

Realities



At the Morgan Centre

Realities Toolkit #18

Using diaries in research with people with dementia

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Introduction

This toolkit draws on my experiences of using diaries for research into the lives of people with dementia who campaign for social change¹. The research involved sixteen individuals with dementia keeping a diary for around one month about their experiences of campaigning (e.g. lobbying politicians, meeting Chief Executives, media work, and talking to students), and me (with research assistance) observing them 'in action' at key events, such as conferences and Annual General Meetings. The diary-keeping phase was preceded by and followed up with an in-depth interview. The toolkit focuses on my reasons for selecting diary method, explains why and how it was modified for this study, and highlights its main advantage, namely to enable people to be in control.

Why use diaries for research into the lives of people with dementia?

The aim of my research was to understand why people with dementia campaign for social change and to look at how it impacted on their social well-being. I was particularly interested to find out how people felt about campaigning, and the difference they believed it made to their own, and other peoples' lives.

I chose to use diaries to collect data for this study for three main reasons. First, methodologically, it seemed the most appropriate method for gaining rich insights into a person's motives and inner thoughts and feelings. Second, many people with dementia, particularly those who lead busy lives, are used to keeping an appointment diary, so

¹ The toolkit draws upon work undertaken for a completed qualitative study funded by the Economic and Social Research Council (ESRC) First Grant Scheme, which investigated the motives and experiences of people with dementia who campaign for social change. I would also like to acknowledge the contribution of EJ Milne in the development of diary guidance for this project. For more information, see www.nolimitsdementia.com

asking someone to keep a more detailed research diary had some synergy with what my target sample were already doing. Third, related to the above, from an ethical point of view, diary method seemed the best option. It is relatively unobtrusive, as people can record information in their own time and at their own pace; plus it puts the person keeping the diary (as opposed to the researcher) in control. This was especially important, as I did not want the data collection method to become an additional burden to people who were already dealing with a serious disability.

To my knowledge, diaries have not been used for research with people with dementia before. This is perhaps surprising, as diary keeping offers people with dementia another valid way of telling researchers about their lives. Reviewing the literature, there are several reasons why one might consider using this method with this group:

1. When combined with a pre and post diary-interview, the method allows the researcher to access specific and recent information from participants where recall may pose a problem (Zimmerman & Weider, 1975).
2. Diaries encourage participants to record thoughts and feelings as and when they occur and wherever they feel most comfortable; it therefore has the potential to compensate for short-term memory problems associated with dementia, plus it could help to minimise 'respondent burden' traditionally associated with interview based studies involving people with dementia (Cottrell and Schulz, 1993, p. 209).
3. Writing is an activity considered beneficial for people with early dementia who still retain language skills - researchers have found it can help people work through the main changes in their life (Ryan, 2006);
4. That said, the method can be easily modified to enable people with varying abilities to participate – not everyone has to keep a written diary.

Why and how was the diary method modified?

The traditional diary method involves research participants keeping a written diary. However, this excludes people who cannot write, and may not appeal to people who think 'visually'. It is therefore recommended that researchers adapt the method and make it 'bespoke' for their study (Kenten, 2010). In thinking about the modifications to make to diary method for my study, I took into account the fact that a person's language skills were likely to be impaired to some degree by the dementia. In addition, I was aware that some campaigners were already using digital cameras and voice recorders to help them remember where they had been and what they had done. As a result, the method was modified for this study to include not only written diaries, but also photo and audio diaries. In this way, participants could opt for the style of diary-keeping which best suited their natural strengths and personal preferences.

My study involved people with dementia who were living at home and, relative to their mental health status, were relatively young, verbally fluent, and dextrous. If you are considering using diary method for research with people with more advanced dementia, or who are physically frail, or maybe in hospital, further modifications to the method might be required. For example, I would suggest enlisting an 'assistant' to help the person keep their diary; this person might be, for example, a spouse or other family member (e.g. a grandchild might enjoy this role), family friend, or paid support worker.

How the process worked

Everyone involved in the study was provided with a 'diary-keeping pack' which included an A5 notepad, pen, contact information, personal copy of consent forms, written instructions about what to record in their diary, and if appropriate a simple step by step guide about how to use the camera or voice recorder.

With research assistance, I created three versions of written instructions – one for written diarists, one for photo diarists, and one for audio diarists – other than a few changes to the language used (e.g. 'write about..', 'say.., take photos of...), instructions were essentially the same.

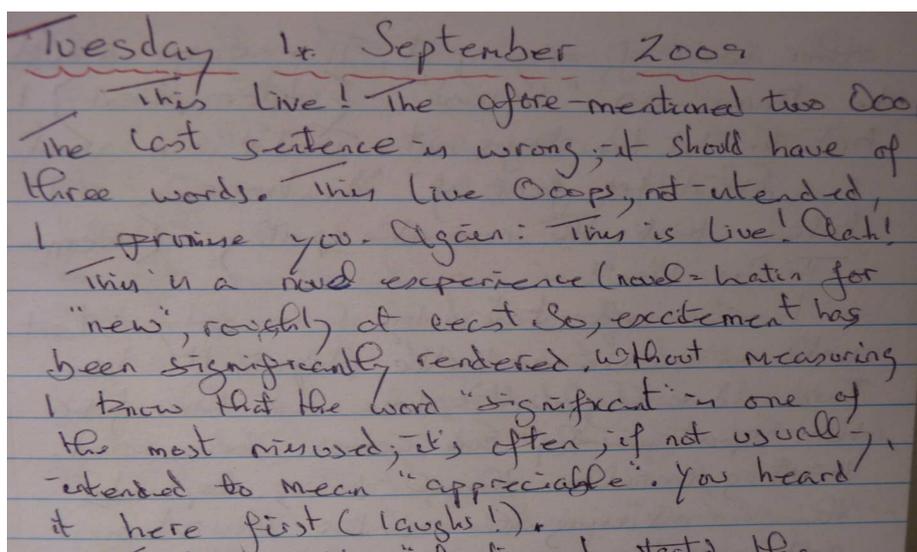
See www.manchester.ac.uk/morgancentre/realities/toolkits/diary/ for an example of the instruction leaflet used for written diarists.

In addition, audio guidance was provided on a CD Rom for one participant with visual impairment. As part of the guidance I provided an example of a diary entry, as I thought this might be helpful for people. However, as nobody referred to the example during either the pre or post diary interviews I am not sure it was necessary.

Examples of the kind of data collected from diaries

Written

Some people wrote a great deal in their diaries. They reflected on their day and provided detailed accounts of what they were doing and how they were thinking and feeling. For example, one participant, who chose to word process her diary, rather than write in the notebook we provided, produced over 6000 words. This provided rich data on her life, not only as an 'activist' but also as an 'ordinary woman' with other interests. Another participant reflected on, not only his life as a campaigner, but also on the actual experience of keeping a diary; take a look at his first entry:



"Tuesday 1st September 2009: This live! The afore-mentioned two Ooops. The last sentence is wrong; it should have of three words. This live ooops, not intended, I promise you. Again: This is live! Aah! This is a novel experience (novel is Latin for "new", roughly at least. So excitement has been significantly rendered. Without measuring I know that the word "significant" is one of the misused; it's often, if not usually, intended to mean "appreciable". You heard it here first (laughs!)."

Others used it more perfunctorily, to simply record what they had done, with whom, why and when. Take for example, the following diary entries from one participant:

- Catching up on emails and housework. Done big washing and main food shopping.
- Relaxed in evening watch a DVD got to bed 11.30
- Carpet fitters arrived today to do middle room. Looks nice happy with it.

People have different personalities and therefore approach diary keeping in a different way. This is not a problem. On the contrary it shows how flexible the method can be.

Photo

The seven photo diarists involved in my study took 994 photographs between them. Of these, 293 were closely analysed for content. The remainder were either duplicate images, blurred, or taken to test the camera and/or inadvertently, and so these were omitted from the analytical process.

Tip: photo diaries using digital cameras will generate a great deal of images. However, they do not all have to be used or interpreted; ask the participant to select their favourite ones and together decide which are important.

One of the advantages of photo-diary method is that it can naturally transport you to the kind of life a person is leading and places they live and visit regularly. For example, in my study, 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, gardens). As such the photo diaries helped me to gain a sense of the 'whole person' not just the 'campaigner'.

Audio

The audio diarist created 121 min of spoken data over the course of fifteen days, with the smallest entry at 2 minutes in length, and longest at 31.55. Even though there was only one, it provided a different kind of data on that participant's life. For example, one was able to hear the range of domestic sounds that the participant experienced, and also some of the word-finding difficulties this particular participant had (at one point he said 'worm' instead of 'word').

Tip: an audio diary might be a particularly useful method for researching language change in people with dementia.

Advantages of using different kinds of diaries

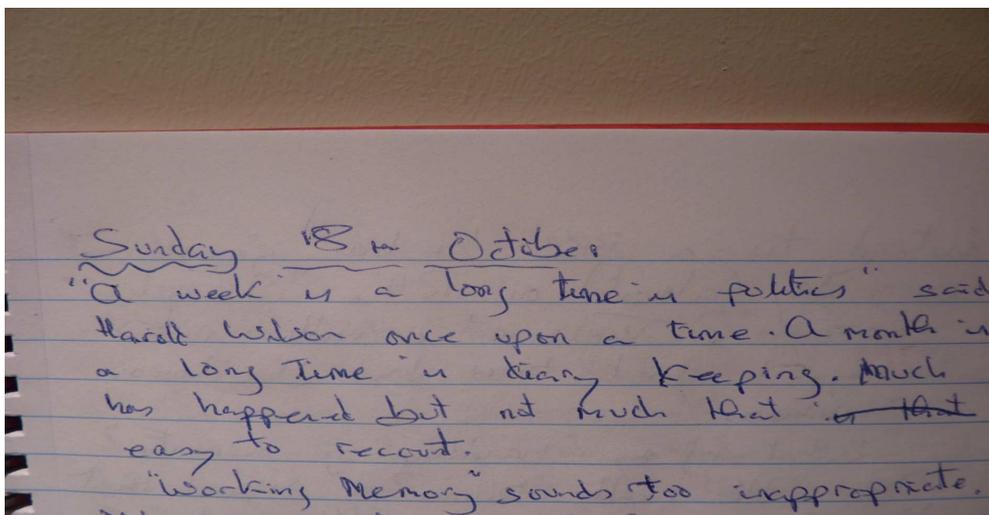
There were several advantages of using different kinds of diaries, the main one, which I've already mentioned, was that it allowed people to be in control of the pace and means of data collection. In particular, at the start, people were able to choose and switch between diary-keeping methods and 'play with the method' as they saw fit. For example, one photo diarist took photographs of other photographs he already had, because they were relevant to the study.

An added advantage of the photo diaries was that it generated data about all aspects of a person's life (not just their life as a campaigner). This was somewhat unexpected but essential for gaining a rounded understanding of both the person and the environment in which they live.

Some potential problems and suggestions on how to overcome them

If you do decide to use diaries for research with people with dementia you should bear in mind the following potential problems, most of which can be overcome.

One well-known problem with diary method is 'respondent fatigue' – having to keep a regular record of one's actions over a specified period of time can be tiring for anyone, but for someone with dementia, given the main effects of the condition are forgetfulness and fatigue, it can be particularly demanding. I asked people to keep their diary for around one month, and most people seemed to manage this relatively easily. That said, not everyone made an entry every single day, and typically entries began to tail off toward the end of the one month period. The following entry, made by one of the most prolific diarist in my study, reveals how long one month can feel:



"Sunday 18th October: '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 much that easy to recount. ..."

A particular problem with written and audio diaries is that they both depend on language. The diarist has to have a certain command of the written or spoken word to express themselves. Reflecting on the method, one participant revealed how exasperating this can be:

'(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'

This was helpful feedback, and so I would suggest that if you do decide to use diaries for research with people with dementia, make sure you include in the information leaflet the possibility of becoming frustrated so potential participants can make an informed decision about whether to take part.

A practical problem with photo and audio diaries is that some people may find the equipment difficult to use. In my study, for example, one participant said he 'gave up'

trying to keep an audio diary because he was having trouble using the digital voice recorder, which was quite small and fiddly to use. One way around this is to use recording equipment specifically designed for people with sight problems, as these are larger and have more robust function controls (see, for example, the RNIB catalogue for a range of such devices). Alternatively, a person could use their own camera or voice recorder if they have one and use it regularly.

Also, despite giving people quite detailed written instructions, including examples of what to photograph, some people revealed in their diaries that they were not sure what to take photographs of, or were uncertain that what they were doing was what 'the Uni. wanted'. Clearly not everyone thinks visually and/or feels comfortable taking photographs; hence, the importance of modifying this method to include a variety of diary keeping modes.

Finally, the following pointers have been developed to encourage a bespoke approach for diary-keeping research involving people with dementia:

- Do not make assumptions about what someone with dementia can and cannot do
- Consider whether someone regards themselves as a diarist
- Be flexible: different people will want and need to keep a diary in different ways
- Allow people to experiment with different ways of keeping a diary
- Bear in mind that some people may get better at keeping a diary over time
- Endeavour to find the medium of data collection that suits each participant.

Conclusion

Based on my singular experience of using diaries for research with people with dementia, and taking into account the diary method literature, I would say the method has the potential to be used much more widely with this group. In my opinion, the main advantage of this method is that unlike interviews, the diarist, rather than the researcher, is ultimately in control of how and when data are collected. As long as people are happy and able to record their thoughts and feelings on a regular basis, and are informed at the outset that the process may be tiring and frustrating at times, I see no reason why diary method should not be part of the dementia researcher's toolkit.

Lastly, I think diary method has the potential to be used much more broadly in relation to people with dementia, or indeed any group of people for whom communication can be an issue. This is not least because it offers another way for individuals (and their families) to tell service providers about the quality of care – e.g. a spoken account or image of poor treatment might be more powerful than a written description. However the method is used, the diarist will remain in control, as they are the one holding the pen, camera, or recorder.

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Further reading

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Feedback welcome! If you have any comments on this toolkit or if you can tell us how you have used it in your research or teaching please do drop us a line at morgancentre@manchester.ac.uk and let us know.



Realities is part of the Morgan Centre for the Study of Relationships and Personal Life at the University of Manchester.

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