Involving people living with dementia in systematic reviews

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Summary

In health and social care, the involvement of people who use services is an essential part of making sure the services are relevant and useful. Yet there is little evidence that people with a diagnosis of dementia have been involved in helping to shape policy and practice.

This project reports a small step along this road. There are now over 200 studies of the views of people with dementia and we need to examine the messages from this work. At the same time, it is vital to involve people with dementia in the review. With funding from the Averil Osborn Memorial Fund, we undertook the pilot stage of a systematic review of the views of people with dementia, and tested ways of involving people with dementia as partners in the research.

Our findings were that people enjoyed participating in the group. All members of the group voiced opinions and experiences and there were high levels of positive mood and engagement. Participants welcomed being asked their opinions and often had strong views about how they wanted other people to treat them. Group members were respectful and supportive towards each other even when they did not share the same point of view.

The group demonstrated that people with dementia could offer clear opinions with direct relevance to the conduct of a systematic review. Participants had strong views about what should be included, what counts as quality and whether the key themes made sense. In preparing for a full systematic review, their views provide a key starting point that would not have been possible without the contribution of people living with dementia.

Acknowledgements

We would like to thank the seven people living with dementia whose participation was so instructive and illuminating. We also thank the Averil Osborn Memorial Fund for funding the study, Kim Edwards at the Memory Assessment Service in Bedford (the South Essex Partnership University NHS Foundation Trust), and Jane Tooke from Alzheimer’s Society.
1 The aims of the study

The study had two aims – to undertake the initial stages of a systematic review of the views of people living with dementia, and to explore ways of ensuring that people living with dementia have a say in how reviews of this kind are undertaken. The systematic review focuses on the views of people with dementia, while the group concerns participants’ opinions on the criteria used in the systematic review.

Systematic reviews are becoming a core part of policymaking, because they summarise all the research on a given topic, and provide a transparent way of identifying ways of improving services.

This pilot work provides the basis for a full systematic review, underpinned by a tried and tested means of ensuring the involvement of people with a diagnosis of dementia.

The research team received funding from the Averil Osborn Memorial Fund to undertake this pilot study, and fieldwork took place in August and September 2013.

2 Ethical issues

Involving people who use social and health care services in research is a key way of ensuring their views are taken into account in policymaking. However, it may be argued that it is asking too much of people who are dealing with serious ill-health to contribute to research.

Receiving a diagnosis of dementia is a potentially life changing event. It often follows a period of feeling something is amiss, and has serious implications for the person’s health and well-being, both for the present and the future. Although some members of the team had experience of involving older people in a systematic review (Fisher et al., 2005), the team did not know whether people living with dementia would wish to participate.

We recruited people who were attending a local Memory Assessment Service (MAS), and focused on people who knew they had a diagnosis of one of the forms of dementia. Since the group would work on studies of people living with dementia, we wanted to ensure that people were already aware of their diagnosis.

We initially considered including people with a diagnosis of mild cognitive impairment (MCI), a diagnosis that has recently emerged indicating the possibility of progression to a diagnosis of dementia. We decided against this because we did not want to suggest, through the study’s focus on dementia, that such a progression is inevitable.

We planned that the work would be undertaken in a group setting. We thought that a group could provide a supportive environment for people to express their views, and we knew that many people attending the MAS had experience of attending a group for cognitive stimulation therapy.

In planning the group, we made sure we could support people in case discussion was distressing. Although the group was not for relatives, they were welcome to accompany the person with a diagnosis to the group, and had a separate room equipped with
refreshments and newspapers while the group session took place. We offered to pay the travel costs of relatives (although no-one took this up). For those participants who wished to travel independently, we arranged taxis and then reimbursed them. The research team included two facilitators, a nurse member of the MAS, a senior social work academic, and a social work student undertaking aspects of the systematic review. All had experience of working with older people and all except one facilitator had recent experience with people with dementia.

The team was organised so that members could meet people as they arrived at the University, accompany them to the meeting room and escort anybody that needed a break from the group. In addition, two members of the team had a specific role to monitor the participation of group members and the impact on their well-being (using aspects of Dementia Care Mapping¹).

The aim was to provide a supportive environment, but not a support group. We made it clear from the outset that this group was limited to three sessions, and avoided direct discussion of personal health questions participants had (e.g. about their exact diagnosis). Importantly, members of the MAS participated in the group and could offer discussion outside the group. In addition, the MAS offered a follow-up session after the three group meetings to address any issues people may have had. In the event, no-one took advantage of the offer of a follow-up session.

The proposal was reviewed by the University of Bedfordshire Research Ethics Committee (REC), and by a NHS REC, both of which approved these arrangements.

In the event, only two relatives accompanied the person with a diagnosis to the first meeting, and for subsequent meetings they were happy to drop their relative off and pick them up later. No group participant appeared to be significantly distressed during group discussion and no-one needed to take time out.

The process of ethical approval threw light on the discrepancy between the experience of staff providing services and the approach of the NHS Research Ethics Committee (NHSREC). Despite the fact that we intended to work only with people who had capacity to make decisions in their own right, the NHSREC appeared to operate on the basis that people with a diagnosis of dementia needed additional protection. The NHSREC stipulated that people with dementia should not be approached by phone (despite this being a common form of communication between MAS staff and patients) and at one point considered requiring the research team to notify GPs as part of approaching participants. In our view, the NHSREC’s approach was not based on an up-to-date understanding of the changing population of people attending MAS.

¹ Dementia Care Mapping is a set of observational tools developed by the Bradford Dementia Group (2005) for use in the communal areas of formal care settings such as residential care homes, nursing homes, day care and hospitals.
3 The systematic review

The central research question underpinning the review was to discover the views of people with dementia in relation to the services they receive. The intention is to provide a summary of people’s views to policymakers and practitioners so that they can take them into account in planning and providing services.

The initial work was based on a list of 214 studies of the views of people with dementia. At a very early stage, we decided that it would not be helpful to restrict the focus to views on services. Many studies collected people’s views on a variety of issues and views on services were just a part of these. It was also clear that many studies that collected views on the impact of receiving a diagnosis were relevant to service providers. For example, studies of how a diagnosis changed people’s willingness to socialise were directly relevant to advice that services might provide.

This initial list of 214 studies raised a series of questions about
- what should be included;
- which studies were high quality (and therefore more reliable sources); and
- whether the researchers had correctly interpreted the key themes.

We decided to make these three issues the focus of discussion with the research group of people with dementia.

What to include
Over half of the studies concerned thirteen countries other than the UK, so we wanted to know people’s views about whether these studies should be included.

Several studies collected people’s views as part of testing a questionnaire (such as a measure of quality of life). This meant that the researcher had already decided what the topic would be, and we wanted people’s views on whether this was too restrictive.

What counts as quality?
Some studies gave no information about the background of participants (e.g. their age, sex, or living arrangements), and we wanted to know what people thought about this.

Similarly, in some studies participants were selected by service providers rather than being approached directly, or permission was sought from relatives prior to contacting the person with a diagnosis.

We also wanted to know whether people valued the approach taken in some studies to check with participants whether the analysis made sense. We gave examples of feedback in written form and through group discussion, and one example where the researchers had decided not to give feedback.

Making sense of key themes
We selected ten studies and identified the key themes in people’s views. The studies were UK-based and involved direct discussion with people with dementia about their views. The three themes were that
- having a diagnosis of dementia sometimes makes you angry with yourself;
- people decide to ‘live from day to day’ (because the effects of having a
diagnosis of dementia are unpredictable); and
- people sometimes cope by avoiding socialising.

4 Recruiting people to participate

There were aspects of recruitment which we had not anticipated would be so difficult. In seeking to conduct research with potentially vulnerable adults, our ethics protocol and procedures were quite comprehensive in order to ensure people were safe and their well-being was protected. For example, people were initially approached by a known staff member in the Memory service. We would only approach people in person during planned appointments; would not ‘cold call’ known and familiar clients; and we would have contact several times so that people could think things over and ask questions. These steps may appear entirely necessary when working with people whose ability to retain information and consider the pros and cons of the proposed commitment may be in decline. However, we found that the safeguards we employed limited the team’s ability to recruit clients.

As we have suggested, the group of people with dementia is changing with earlier diagnosis and improved treatment provisions and we wonder whether the ethics procedures should take account of this. For instance, if we had been able to involve a representative expert-by-experience from the beginning, we suspect we could have avoided the pressure to assume that people with dementia cannot assess risks for themselves and had more straightforward procedures for contacting people. We also think this would have been more consistent with our wish to treat people who use services as equal partners in research.

We set out to recruit up to 10 people, and three individuals declined to take part in the research project. Two of these clients considered participating in the research but their families were cautious about their participation. It is unclear as to why this is. We can only think that it could be that they felt their loved ones had enough to worry about, they were taking on board too much, or that the timing of the research just wasn’t right for them. It may also relate to the perfectly natural inclination to ‘look after’ our loved ones diagnosed with a serious disease. However, this may be counter-intuitive. Our research went on to show that our participants wanted to be given the opportunity to be heard and be challenged in a stimulating and novel environment. In future research, the reasons families or carers have for declining research opportunities on behalf of their loved ones may provide an opportunity to explore any misconceptions they have about living with dementia and help identify the barriers to engagement. Likewise, it may also help establish how best to empower individuals to take part in a supportive manner for all parties involved.

Overall, the recruitment process appeared to have been received well by most clients. It was often seen as an attractive opportunity to ‘do something about dementia’ and to assist in service development. Many clients felt motivated to participate through a sense of duty and that without their engagement an effective service delivery was unlikely to be sustained over time. People also seemed motivated by a sense of ‘belonging’ to a community whereby it was essential to acknowledge similar experiences and yet emphasize individual differences. The recruitment process seemed an empowering experience for the individual as they were asked to participate as a valued expert and partner in our explorations, rather than as a ‘research subject’.
5 Using dementia care mapping to evaluate participation and well being

Dementia Care Mapping (DCM) is a set of observational tools first developed by the late Professor Tom Kitwood and the Bradford Dementia Group in the early 1990’s. Over the past twenty years it has been used extensively in formal dementia care settings such as hospitals, care homes and day care settings both in this country and internationally in order to develop good practice in the field of dementia care. The most recent version of DCM was produced in 2005 and is referred to as DCM 8.

As already noted, there were two observers present while the three groups were running. One of the observers had been trained in DCM in 1994 and 1995 at both the basic and advanced levels. This observer had also used the tool extensively for about five years following the initial training. This team member familiarised herself with the modifications in the DCM 8 User Manual (2005) and then provided some very basic training to a second observer.

A person using DCM is called a mapper. A mapper records two things every five minutes: what an individual was doing according to a range of possible actions or behaviours and what the associated level of engagement and mood seemed to be on a six point scale. This is helpful because it provides a structured and accessible record, based on defined conditions and rules, which moves the task of observation beyond that of recording general impressions. In addition to this, both mappers made narrative notes which linked to the five minute time frames.

A record based on DCM principles was made by both mappers for each of the three groups. Up to five people can be observed by a mapper at a time. At each group, six of the seven participants attended, so it was possible to arrange for a high degree of overlap between the mappers.

It is important to note some limitations to the use of DCM. Firstly, the task undertaken by the group members was quite different in nature to the types of activity which would ordinarily be expected in the formal care settings for which DCM was designed. Secondly, all of the participants in the group had the capacity to decide that they wanted to participate and as such are likely to be much more able than people in formal care settings. Thirdly, it had not been possible for one of the mappers to undertake the training provided by the Bradford Dementia Group prior to the groups meeting. Fourthly, because of the nature of the activity being undertaken many of the behaviour or action codes contained within DCM were not relevant. Finally, it should also be noted that whilst it was made clear to group members that there were two observers and they would be recording what happened, the term DCM was not specifically mentioned.

6 The group process

In planning the group process, we drew on Tooke’s studies for Alzheimer’s Society of involving people with dementia in organisations (2012; 2013). In line with this work, the groups were planned to be informal, to offer people a chance for social chit-chat as well as getting the work done, but not to be a social support group that people may come to rely on. Careful attention was paid to using plain language and to minimising the use of phrases and terms that had multiple meanings.
The groups took place at a small local university campus, which offered several rooms in close proximity so that we had a break-out room (in case people were distressed), and space for relatives separate from the meeting room. The meetings took place out of term time so that fewer people were using the campus. Whilst it might have been an obvious step to use space at the Memory Clinic, it would have been difficult to secure enough rooms. Using the campus also brought people into contact with the local university and was intended to help participants understand that their role was different from that of being a patient, and that we valued their contribution as partners in a research process.

We ran the groups from 10.30am – 12 noon on the same day in three successive weeks. We chose this timing on the advice of MAS staff that mornings were generally better for participants, and that it would help to keep to a regular time. In fact, people would arrive from 10am onwards, and we had refreshments available in the break-out room so that people could sit and catch up with each other’s news. The research staff joined the participants for refreshments, and also used this time to sort out practical issues such as taxi fares. The research staff then ushered people to the meeting room at 10.30am.

Seating was arranged around a small group of tables, with a view of a presentation screen. Participants had written information as well as the presentation, and the tables offered an opportunity to write notes. The small group of tables was designed to make it easier to hear one another and to bring people into conversation. Three research staff sat at the table and two staff undertaking observation positioned themselves so they could see the relevant participants, but slightly outside the circle, indicating that they were not directly involved in discussion.

Participants introduced themselves, and the research staff explained their role, including the role of the two observers. The facilitators then explained both the general purpose of the group and the day’s activity, and then the groups were run as a series of tasks where people were asked to comment on the material presented. The conversation was audio-recorded so that comments could be recalled word for word if required.

The presentations gave participants background information on the research studies, in plain language without technical terms, and often using direct quotations. They consisted of eight to ten slides.

Towards the end of group, participants were asked for their views on the group process, and the observers offered their views. Participants often commented that they had enjoyed the process, confessing sometimes that they had surprised themselves by their ability and willingness to contribute. As the university was approaching a new academic year, some commented wryly that they were now considering enrolling.

It may be a minor point to say that the groups were run on time, but this was important so that people could make arrangements to leave. Where appropriate, research staff accompanied participants to reception to meet taxis or relatives.

Changes made during the three sessions
The five research staff held a brief discussion after each group. In addition, the two staff undertaking observation communicated between groups to compare notes and to improve the consistency of their observations. As a result of these meetings, some
refinements were made as the groups progressed.

Observational feedback at the end of the first meeting indicated that one participant was less involved. She pointed out that she used a hearing aid and had been unable to catch much of the discussion. While this showed the importance of gathering feedback as the group progressed, we should perhaps have checked this more thoroughly from the outset. This led to a decision to reduce the size of tables further so that the participants were more closely grouped and to place the person with a hearing aid next to one of the facilitators.

After group one, we also felt that we had allowed discussion to range too broadly, and that we should try to achieve a closer focus on the tasks. We alerted the participants to this at the beginning of the second group and one facilitator took on the role of bringing discussion back to the task if it wandered. Lastly, we numbered the presentation slides to make them easier to follow.

Observations on people’s participation and well-being
The broad message from the DCM results was that people appeared to enjoy participating in the group. All members of the group participated in voicing opinions and experiences and this occurred in all three groups. There was consistent evidence of high levels of positive mood and engagement recorded by both mappers across all three meetings. The records show that participants welcomed being asked their opinions and often had strong views about how they wanted other people to treat them. Group members appeared to be respectful and supportive towards each other even when they did not share the same point of view.

7 Outcomes

For the process of involving people with dementia
Prior to this pilot project we did not know how people living with dementia would respond to being asked their views on what should be included in a systematic review. Using elements of DCM has provided a structured record of what happened at both an individual and group level in addition to the general impressions of the research team. This enabled modifications to be made which facilitated further individual engagement. All members of the group demonstrated an ability to engage with the task and to remain focussed on the task. Over the course of the three groups, no doubt influenced by greater familiarity with the process for everyone concerned, levels of well being and engagement by group members improved slightly. This was from a baseline, in the first group, which was already high. By the third group, the DCM record shows that group members were either directly responding to the question or listening to what other people were saying with an associated high level of well being and with a slightly higher degree of apparent focus than in the first group. It was sometimes difficult to distinguish between when a group member appeared to be reminiscing about something from the past as opposed to directly responding to the question. Over the course of the three groups it became more evident to the observers that there was a connection between the question being posed and the response. This was in situations where the response was grounded in talking about something which happened in the past. This suggests that it might be useful to think about how we might further clarify the meaning contained within a response whilst at the same time maintaining well being when running future groups.
For the systematic review
The group demonstrated that people with dementia could offer clear opinions with direct relevance to the conduct of a systematic review.

What should be included?
Participants suggested we should pay attention to the context before deciding whether to include studies from other countries. For example, a study of people with dementia in Taiwan (Liou & Jarrott, 2013) might be relevant if that country had some kind of national health service. The same study might, however, be less relevant if a culture of respect for elders, different from that in the UK, strongly influenced the treatment of people with dementia. Where researchers spoke to people with dementia about a questionnaire or measurement tool they had developed (e.g. Brod et al., 1999), participants thought this could be included if there was an attempt to explore people’s views.

What counts as quality?
Participants thought that studies should give details about the background of people who participated (such as age, sex and living arrangements), and should try to include a wide a range of people (rather than restricting participation to one geographical area, or drawing people from one service provider – see, for example, Aggarwal et al., 2003). Participants were critical of studies that approached people with dementia only after permission from staff or relatives (e.g. Bamford & Bruce, 2000), arguing that all people had the right to be asked to participate. Participants valued researchers who checked whether their findings made sense to people with dementia, and who provided a written summary (e.g. Beattie et al., 2000).

Do the key themes ring true?
Participants were very critical of the draft conclusions we had drawn on the basis of selecting ten key studies. Most group members were outgoing and determined to keep up their social life. They had a very strong sense that they were entitled to express their views (and of course this probably influenced their decision to participate in the group). While this may mean they are not typical of people with dementia as a whole, they may well be typical of the new generation of people receiving an earlier diagnosis as a result of the policy of intensive screening.

Participants argued that they had to get on with their lives, and not to hold back from socialising in case they might forget someone’s name or lose the thread of a conversation. There sometimes were practical difficulties (such as remembering the right terms in order to talk about politics), but the general view was that ‘you have to get on with it’.

In a wider sense, it may be that the research has not caught up with this new generation of people living with a diagnosis of dementia. We included studies published up to 13 years ago, well before national policy began to emphasise early screening, and it may be necessary to consider prioritising more recent studies if we want research that reflects the views of people at an early stage of living with dementia.

Conclusion
This pilot study showed that it is possible to involve people living with dementia as partners in the review process. By paying careful attention both to how the material is presented and to group processes, the group allowed people to participate and express
their views, while preserving their emotional health and well-being. The general principles emerging from group members about what should be included, what counts as quality and whether the key themes make sense, will still need interpretation in a systematic review process, but they provide a key starting point that would not have been possible without the contribution of people living with dementia.

8 The next step

Our next step is to request feedback from participants, after which we will write up the work for the journal *Generations Review*, a step that is required by the funding body. We will also write a paper for researchers on involving people with dementia in a systematic review.

At the same time, we will find out whether we can obtain further funds to undertake the full systematic review on the views of people living with dementia, so that their views are taken into account in policy and practice.
## Appendix

### Table 1: Characteristics of participants

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References


