphasize that it was precisely these things that we wanted to find out about through videoing everyday support interactions. Equally, we mentioned that there might be areas of communication that could be altered to better suit both participants.

In the early presentations, we ended by giving those who expressed an interest a participant information sheet, a consent form, and stamp addressed envelope to take home. However, many potential participants expressed the belief that what they had just done *was* the research. Clarity in explaining our purposes and taking time to build a relationship proved to be critical for recruitment (Hubbard et al., 2003). It became apparent that visiting a location once to recruit participants was not sufficient to explain about the project nor to understand people's particular communicational competencies and needs. Equally, one could argue that the people we met in the groups were actively reshaping the research to make it fit to their preconceptions and the way in which they managed their own memory loss. All they wished to do was to attend a group, have an interesting discussion, and go home to get on with their lives without having to consider the information further. Indeed, the MCA (2005) states that one facet of being able to make an informed decision about research participation is being able to retain the information. This was not always possible to determine over a single visit. In places where there were larger groups of people (memory cafes or activity groups), we attended for months in some cases, drawing on Dewing's (2007) work which refocuses consent as a process that runs through the whole of a research project. This enabled a more nuanced understanding of the extent of participants' ability to give informed consent, to understand their level of communicational ability in order to adjust our approach where necessary, and to build trust with potential participants. Our experiences were in line with Smebye and Kirkevold's (2012) argument that decision-making competence is not an absolute issue; rather, a person with dementia may be competent in some domains and not others. As research is a multi-faceted process, understanding which parts they may be able to consent to takes repeated visits to assess over time. Thus, we adapted recruitment processes and practices as we went along to better fit the reality we found in the field.

Designing (and Adapting) Research Materials

For research to be fitted to individuals, it may need to evolve from the pre-planned research design processes. For example, the participant sheets we prepared prior to the ethics application included a large amount of information for people to make an informed decision about taking part. We encountered a tension between the simplicity of the message we were trying to convey and the rigor required by ethics boards. Later on, this resulted in many potential participants finding the amount of text impenetrable. The amount of text and complexity of language in information sheets is a problem in research in general (Ennis & Wykes, 2016) but surprisingly has been little reflected on recruiting participants living with dementia (see McKeown et al., 2010, for an exception).

There were a number of ways that we attempted to ameliorate this issue. Firstly, our co-researchers suggested making a recruitment video/DVD with them putting the research in their own words, thus adding to the richness and meaning of what our project could achieve. To quote from their introduction to the recruitment DVD, "It does help to talk to people. That's what this research is about. Do you have somebody to listen to you? If you don't, find someone who will listen to you, just talk to them". Misfitting became an active process here, with the Forget Me Nots members reshaping and articulating what the research could mean to them. The video also showed the group interacting with staff members, and each other, and emphasized the point that we were interested in the type of natural everyday communication that was happening on screen. Often, this proved to be a far more impactful and engaging way of illustrating the aim and focus of the project.

One of the first points of advice from the Forget Me Nots was regarding the inclusion of the phrase "people with dementia" on the tag line of the participant information sheet. The group discussed issues on identity being linked to dementia and, for some, the feeling of alienation and disassociation with the phrase/terminology (see also Swaffer, 2014). Some of the group felt that this phrase should not be included because it labels participants and reduces them to a diagnosis. There was also the potential issue that the participant information sheet could cause distress if given to a person who was not fully aware of their condition or had not yet received a diagnosis. The group members suggested the inclusion of "memory problems" as a proxy term to go alongside "dementia," so that the headline on the participant information sheet now read "people with dementia or memory problems." Whereas Hellström et al. (2007) decided to use the term "memory problems" and to use "dementia" only if it was introduced by the person or their family, we found that (on occasion) this could also lead to people *without* a diagnosis of dementia wanting to take part. While it was conceivable that some participants might not be aware of a dementia diagnosis, they were more likely to be aware of issues around memory. We therefore thought it apposite to include both terms in the recruitment materials.

Effective Communication: Building Relationships With Participants

Due to the high number of potential participants that we met, it was useful to keep an informal notebook, writing down names, what was talked about, and any possible communication issues. This aided communication by refreshing the researchers' memories about what was important to potential participants. These topics could act as jumping off points for future conversations.

Issues with communication that are associated with dementia also necessitated a careful and reflexive approach. Although our research design revolved around observation, videoing, and analysis of interaction, we nevertheless often found ourselves engaging in direct communication with participants and in a sense enacting the interactions we were analyzing. We found it useful to have a grasp of common interactional issues before fieldwork (Chatwin, 2014) and strategies to work with the person's communicational competencies (e.g., Wilson, Rochon, Mihailidis, & Leonard, 2012). This included getting to know potential participants through active–empathic listening (Gearhart & Bodie, 2011), making eye contact, having an interest in them as a person beyond their status as a potential research participant, following their communication cues, not contradicting them, and not quizzing them by asking too many direct questions (Bourgeois, 2002). As our research progressed, we naturally learnt more about interactional strategies that caused difficulties and those which were more successful. For instance, when concentration lapses occurred (Downs, 2005), we tried to be sensitive in our reactions by going with changes of subject, and only steering the conversation back to the research at topic termination, and if the person showed they were happy for this to happen, verbally or non-verbally (see Downs & Collins, 2015, for advice on person-centered communication).

It was imperative to be sensitive to non-verbal signals and non-topic-related verbal interactions. This is the case regardless of whether informed consent had been given. For example, one man was asked whether he would mind being filmed, after consultee consent was obtained and after he had previously expressed interest in being involved. However, he subsequently replied on two separate occasions that he "needed to work" so did not have the time now. The action that his talk accomplished (a polite rejection) was respected and upheld.

Even though we had a pre-existing awareness that some participants might respond slowly to questions, long pauses between questions and the participant's reply could elicit a desire to suggest possible answers. Killick and Allan (2001) argue that "[o]ne of the ways in which people with dementia are disempowered in communication is that of being continually outpaced, having others speak, move and act more quickly than they are able to understand or match" (pp. 60–61). While leaving pauses has been noted to be a useful skill in qualitative research (Adams, 2015), we became aware that not all pauses were equal, especially when a person may feel "stuck" when trying to find a word. By this point, the Forget Me Nots group who had advised the initial stages of the research had taken on a more in-depth role and were meeting regularly to review our video data and suggest ways of interpreting communication. They suggested that we should allow the participant ample time to answer for themselves, unless the word search becoming frustrating and/or they indicated they would like help. Thus, while many "taken-for-granted" good practice qualitative research approaches can be adopted, our research group also helped us to become attuned to the specific and fine-grained ways these need to be adapted in the moment.

There were also issues relating to keeping the conversation "on track" when discussing the research. However, we realized that the notion of "on track" needed scrutiny; we recognized that a person (with or without dementia) will have less interest in talking about the research than a researcher. For example, we often found that people wanted to talk about who we were and were interested in personal details of our lives rather than just the research. This helped us realize that this stage of research is as much about establishing a relationship as a person as it is about the proposed research (Lloyd, Gatherer, & Kalsy, 2006). We then tried to approach the person at a later date or time to see whether a conversation about the research was possible. While it was not a premeditated strategy, sharing some aspects of our everyday lives was a way to connect and find common ground. However, this does raise the issue of disclosure. Here, we found it led to more equitable relationships, given we were asking participants to share their everyday interactions and experiences for research purposes. Topics such as where we grew up, favorite music, and memories of holidays frequently came up. We recommend only sharing stories where participants are interested or initiate such conversations and not disclosing anything that could be distressing or an emotional burden. However, if we want to approach participants as people and ask them to share aspects of themselves, not just as research subjects, then we must be willing to make interpersonal connections and share who we are too. Dementia does not affect any two people in quite the same way (Bourgeois, 2002). Therefore, a reflexive and flexible approach to communication must be adopted at all times and that can only be achieved by getting to know people and taking our cues from them.

Factors Enabling Data Collection

Building Good Relationships With Staff

There was a good deal of groundwork to be done before data collection could begin. We were reminded of Tarzia, Bauer, Fetherstonhaugh, and Nay's (2013) experience that "[t]he only effective recruitment strategy . . . was having a reliable and enthusiastic 'insider' at a facility management level" (p. 363). In order to "fit" each scenario and setting, we built relationships with staff by arriving early in their shift to talk informally about the research and to learn the day-plan in advance, how we could help, and to work collaboratively together to identify opportunities at which potential participants could be approached about the research. We found that it was appreciated if we assisted staff in the early stages, where appropriate.

This sometimes meant helping with activities, assisting with routine events (i.e., walking with people to the lunchroom), or making drinks for attendees.

It was useful to find out the groups' schedules weeks in advance, especially where particular participants had already agreed in principle. This enabled us to work with staff and participants to avoid clashing with planned activities. A huge part of making this possible was staff introducing us to the people they worked with, explaining briefly about the research and asking whether they wanted to hear about our research plans. This had the advantage of demonstrating to the attendees that the staff members knew who we were and supported our presence there, which helped build trust. Thus, establishing a good working relationship with staff *in the first instance before data collection* was crucial to identify moments where research conversations could take place.

Minimizing Disruption

Much of the research on recruiting people living with dementia quite rightly focuses on building relationships (Hellström et al., 2007; Hubbard et al., 2003) and ethical issues (McKeown et al., 2010). However, an aspect that can be overlooked is how to minimize disruption of existing work practices once "in the field" (see McMurdo et al., 2011). This is especially pertinent in congregate settings where activities are planned in advance and which people living with dementia may feel aggrieved at the disruption that the researchers' presence may cause. The presence of a researcher has the potential to disturb a meaningful activity due to the potential conflict of expectations and priorities that researchers and potential participants (and staff) may have. We therefore found it to be essential that researchers work with staff and organizers in advance and, in situ, to fit to the service or group. This meant that research plans and strategies had to be altered for each service. As above, this hinged upon a good working relationship with staff who planned and ran these services (see Mckeown et al., 2010; Bartlett et al., 2019).

Adapting Signifiers and Demystifying the Research Process

Initially when we first met participants, we wore university badges on a lanyard. We did this in an effort to show both names and faces that we were from a trusted institution and to display professionalism. However, the lanyard and university name badge were often conflated with notions of *medical* professionalism. This could be problematic given that some potential participants had negative experiences with medical professionals, which colored their perception of researchers. The lanyard and staff badge were soon dispensed with in favor of a colorful homemade badge displaying only a first name written in bold font. The difference in reaction was startling. People started using our names more frequently, making the conversation more congenial and smooth flowing, and they no longer thought of the researchers as representatives of medical authority.

Once "through the door," there was yet another hurdle to negotiate, as our research involved making videos of naturally occurring interaction in order to collect data for conversation analytic research. When films or video were mentioned however, participants assumed these were to be professionally produced videos in which they would act or play a part; since this was quite the opposite of what was intended, we found that introducing our small, inconspicuous video camera at an early stage allowed participants to familiarize themselves by looking through the viewfinder, ensuring that their perception of filming would become simply part of the daily routine in the group. We were reminded of the importance of material resources in helping to shape practices, a key point made by Shove and her colleagues in relation to everyday social practices. Research becomes less of an "expert" and esoteric phenomenon, as these resources become handled, shared, and understood by all parties.

Using Video in Dementia Research

We found using video and visual methods hugely beneficial and inclusive in a number of areas. Our primary method was CA (see Sidnell & Stivers, 2012), typically requiring recording real unscripted interactions.

Researchers often adapt research methods, or redesign approaches to research, to better fit people with dementia (e.g., Bartlett et al., 2019; Cridland et al., 2016). However, often these methods still are predicated upon the person with dementia somehow completing some task that the researcher has set in order to capture something of their world or life experience. Certain methods are likely to be more suited to people in early stages of dementia or for those people who retain a high degree of verbal fluency. Videoing normal interactions as a method of data collecting has the advantage of capturing life as it is lived, with all the complexity, richness, and detail that communication entails, using visual methods can help to capture some of the routine detail of health and social care services (Parke, Hunter, & Marck, 2015). In addition, the use of observational research techniques may prevent the exclusion of people in later stages of dementia (Puurveen, Phinney, Cox, & Purvest, 2015) where other forms of qualitative methods that rely on memory, recall, and a level of verbal fluency may not be fitted to their competencies.

In addition to using video to promote inclusion of participants, we found it beneficial in working together with the Forget Me Nots group, and this is where they developed their involvement to take on quite new roles in the project, as analysts "behind the scenes." CA is generally considered an inaccessible and technical, detailed approach. However, building on previous research we had carried out to include people with intellectual disabilities in CA (Williams, Ponting, Ford, Rudge, & [Skills for Support Team], 2010), we wished to experiment with similar methods in this project. In the first instance, we went through the video data with them, and they were guided

by their insights into what to focus on for our analysis. Their interactional observations led to a successful grant proposal to create a series of communication training videos in which they recreated some tricky interactional moments based on our co-analysis, followed by their thoughts and opinions about what had happened in the interactions, as well as suggestions for ways to do interaction differently. These have been jointly presented at conferences and written about together (Webb, Williams, Read, James, & Davis, 2019; Williams et al., in press). Repeated evaluations of the training package by practitioners and professionals stressed that it was the involvement of the Forget Me Nots' "direct voice" that was a crucial element in its success. We have also reflected elsewhere in an academic CA paper (Williams, Webb, Dowling, & Gall, 2019) that their contributions also gave us faith that the interactional details we were focusing on mattered to people living with dementia. They reported that video of everyday interactions was an engaging medium for them to get involved, both because it did not require a text heavy approach and because they could relate to and reflect on the interactional issues they identified on the videos.

Lastly, we were also able to use the videos we made of interactions between participants living with dementia and their conversation partners to scaffold reflexive interviews about communication. This reflects a growing trend recognizing the potential for the use of video in dementia research (reported on in this journal, e.g., Li & Ho, 2019). Watching the videos meant that we did not always have to ask questions but could leave it up to participants (in many instances) to react and notice things themselves, which we could follow up on. This had the advantage of avoiding issues such as how to word questions, which others have reflected upon (Hubbard et al., 2003; Nygård, 2006), and avoiding questions that rely on memory (Lloyd et al., 2006; Nygård, 2006), by making reference to what was happening on the video in the here and now. In all these ways, the conventions and intellectual contribution of CA were not abandoned, but they were built on and recreated as accessible tools for a more equalizing method, with both participants and coresearchers.

Discussion

Throughout the adaptations to the research process, we found Garland-Thomson's feminist–materialist idea of misfitting illuminating. Research is so often seen as a "given," without questioning the protocols and processes that have arisen from methodological considerations such as robustness and ethical practice. However, people who have direct experience of the embodied difference associated with dementia can illuminate for us the ways in which these unquestioned practices may indeed be "misfitting" wider populations of people living with dementia. Further, our reflections on the research process reveal how identity is central to the way in which people living with dementia might approach research. For instance, their self-identification as "having dementia" is not a given, and thus, terminology is vital in negotiating any kind of

involvement in research. The lived experience of dementia is to some extent a way of developing new identities and certainly new ways of coping with the world. It was only by working with the Forget Me Nots group, and by taking cues for changes to the research approach from participants themselves, that we were able to understand these subtleties and to reshape our own ways of doing research. In the process of doing this, the political reality of the research process is brought into sharper focus. So often, an academic research team follows unquestioningly a protocol set out by their training, by "good practice in research," and by the requirements of ethics committees. Unwittingly, as we have seen, this could lead to the subjugation or silencing of people experiencing dementia. Knowledge about their own reality is then taken from them and produced by powerful others. Changing research processes and qualitative methods from a "misfit" into a "fit" also means sharing power and including voices and the suggestions of the population you are studying. This can be achieved through working with people living with dementia in the research process.

Throughout the article, we have made reference to the developing role of the Forget Me Nots from project advisors to "co-researchers" whose insights and jointly created outputs became central to the project (Webb et al., 2019; Williams et al., in press). Despite the recognition that people living with dementia should be included in research as *active* participants, not just as subjects (McKeown et al., 2010; Sabat, 2003; Tanner, 2012), they are often still excluded from having an active role in the research process (Gove et al., 2018). As the research team changed the research design to fit participants rather than expecting participants to fit our research design, we worked constantly with our "co-researchers" in order to aid reflexive practice and explore how to reshape practices that misfit participants. The potential benefits of co-produced research have long been recognized as adding value and insight, not to mention the possibility of leveling power imbalances between researchers and the people being researched (Johnson, 2009). These aspects are increasingly being used actively in dementia research (Clarke et al., 2018), and we would suggest that they lie at the heart of a fundamental shift of power in dementia research. For example, our collaboration in this project has led to subsequent research projects entirely instigated and led by the Forget Me Nots, based on their research interests.

What has this process added to our understanding of social practice theories? Material elements are key to many of the changes made in this project including, for instance, the use of video or simplified participant recruitment sheets. Competencies too were developed, particularly by the research team as they interacted with participants and with those around them. Nevertheless, perhaps it is above all Shove et al.'s (2012) third set of elements that are a key to understanding how to adapt research and those related to values and meaning. It is only when we really value what people with dementia can offer that we can develop new ways of fitting the research process to their needs. Research becomes less of a power-driven, esoteric, and specialist enterprise and more of an equalizing, democratic process. Success relies on not only the suitability of the

research method for the population but also the way that research method can fit (or "misfit") in the research setting. Other researchers have also adapted research methods, or redesigned approaches to research, to better fit people with dementia (e.g., Bartlett, 2018; Cridland et al., 2016). However, often methods still are predicated upon the person with dementia somehow completing a task that the researcher sets. Using video in the ways described here can provide opportunities to include and fit a population for whom traditional research methods may be ill-suited and provide opportunities to focus on the importance of non-verbal behaviors (Hubbard, Cook, Tester, & Downs, 2002). It can also be used to scaffold interviews that are grounded in the here and now of the video. The adaptability of video and observational methods, including interaction analysis or CA, has proved to be a very much more productive platform to include and fit a population for whom traditional research methods may be ill-suited. We would thus suggest that they create opportunities for involvement of participants who have previously been overlooked in the field of CA.

Research processes need to be reviewed constantly, to ensure that they do not become part of the disabling barriers faced by people living with dementia. As shown in this article, we adopted some very particular strategies that seemed to "fit" with the needs of our participants living with dementia, which resulted in a more organic, shifting, and fluid practice than would often be expected in qualitative research, including in CA. This involved taking time to build relationships with potential participants; staff and the research setting; being willing to adapt to both individual participants and the specific research context; using methods that can be adapted to fit the population; adapting to the rhythms of research sites to minimize disruption; using visual methods to aid recruitment, data collection, co-analysis, and outputs; and allowing the role of coresearchers to grow and enrich the research. Adapting such research practices at each step is vital to ensure that research does not exclude and misfit the very people we seek to include.

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