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Abstract

Debates about involving people with dementia in qualitative research are extensive, yet the range of methods used is limited. Researchers tend to rely on interview and/or observation methods to collect data, even though these tools might preclude participation. I modified the conventional diary interview method to include photo and audio diaries in an effort to investigate the lives of people with dementia in a participatory way. Sixteen people with dementia kept a diary—written, photo, or audio, whichever suited them best—for 1 month. The purposes of this article are to share the methodological insights gained from this process in the context of emerging literature on sensory ethnography, and to argue for the broader application of the diary interview method in dementia-related research, on the grounds that it mediates an equal relationship and makes visible the “whole person,” including the environment in which that person lives.

Keywords

dementia; diaries / journals; research; qualitative; research participation; visual methods

It is a generally accepted wisdom that people with dementia are entitled to have their voices heard (Cantley, Woodhouse, & Smith, 2005); thus, the views of people with dementia are increasingly sought by qualitative researchers. Typically, researchers explore the lives of people with dementia using interviews (Allan, 2001; Barnett, 2000; Proctor, 2001) and/or observational methods (Briggs, Askham, Norman, & Redfern, 2003), most notably dementia care mapping (e.g., Brooker, 2005). Although using these strategies extends our understanding of dementia, there remains a concern about the extent to which the expression of personal experience and participation is allowed (Sabat, 2003). Answering this concern are those who call for a multimethod approach for research with people with dementia (Nygard, 2006), including the adaptation of other, more participatory methods such as photography (Mitchell, 2005), talking mats (Murphy, Gray, & Cox, 2007), and participatory video (Capstick, 2009).

With the increased involvement of people with dementia in social research, questions about how best to involve such individuals are becoming more pertinent (Bond & Corner, 2001). The neurological effects of dementia, such as memory deficits and expressive language difficulties (Morris & Becker, 2004), can render standard approaches to data collection inappropriate, and

possibly even harmful. For example, people with dementia might find a traditional research interview to be a stressful experience (McKillop & Wilkinson, 2004), possibly because of concerns about being recorded and sounding inarticulate (Hellstrom, Nolan, Nordenfelt, & Lundh, 2007). More generally, participants with a serious illness, like dementia, are potentially vulnerable and prone to marginalization in research (Read & Maslin-Prothero, 2011).

One way to address this situation is to take a participatory approach (Aldridge, 2007). Such an approach is promoted for securing “process consent” from people with dementia, but it has yet to be fully considered in relation to actual data collection (Dewing, 2007). Participatory approaches involve the researcher working with participants in a respectful and engaging way, and on equal terms (Trivedi & Wykes, 2002). The essential difference between participatory and nonparticipatory approaches is that with the former, attention is paid to power dynamics (Cornwall,

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1995). A focus on participation is particularly apposite in dementia research, because a massive imbalance of power has historically existed between researchers and participants who have disabilities (Stone & Priestly, 1996). For instance, researchers have used the Mini Mental State Examination (Cockrell & Folstein, 2002) to assess a person's ability to participate in a study, even though individuals with dementia might find this a humiliating experience (Hellstrom et al., 2007). Clearly, the onus is on health researchers to be flexible and experimental in their choice of methods in an effort to equalize research relations.

Modifying conventional methods is essential for health research (Thorne, 2011). Rather than dutifully complying with rigid procedures, researchers must be prepared to adapt standard tools and practices in the interest of respecting participants and enabling their participation (Aldridge, 2007). The purpose of this article is to share my insights on modifying and using the diary interview method for research involving people with dementia. Drawing on the experiences of myself and others, I examine the main advantages and drawbacks of a modified diary interview method, and argue for its wider use in dementia-related projects on the basis that it affords individuals control over the process and pace of data collection. This discussion takes place within the context of sensory methodology. This is a relatively new approach to gathering research, in which the fieldworker seeks to capture and engage with every aspect of the human experience, not just those that are reducible to language (Mason & Davies, 2009). As such, in this article I provide fresh, critical insight into engaging people with dementia more collaboratively in qualitative research processes.

The Diary Interview Method: An Overview

The solicited diary, in which a participant records his or her thoughts and feelings under the direction of a researcher, has been used in health research since the 1930s (Burman, 1995). Asking people to keep a regular record of their experiences captures rich data on personal motives, feelings, and beliefs (Jacelon & Imperio, 2005) in an unobtrusive way (Lee, 2000) over a period of time (Markham & Coudry, 2007). Researchers have used diaries, for example, in health research of marginalized groups, including people with disabilities (Kenten, 2010), older people (Jacelon & Imperio; Milligan, Bingley, & Gattrell, 2005), and the caregivers of people with dementia (Clarke, 1999; Valimaki, Vehviläinen, & Pietila, 2007). However, hitherto the diary method has not been used to research the lives of people with dementia, which is perhaps surprising given the aforementioned commitment to soliciting the views of people with dementia, and the benefits of this technique.

The solicited diary method has several reported advantages. First, researchers who use this method can access specific and recent information from participants when recall might pose a problem (Zimmerman & Weider, 1977). Participants who write in a diary are encouraged to record thoughts and feelings when they occur, which helps “diminish memory errors” that can happen in retrospective interviews (Palojoki, 1997, p. 127). Thus, the method has the potential to compensate for short-term memory problems associated with dementia. Second, people using this method can report their thoughts and feelings in their own way, on their own time, and wherever they feel the most comfortable (Markham & Coudry, 2007), thus minimizing the “respondent burden” traditionally associated with interview-based studies involving people with dementia (Cotrell & Schulz, 1993, p. 209). Third, diary keeping is an opportunity to write—an activity considered beneficial for people with early dementia who still retain language skills. Through journal writing, individuals “rediscover their sense of self, to release complex emotions by naming them, and work their way through the many changes in their daily lives” (Ryan, 2006, p. 423). In sum, the diary method has the potential to involve people with dementia more effectively in the research process.

Diary keeping is commonly supplemented by an interview to expand on entries made in the diary (Elliot, 1997). Known as the diary interview method (Zimmerman & Weider, 1977), this technique involves a prediary interview, a postdiary “debriefing” interview, and the diary keeping itself (Alaszewski, 2006). Greater depth can be obtained by the diary interview method because participants have the opportunity to talk about their diary entries, and the researcher is able to explore in more depth the entries diarists have made (Kenten, 2010).

Researchers often use the diary interview method in ethnographies to complement participant observation (Denzin & Lincoln, 1998). Researchers who use ethnography seek to create and represent knowledge based on personal experiences of observing groups in the field (Pink, 2007). Data generated through diary interviews provide the researcher with insights into a person's thinking, an inner world otherwise unknowable through participant observation alone. The diary interview method fits with an ethnographic approach because data collected through diaries “approximate the real activities” of research participants (Palojoki, 1997, p. 127). In other words, what people write in their diaries is likely to be accurate accounts of what they did and how they felt at that time. Moreover, participants using this method have the time and space to think about what they want to express and how they want to express it. In this sense, the method fits not only with an ethnographic approach, but a participatory one as well (Worth, 2009).

Traditionally, the diary interview method involves participants keeping a written diary. Thus, the method can exclude nonwriters (Valimaki et al., 2007) and impose a certain kind of ontology: one that is describable in words alone (Law, 2004). However, with the advent of new, relatively easy-to-use technologies such as digital cameras and Dictaphones (Gibbs, Friese, & Mangabeira, 2002), as well as emergent sensory methods (Mason & Davies, 2009), researchers are beginning to modify and modernize the diary method. In doing so, they are making diary keeping more inclusive and open to other ways of knowing. For example, photo diaries are increasingly used in research studies involving marginalized groups or communities (Carlson, Engebretson, & Chamberlain, 2006). Pictorial diaries have been used in settings in which there are low literacy levels (Wiseman, Conteh, & Matovu, 2005). Audio diaries have been used for research with older people (Hislop, Arber, Meadows, & Venn, 2005) and those with visual impairments (Worth, 2009). Using digital technologies to collect diaries creates new possibilities for this method, especially in relation to people with some form of impairment or disability.

Research Outline

Background

I used the diary interview method, in conjunction with participant observation, within an ethnographic study designed to investigate the rise of activism among British people with dementia. Activism—or action on the behalf of a cause that goes beyond what is conventional or routine (Martin, 2007)—by people diagnosed with a health condition has become an established subtopic in sociology (Brown & Zavestoski, 2004). After decades of silencing and discrimination, some people with dementia are becoming empowered and taking social action; they are, for instance, influencing governmental strategies (Department of Health, 2009), joining and running campaign groups (Clare, Rowlands, & Quin, 2008), and educating students about the experience of living with dementia (Hope, Pulsford, Thompson, Capstick, & Heyward, 2007). This study was designed to establish what motivates people with dementia to engage in such actions, and to discover the impact activism has on a person's well-being. I selected the diary interview method to address these questions, not only because of the benefits outlined in the literature but also because anecdotally, I was aware that people with dementia were using appointment diaries, cameras, or voice recorders to keep track themselves of the activities they were involved in. Therefore, asking participants to keep a more detailed diary had some synergy with what this subgroup was already doing.

Participants

With research assistance, I recruited 16 people with dementia who were involved in activism (11 men, 5 women; *M* age = 64 years; range 55 to 78 years) through different media, including the newsletter of a large charitable organization, talks with relevant campaign and community groups, and the local radio station. Participants were all White and of British origin. Twelve had previous experience campaigning and had worked in professional or managerial roles; the remainder had never campaigned before, and had instead worked in either the trade sector or in public transport. Thirteen participants lived with a spouse, 2 were “living apart together,” and two were single and lived alone. All participants confirmed they had been diagnosed with dementia for varying periods of time, most between 2 and 11 years previously. None declined to take part in the study after being informed that they would have to keep a diary for 1 month.

Procedure and Practicalities

A prediary interview was conducted with each participant to begin to explore his or her motivations for taking action and to explain the diary-keeping process. With four exceptions, interviews were conducted on a one-on-one basis and in the person's own home. A focus group was conducted in a meeting room with four participants who were members of the same campaign group. This combination of interviews allowed me to explore the topic within an individual (Rubin & Rubin, 1995) and social context (Kitzinger, 1994). During the prediary interview, I or my research assistant invited participants to talk about their understandings and experiences of campaigning, and answered any questions they had about keeping a diary.

At the end of the prediary interview, I or my research assistant agreed with each individual participant regarding the exact timeframe and means by which to keep his or her diary. In the case of focus group participants, I arranged a separate meeting in the privacy and comfort of each person's home. Like other researchers, I offered participants more than one option for keeping a diary, including written, audio, or photo (Jacelon & Imperio, 2005). I did this hoping that participants would feel more in control of the process and in a better position to utilize their strengths in keeping their diaries (Milligan et al., 2005). Furthermore, I believed that photo and audio diaries would provide a more dynamic understanding of peoples' motives and lives (Pink, 2007). Five participants kept a photo diary, 3 kept a written diary, and 1 kept an audio diary. The 7 remaining participants kept a combination of either a written and photo diary, or a written and audio diary, but no one chose to keep all three. Every participant kept a diary for about 1 month.

Each participant was provided with a “diary-keeping pack,” which included a large notepad; pen; my contact information; a personal copy of the signed consent form; a simple, step-by-step guide on how to use the camera or voice recorder (if applicable); and a set of written instructions on what to record in the diary. Instructions included prompt questions such as: What campaign activities did you do today? What did you most enjoy about these activities? What (if anything) did you least enjoy about these activities? What made you do them? Who was with you when you did them? How long did the activity take? Did you get paid for doing these activities, or was it voluntary? In addition, specific examples of the kinds of situations or issues I hoped people would report on were included in the instructions (Jacelon & Imperio, 2005). For instance: “If you felt really good after making a phone call to complain about something, or if you were completely exhausted after speaking at a conference, tell us about that,” and, “You might want to tell us about the range of technology and equipment that you use to support your campaign activities, such as computers, mobile phones, and so forth.”

Participants were contacted while they were keeping their diaries through their preferred means of communication, which was either by telephone or email. This allowed me to provide further guidance and encouragement, and to field any questions or concerns a participant might have. The amount of contact time varied for each participant; I spoke to or emailed a few people on a weekly basis, and others hardly at all. People seemed to feel differently about being supported while keeping a diary.

While participants were keeping their diary, my research assistant and I spent approximately 30 hours participating in and observing key events that participants were involved in, including an annual general meeting and a national conference. Observing allowed us to collect ethnographic data from participants “in action,” and to experience and visualize for ourselves some of the events they were reporting in their diaries. Consistent with a sensorial participatory approach, during this period I perceived the camera as an “integral part of my identity as a researcher” (Pink, 2009, p. 101), and took a total of 116 photographs. These images were not analyzed with participants’ photos; instead they were used to provide a visual record of the research.

I or my research assistant then conducted a postdiary interview with each participant; these were conducted face to face in the person’s home or in a meeting room. The purpose of this interview was threefold: (a) to collect people’s diaries, (b) to ask how they found the process of diary keeping, and (c) to talk about the entries people had made. I asked diarists the following questions: Tell me

more about this comment. Why was this day different? What comments do you think are most important, and why? Photo-elicitation techniques were used with participants who kept a photo diary; that is, conversation revolved around and was prompted by the images. We asked, for example: Tell me about this picture. What made you take this photo? What do you like about this photo? What does it mean to you? What are you doing here? How did you feel when this photo was taken? Questions were asked in a sensitive and unhurried way, and breaks were taken when necessary.

Data Management and Analysis

I handled data manually, using a combination of content and thematic analysis techniques, and interpretive techniques proposed by Richards (2005). I decided to use manual methods to gain an intuitive sense of the data (Webb, 1998) and to determine my own approach to managing and coding data, rather than have it defined by software (Ezzy, 2002). I coded and catalogued data using basic search techniques and categorization macros. I also examined diaries for content; I looked closely at what people recorded about their subjective experiences as activists and about life generally. I examined photographic images and classified them according to how I saw their meanings, but also according to the meanings invested in them by participants during the postdiary interview (Pink, 2007). Having coded the data, I examined how categories related to each other and constructed themes to explain the linkages. I had research assistance throughout the process. Because the focus of this article is diary methodology, there is limited scope for a discussion of the study findings. However, findings are discussed in other articles, currently under review.

Ethical Considerations

I gained formal ethical approval to carry out the study from the University of Bradford Ethics Committee. I asked each participant to sign two consent forms: one in relation to taking part in the study, and one in relation to their diary (including photographs) being used for appropriate, specified purposes, including publications and presentations. I advised photo diarists that any images they had taken of other people would not be used without the written permission of person(s) involved, and that photographs of children would not be used under any circumstance. I decided to adopt a form of “process consent,” meaning that participants were asked for verbal consent at each stage of data collection, and reminded that they could withdraw their consent at any time (Dewing, 2007).

How Participants Approached Diary Keeping

Whichever type of diary a person kept, he or she approached it in the conventional way; that is, participants recorded events and dated entries chronologically. Most participants were already using a simple appointment diary, but none had previously kept a postreflective account of what they were doing. Nevertheless, participants seemed to know intuitively what was required. One diarist, for instance, wrote, "This I reckon is beginning to sound like a diary." The ease with which participants seemed to take to the method is perhaps unsurprising given that "diary keeping is a recognised form of social activity" (Alaszewski, 2006, p. 20). This is an added advantage of using this tool.

The process of keeping a solicited diary for 1 month impacted participants in different ways. One participant reflected on how everyday life took on a new significance during the process. He recorded in his diary, "Oh! It's just another day isn't it? No. Not when you're a diary keeper." Another participant stated how much he enjoyed the discipline of keeping a diary. He made entries every day, and found it instructive to look back on what he had written about the day before. Other participants commented on the value of documenting their everyday lives. For example, one participant, who was a high-profile campaigner, said that it had made him realize how busy he was—not just with the campaign work, but also socially—and he realized that he was rarely in before 11:00 p.m. Another participant said that she had enjoyed keeping her diary because it helped her realize where her "strengths and weaknesses" were. Such comments provide additional evidence that journal writing is beneficial for people with dementia (Ryan, 2006).

For most participants, the process of keeping a diary was a collaborative one. Diarists, particularly those who used photo and audio diaries, enlisted the help of someone they knew to help record entries and construct their diaries. In three of the audio diary entries, for example, I could hear the participant's spouse call out the dates and names of places they had visited. Another participant constructed her photo diary with the help of her husband—a keen photographer; he took photographs of her at key events and while talking to health care students. From my own observations at events, maintaining a diary was a team effort:

Saw [participant's initials] at Journal of Dementia Care Congress; he told me he had the camera and was asking people to take photographs of him doing things. He seemed to be enjoying the activity. A former carer (who belonged to the same group) told

me that he would take some photos of [participant's initials] co-chairing the session. (Fieldnote)

Keeping a diary also impacted participants in negative ways. One participant reflected on the length of time he was asked to keep a diary. He noted, "A week is a long time in politics" said Harold Wilson once upon a time. A month is a long time in diary keeping. Much has happened but not that much that is easy to recount." Another participant reported a lack of motivation to write in her diary when she was told she was no longer able to attend an art group she enjoyed. Reflecting on this diary entry in her postdiary interview, she said, "When I got the bad news, you'll find that it stops, because I couldn't concentrate and I was clinging on to day-to-day living." The demands of writing a diary became far too much for her.

The Nature of Data Collected Through Diaries

I amassed a large amount of highly differentiated primary data using the diary interview method, including photographic images, solicited written diary entries, audio clips, and interview text. Openness to other ways of knowing is important when taking a sensory ethnographic approach (Pink, 2009). A total of 994 images were collected. Of these, 293 were closely analyzed for content, and the remainder were either duplicate images, blurred, or taken either inadvertently or to test the camera, and were therefore omitted from the analytical process. The amount of written diary entries varied considerably from participant to participant. For example, one participant made just three entries, whereas another provided 36 pages (6,000 words). The audio diarist created 121 minutes of spoken data over the course of 15 days, with the shortest entry at 2 minutes in length, and longest at 31.55 minutes.

I gathered secondary data because diary keeping encourages people to collect public documents and other physical artifacts, including, for example, annual reports from organizations, newsletters, periodicals, and conference badges and passes. As I reviewed these documents, I gained a sense of the material worlds in which participants were operating (McCulloch, 2004). Certainly, in the context of this study, amassing such materials enabled me to gain rich insights into the campaigning scene. Unfortunately, time did not permit a thorough analysis of documents gathered. Nevertheless, it was possible to discern the full spectrum of activities people were engaged in from these materials, from speaking at a conservative party conference to attending regional mental health networks and forums.

In terms of the nature of data collected through written diaries, some people used the diary cathartically to write about how they felt and to express problems they had; they said and wrote a great deal in their diaries. Others used their diary more perfunctorily, to simply record what they had done, with whom, why, and when. Variations like these are common in diary-based studies; they reflect the different personalities, backgrounds, and lifestyles of participants, while at the same time showing how accommodating the tool can be (Valimaki et al., 2007). Because of the different ways participants approached diary keeping, some data were not usable, being either too intimate or unrelated to the project. Therefore, postdiary interviews became essential with certain participants, particularly those whose written diaries were brief.

Photo diaries were particularly useful for generating visual data on the environment. A large proportion of the photographs taken were of the external and internal spaces participants occupied. For example, several diarists took images of the transport systems they regularly used, including trains, mini buses, and taxis. Other participants had photographs taken of themselves networking at conferences, meeting other people with dementia, and relaxing at home. Many photos were simply of the natural landscape (e.g., rivers, hills, trees, fields, and gardens). In essence, each photo diary told a similar story: "This is what is important to me. This is where I spend most of my time. These are the people I spend time with. This is what we do together, and this is where I live." As such, the resulting data from photo diaries helped to ground and embed my understanding of participants as "campaigners" into an authentic holistic and visual context.

The audio diary revealed a different kind of data. Even though there was only one, the data revealed insights into the aural aspects of that participant's life. I was able to hear the range of sounds that the participant experienced. For example, while he spoke about his day, I could hear dishes being washed in the background. Additionally, this mode of diary keeping is helpful methodologically because I gained insight into the problems a person with dementia might have keeping a diary. At one point, for instance, I could hear the diarist asking his wife for help in operating the recording equipment and to remind him of the date. Overall, although the use of an audio diary was limited in this study, it highlighted for me the potential of this method in eliciting the sensorial experiences of people with dementia.

In sum, the data set was highly varied and voluminous, which resulted in a multilayered account of the participants' lives, not only as campaigners, but also as ordinary persons with dementia. Moreover, I gained rich insights into the material and environmental contexts of the participants' lives through the content analysis of diary data.

Insights Gained From Using the Diary Interview Method

I gained several methodological insights from modifying and using the diary interview method for this study involving high-functioning people with dementia. First, I found that it offered participants the opportunity to take some control over the content and pace of data collection. Participants determined when, what, and how to record data in their diaries, and "played around" with the method as they saw fit. For example, one diarist preceded an entry by commenting, "Time to finish off from yesterday. Doesn't that break diary rules?" This diarist was aware of the expectation to record thoughts and feelings when they occurred, but nevertheless chose to record them later. Likewise, the audio diarist took his time to find the right word—he said "worm" instead of "word"—and switched the recorder on and off, presumably to prepare to speak. However, he was not under pressure from anyone to relay information at that precise moment; his finger controlled the record button. In addition, although not requested to do so, many participants chose to collect and include various materials associated with their campaigning as part of their diaries. This, I would suggest, is further evidence of how the diary interview method can put the participant—rather than the researcher—in control of gathering data.

Participants also had some control over how they represented themselves. Although instructions were provided, ultimately each participant decided what to emphasize and record in his or her diary. Take, for example, a written record made by one woman; she wrote, "We are NOT going to be tick boxes!" By using capitalization and punctuation, she could convey how strongly she felt about tokenism. In addition, photo diarists were free to photograph whatever and wherever they wanted. One participant kept a photographic record of his route to the campaign office; others provided images of themselves "in action" talking to students, preparing for meetings, and presenting at conferences; whereas others took images of their favorite people and places. As visual ethnographer Pink (2007) highlighted, photographs "can inspire people to represent and then articulate embodied and material experiences that they do not usually recall in verbal interviewing" (p. 28). Furthermore, the audio diarist chose to use local dialectic at one point to convey how he felt. This not only provided more authentic insight into his life, but also shows how individuals were in considerable control of how these insights were constructed.

A second insight gained is that the diary interview method can benefit both the participant and the researcher by facilitating a slower-paced, reflexive style of research. The tool creates useful pockets of time for reflection. For example, because participants had access to the data in

their diaries, they had the time and the opportunity to think about what their diaries meant. A participant speculated on the underlying theme of his diary: “‘Hope’, I suspect belies this diary.” In qualitative research, the interpretation of data is a process traditionally undertaken by the researcher (Chase, 2005). In this study, however, because of the diary method, participants were able to engage in this to an extent. Similarly, I had more time to reflect on and respond to textual data as it was being collected. For example, when two participants emailed me extracts from their written diaries during the diary-keeping phase, I composed additional, more individualized data collection questions for each person.

A third valuable insight gained from using the diary interview method was that connections between the research study and the participants were strengthened in a way that one or two interviews might not have done. Asking people to engage with a task on a regular basis, a task specifically tied to an activity participants felt strongly about, meant that their relationship with the study was reinforced every time an entry was made. This became evident while I was a participant observer, part way through the diary-keeping month when one participant showed me her written diary and some of the photographs she had taken. She told me that she was recording a great deal, including how tired and emotional she sometimes felt. In this way, the method—the diary—helped me build the kind of research partnerships described in ethnographic literature—one that encourages the active involvement of the community being researched (Simpson, 2007).

Finally, I gained insight into the usefulness of the diary interview method for invoking a rooted understanding of the whole person. The diversity of information conveyed in a single diary entry (e.g., “catching up on emails and housework”), the range of images within photo diaries, and the sounds within the audio diary naturally showed me the kind of life each person was leading. For example, one of the single women involved in the study revealed through her photo diary how she lived independently in rural Scotland. She included in her diary a photograph of a pile of wood she had chopped and a newly erected bus shelter in her village, which she had campaigned for. Another participant wrote in his diary about how disappointed he was to have lost his gun license because of his dementia diagnosis—not a topic I would have thought to inquire about. Therefore, not only did I discover what motivated people to campaign and the impact it had on a person’s well-being (i.e., the research objectives), but I was also able to place these issues in the context of a person’s lifestyle and other concerns.

As with any data collection tool, there were limitations to using the diary interview method in this study. One noticeable drawback was that participants became more

aware of diminishing skills. In particular, those who kept a written diary had a record of their prose, which, when they read it back to themselves, they did not always like:

I have just read all of that stuff in black. I didn’t like it. I thought it was poor. Does that matter? It’s not a contest or something designed to please the reader. Nonetheless I didn’t enjoy it. Not for me to enjoy or not, I don’t know, but even so.

Being able to reread what one had written evoked a certain amount of anxiety about how a diary “should be written.” Other diarists commented on this problem. For example, one person said, “I can no longer write the way I did before.” Another reflected, “I mean these diaries, just reading it now reminds me that I was at one point extremely bad.” The negative impact of keeping a written diary was summed up by one participant:

[Diary keeping] is a good core idea, but I can think of lots of people, including myself sometimes, where your command of the written word has gone; remembering particular words for a particular thing, evades you, and they can sometimes become a frustration.

Reminding people of what they have lost is not a problem specific to the diary interview method, because interviewers have found this troublesome, as well (Proctor, 2001). However, a written diary represents a more tangible, reviewable reminder of the language and writing skills one has lost or is losing. Thus, when recruiting and seeking the consent of potential participants, researchers should inform individuals of the possible negative impacts of keeping a written diary, and be mindful of this during the actual diary-keeping phase.

A second drawback to the diary interview method is that, despite providing detailed guidance, some diarists were not absolutely sure what to record in their diaries. Not everyone was confident that what they were recording in their diary was what was wanted, or that they were inspired by what they saw. One diarist wrote, “I hope [the diary] is what the Uni. [university] want and need to get the message across.” Another commented in her postdiary interview, “I haven’t taken photographs. There’s just nothing to take a picture of. I can’t go ‘round taking pictures of old people.” Another diarist, who kept a combination photo and written diary, made just three entries in his written diary. Although each entry was utilizable and poignant, the amount of written data was minimal. A limitation of this method, then, is that it relies on participants to be self-motivated and inspired to notice and record their thoughts about the world around them. If a participant is not inclined

or unable to do this, for whatever reason, the tool is unlikely to yield rich data. For this reason, diaries should be used in conjunction with another method, such as interviews and participant observation, and the issue of motivation should be regularly explored with participants in the spirit of “process consent” (Dewing, 2007).

Finally, respondent fatigue is a well-known limitation of the diary method, particularly in studies involving older people (Jacelon & Imperio, 2005). Age, though, is not the issue, because younger people report finding diary keeping something of “a chore” to do (Emmel & Clark, 2009, p. 19). In my study, at least one participant seemed to find diary keeping somewhat challenging. He said that he had not written much, and of what he had recorded, he thought it was “all very boring. . . . I get up and clean the house, blah, blah.” Given the richness of data provided by this participant through pre- and postdiary interviews, it is possible that he found the process of keeping a solicited diary not so much fatiguing as demeaning. Clearly not everyone is a natural diarist.

Conclusion

Sabat (2003) and others have called for engaging people with dementia more often as collaborators in research. This highlights the need to use data collection methods that afford participants greater control and responsibility in the research process. In this article, I have shown how the diary interview method, when modified, can engage people with dementia as equal partners in the data-gathering process. The quality of the relationship between the researcher and the participant is central to discussions about sensory participatory methods (Pink, 2009). In my experience, the diary interview method mediates an equal relationship by ensuring that the whole person becomes visible.

The refrain, “See the person, not the disease,” has become a common one in dementia discourse (Kitwood, 1997). Modifying the diary interview method to include photo and audio diaries can help a researcher to understand the multiple facets of a person’s life, not simply those of interest to the researcher. Participants are enabled to relay various aspects of their personality and lifestyle through this method. The multiplicity of people’s identities—fund raiser, educator, public speaker, grandparent, husband, football supporter, fisherman, music lover, or advanced motorist—shone through the photo and audio diaries, in particular. Additionally, several participants asked other people to take a photograph of them standing in front of items they were proud of, such as their own artwork or the car they drove, thus ensuring that their individuality was represented. As the sensory diary methodology is developed, more attention

should be paid to how researchers can use the tool to understand the whole person, including the environment in which that person lives.

Finally, health scholars have emphasized the importance of researchers using the “complete research toolbox,” and not just traditional methods (Wuest, 2011, p. 875). The time has come to add the diary interview method to the toolbox of research involving people with dementia. The potential of the diary interview method is extensive. For example, researchers could deploy photo or video diaries to explore peoples’ experiences of care, or audio diaries to enhance understandings of language difficulties, especially longitudinally. Like all data collection tools, the diary interview method has some limitations. Nevertheless, the method has the advantage of ensuring that the participant—rather than researcher—is in control. For this reason alone, it is to be commended.

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