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RESEARCH AND EVALUATION

Co-research with older people with dementia: Experience and reflections

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Abstract

Background: There is growing evidence that people with dementia want to participate in research and benefit from their involvement. However, little attention has been given to date to the potential to involve people with dementia as co-researchers, not just participants.

Aims: The paper discusses the implications for people with dementia of involvement in research as co-researchers.

Method: Older people with dementia participated in planning the research methods, conducting interviews and making sense of the findings.

Results: The project found that it is possible to involve older people with dementia in a meaningful way in research processes and that both co-researchers and participants can benefit significantly from their participation.

Conclusions: The project has wider implications for the development of participatory research with people with dementia and for interventions based on peer support.

Keywords: *dementia, older people, co-researchers, involvement, identity*

Introduction

Although there is now widespread acceptance in policy and practice of the need for citizens to exercise power and influence in issues that affect their lives, “people with dementia remain a silent and excluded voice” (Wilkinson, 2002, p. 9). People with dementia see participation in research as a way of making a valued contribution to family, community and civic life (Dementia Action Alliance, 2010). However, social research has tended to marginalise their experiences, focusing instead on the views of carers, either in their own right or as “proxy” informants (Dewing, 2002; Downs, 1997; Moore & Hollett, 2003). Research that engages directly with the experiences of older people with dementia highlights the ethical and practical challenges it presents, but also the benefits that they derive from involvement. These include gains in self-confidence and self-esteem through feeling they are making a meaningful contribution and the enjoyment of social activity and sharing their stories (Aggarwal et al., 2003;

Cantley et al., 2005; Edvardsson & Nordvall, 2007; Proctor, 2001). At a wider level, involvement in research can challenge the marginalisation of older people with dementia and promote their social inclusion (Cantley et al., 2005; Ward et al., 2008; Wilkinson, 2002).

In recent years, the focus on giving voice to marginalised people through their involvement as research participants has extended to a concern to engage them as partners in research processes (Hanley, 1999). Here, the objective is to include service users themselves, not just their knowledge (Beresford & Croft, 2001, p. 302). Although there are publications about involving people with dementia in research (Wilkinson, 2002), including accounts by people with dementia themselves (McKillop & Wilkinson, 2004), the potential for involving people with dementia as research partners has received little attention.

The project that forms the focus of this paper aimed to involve older people with dementia in all stages of the research process. As the study is still in progress, the focus here is on processes of involvement rather than project findings.

The project

The research is part of a larger national study, carried out across four sites in England, investigating older people's experiences of transitions between care services.¹ The project has two phases: obtaining the views and experiences of older people and carers, particularly those who are "seldom heard"; and working with local stakeholders to implement changes in local policy and practice in response to the findings. This paper focuses on the site concerned with older people's experiences of transition into or between dementia services. In addition to recruiting older people with dementia, separate work was undertaken to recruit carers of people with dementia, who interviewed other carers. This paper focuses only on the work with co-researchers with dementia.

Research methods

There are complex ethical issues involved in research with people who may lack the capacity to consent to participate (Cowdell, 2008; Sherratt et al., 2007). While these need to be acknowledged, they are not the focus of this paper. Full ethics approval was obtained from the researchers' employing institution and the external Research Ethics Committee. This included ensuring that adequate arrangements were in place to establish capacity and informed consent, address any safeguarding concerns that arose and offer independent support to co-researchers and participants. At the time of the first interviews, all co-researchers and participants had the capacity to consent to participation though, as a matter of good practice, carers were also consulted (McKillop & Wilkinson, 2004; Sherratt et al., 2007). For both co-researchers and participants, we adopted a process model of consent, monitoring and reviewing consent within the context of the research relationship and across the duration of the project (Dewing, 2002; Hubbard et al., 2003). By the later stages of the research, two participants were deemed by their carer/consultee no longer to have the capacity to consent or participate meaningfully in an interview so their involvement ceased at this point.

Each site identified a voluntary sector local partner agency (LPA) which was the main source for the recruitment and independent support of participants and co-researchers. The LPA in this site specialised in working with people with dementia. Information about the research and a request for co-researcher involvement was publicised through the agency by various means. Three co-researchers with dementia were recruited (see Table I).² They all had a diagnosis of dementia and had undergone a recent transition within or between care services.

Table I. Co-researchers.

Name	Gender	Age	Living situation	Link with LPA
Alan	M	77	Living with wife	No direct link. Wife on mailing list so received newsheet
Brian	M	71	Living with wife	Attends weekly memory café
Margaret	F	60	Living with husband	Attends weekly memory café

Three preparation sessions were held with the co-researchers to orientate them to the study, engage their views about the interview content and structure, and enable them to practise interviewing skills. It was important that the venue felt comfortable (Cantley et al., 2005), so sessions were held at an LPA setting with which the co-researchers were already familiar. Co-researchers shared their own experiences of receiving a dementia diagnosis and accessing services. This helped them to understand the focus of the research and think about the areas an interview might cover. In the process of discussing their own experiences, they were encouraged to give prompts and ask each other questions. This facilitated discussion of interview techniques. Key points from their responses were written on a flip chart using their own words. Their narratives suggested the following framework for the interviews: first noticing that something was wrong; doing something about it; first contact with services; receiving help and support; living with dementia and hopes and fears for the future. Other research with people with dementia has reported on the usefulness of visual prompts (Aggarwal et al., 2003; Bamford & Bruce, 2002; Cantley et al., 2005). Following discussion with the co-researchers, the stages were typed on different coloured laminated cards. Each co-researcher had a set of these cards, which could be used as guides during the interviews.

I undertook all interviews jointly with one of the co-researchers. We agreed that my role was to explain the research to participants (written information had already been given), obtain informed consent and operate the digital recorder. Beyond this, my role would be flexible, adapting and responding to what each co-researcher was able to contribute in the particular interview. I met with co-researchers in their homes immediately prior to each interview to refresh them about the purpose and process of the interview. The shared car journey to the interview was an opportunity to renew the sense of familiarity and trust that had developed during the preparatory sessions.

Five participants were recruited. Three participants were interviewed twice, with six months between the two interviews, and two were interviewed once. In all interviews, the same co-researcher participated in the first and second interviews. Immediately after each interview, the co-researcher and I shared our thoughts about the process and content of the interview, and co-researchers were given space to talk about their own feelings. After each round of interviews, a meeting was held with the co-researchers to discuss key themes and issues.

Research processes and relationships

Our preparation sessions with co-researchers were valuable for ascertaining the extent to which they were able to engage meaningfully in the interview process, the particular skills they brought and how these could be maximised. Their different personalities also influenced their contributions to the interviews and the form these took. Margaret is very chatty and engaging, and comfortable talking about her dementia; I saw this as valuable in putting participants at ease and encouraging them to talk about their experiences. She is also adept at showing empathy, offering reassurance and using humour, which are all

potentially helpful skills within the interview situation. Brian has good listening skills and is able to attune to the emotional substance of the other person's experience. His observations and reflections were helpful in enabling the participant to feel understood and in moving the interview along. He also offered useful insights into debriefing after the interviews. For example, after an interview where a man had talked extensively about his previous employment, I asked Brian what he thought were the main issues to come from the interview. He replied:

He wanted to tell us what was important in his life and he wanted me to know about them. He wanted to keep those things going.

Although the research focus on care transitions had made me more alert to utterances about services, key messages that Brian extracted from the interview concerned what the participant communicated about himself and his life.

It was also important to be aware of areas that co-researchers found difficult so that these could be managed, with minimum detriment to the interview process. Margaret's memory is very poor; she was able to respond immediately to what the participant said, but easily lost track of the theme of the discussion as it progressed. The dialogue consequently tended to become fractured and disjointed without some reorientation to its main thread. Brian's cognitive processing is slow and he needs plenty of time to frame his thoughts and responses. He does not often initiate conversations, so sometimes needed prompting to ask questions or share his observations.

Our co-research approach was premised on the belief that the shared identity of being someone with dementia would facilitate relationships between researchers and participants, thus enhancing the experience of the interview process for both parties, as well as enriching the data obtained (Miller et al., 2006). This seemed to be borne out in practice. Co-researchers' foregrounding of their dementia identity in their introductions at the start of the interviews helped to establish trust and credibility from the outset, diminishing the threat that "owning" dementia might otherwise have posed for participants. Participants could be open about their difficulties as the interviewer was seen as someone who understood and shared their problems. This is illustrated in the following exchange between Margaret and a participant:

Participant

I think writing's becoming embarrassing, I can't write ... And that's something that's come quite quickly ...

Margaret

I fully understand that because I've, all my life, I've been a really good speller and now I find I struggle, now, when I'm writing, to get the right word down, or to spell it correctly.

Co-researchers helped to create a relaxed, informal atmosphere so that the "interviews" were more akin to conversations in which participants and co-researchers shared their experiences and perceptions. The exchange of humour between co-researchers and participants was particularly notable. As Killick and Allan (2001) observe, many people with dementia

remain sensitive to the humorous aspects of situations. For example, Brian and one participant discussed their difficulty in remembering items when they went shopping:

Participant

Like I said, my wife sent me over the road for a loaf, I'd come back with a bottle of milk or I'd come back and say "what did you want?" It's as if I'm not listening in the first place. Do you know what I'm trying to say?

Brian

I can never get the shopping right either ... And I get it – well, the majority of it I get it wrong, which means that -

Participant

So you have the same for your dinner every day then? [laughter]

The study's focus on transitions implies some attention to the sequencing of experience in terms of moving within or between services. However, like Pratt (2002), we found that participants were much more comfortable discussing their feelings and experiences than recalling dates or the ordering of events. As participants themselves were often not clear about details, such as how they had come to be referred to services, which professionals they had seen or the sequence of experiences, it did not matter if co-researchers did not focus on such issues. Often the significance of what was said resided in the feelings that were communicated, rather than the accuracy or otherwise of descriptive accounts.

In this respect, co-researchers also strengthened the emotional connection with participants. Emotion has been noted to play a particularly significant role in communication for people with dementia (Killick & Allan, 2001) and it can be argued that co-researchers' ability to attune emotionally to participants was more important than their ability to elicit the "factual" dimensions of experiences (Proctor, 2001). For example, in one interview with Brian as co-researcher, the participant called out several times to his partner, who was sitting in another room, asking her where she was. She had already told us that they did everything together as she felt unable to leave him alone. Brian reflected afterwards, "His wife isn't always there for him". I had registered the objective circumstances of them spending all of their time together, whereas Brian highlighted the participant's underlying anxiety and insecurity.

Another example was an interview with Margaret and a woman who lived alone. She showed us how she positioned chimes inside the front door so these would be rung by anyone breaking in. She recounted a long story about some youth breaking into houses nearby and the police not listening when she tried to report it. Some of this account seemed improbable in terms of its factual accuracy and not immediately relevant to the subject of care transitions. However, Margaret reflected, "It must be horrid not to feel safe in your home and to feel that no one takes you seriously". When we looked together at the function and meaning of the story (Bamford & Bruce, 2002), Margaret was able to connect with the feelings of vulnerability and marginalisation that were being communicated.

The main motivation to participate for our co-researchers was the desire to help others. As Alan said in the first training sessions:

If I could feel useful to someone, it would be quite something.

There were many instances during the interviews when they were able to provide information, advice or reassurance to participants. For example, one exchange ended as follows:

Margaret: “There’s plenty of life left in us, Peter, there really is”.

Peter: “Well I think you’ve no idea how much you’ve cheered me up today”.

In sharing their experiences, co-researchers talked positively about some of the services they used, encouraging participants to “give things a try”. Although not an aim of the research, this arose naturally from the interview exchanges. Indeed, as the research progressed, the LPA realised that visits from a co-researcher appeared to ease the transition to using its dementia services, in particular, attendance at the memory café. Participants were potential service users of the LPA’s services and the role and purpose of the research interviews was in danger of blurring into a visit to promote these services. However, this served to highlight the value that access to peer mentors who are comfortable with their dementia identity can have for people more recently diagnosed with dementia.

The ability of the co-researchers to function as interviewers also provided a source of hope and reassurance to participants. Most of the participants had been diagnosed with dementia fairly recently and both they and their partners expressed surprise when they learned how long the co-researchers had been living with dementia. For example, one participant was very concerned about the loss of control and inability to function that he foresaw as an inevitable part of his “decline”. He repeatedly expressed his astonishment that Margaret had been diagnosed with dementia six years ago, yet was, in his words, “still able to do what you do”.

For co-researchers, the small group meetings for training and analysis provided opportunities for social activity and peer support, in addition to the interviews themselves. Their carers said how much they enjoyed the meetings and the LPA commented on the extent to which the co-researchers’ involvement in the research was enhancing their self-esteem and social skills.

Reflections

Although it is too early to evaluate the impact of the participatory approach on findings and implementation, we can begin to consider what difference it has made to research processes and to co-researchers and participants. These are relevant areas to consider as they form part of the evaluation of impact (Staley, 2009).

In terms of our learning about research processes, the relationship between the researcher(s) and the individual co-researchers, and between the co-researchers themselves, was crucial. Considerable effort had to be devoted to nurturing and sustaining these relationships throughout the project. It was necessary to maintain contact, even in “fallow” periods, for example, during the slow recruitment phase. In our co-research model, people with dementia were working in partnership with me in each interview. My presence as a second interviewer to guide, prompt, adapt and respond in accordance with how co-researcher and participant communicated in each interview was vital, both to useful data being obtained and the process being

experienced as comfortable and meaningful by all parties. Knowing the co-researchers well as individuals was essential to help them to feel comfortable within the research relationship, but also to enable me to become familiar with their strengths and limitations so that I could maximise their contributions in the interviews and offset any difficult areas.

Although the initial preparation sessions were useful in providing a foundation of training, in practice the co-researchers had little recall of this subsequently. A folder of simple summary information and the laminated “cue” cards were invaluable in prompting memories of what had been covered. The time spent with each co-researcher immediately before and after each interview for briefing/debriefing was an essential part of the process and needs to be allowed for in timings and costings.

Moving on to consider what co-researchers added to research processes, researchers have an ethical obligation to ensure their technical competence (Butler, 2002), so it is reasonable to question whether co-researchers with dementia had the skills necessary to undertake the research. In qualitative research, interviewers can be seen as the central research “tool”; hence their qualities are crucial to its success (Legard et al., 2003). Legard et al. identify the qualities required of interviewers:

First, the ability of the researcher to listen is fundamental to the art of interviewing. The researcher must hear, digest and comprehend the participant’s answers in order to decide how to probe further. Second, good in-depth interviewing requires a clear, logical mind. The researcher needs to be able to think quickly to distil the essential points of what the participant is saying, exercise judgement about what to pursue, and simultaneously formulate the relevant question. Third, a good memory is an important attribute. It is often necessary to make a mental note of a point made earlier on by the participant and return to it at a judicious moment in the interview to seek further clarification or elaboration. (Legard et al., 2003, p. 142)

This brings into sharp focus the potential difficulties of involving people with dementia as co-interviewers. However, although Legard et al.’s criteria might suggest that people with dementia do not have the skills and capacities to undertake effective qualitative interviewing, our experience suggests the need for a wider and more inclusive interpretation of “communication skills” than that envisioned in more traditional texts on qualitative research.

Co-researchers contributed to the understanding of the experiential world of dementia and the ways in which people with dementia express their experience, which is necessary for researchers in this field (Hubbard et al., 2003). Authentic and honest relationships seem to be particularly important for people with dementia (Langdon et al., 2007; McKillop & Wilkinson, 2004) and co-researchers were able to communicate authenticity and honesty more readily than “academic” researchers. This facilitated a relaxed, non-threatening climate for the interviews, in which co-researchers and participants shared experiences and feelings. As Killick and Allan (2001) point out, “... a window into another’s world is worth a dozen correct chronologies” (p. 219) and the exchanges between participants and co-researchers represented “windows into the world of dementia”.

People with dementia are aware of the threat to selfhood presented by a dementia diagnosis, cautious about sharing their diagnosis and highly sensitive to the reactions of others (Beard, 2004; Langdon et al., 2007; Page & Keady, 2010). The presence of an interviewer who shared the stigmatised identity seemed to encourage openness and trust in the participants. In addition to fostering a facilitative interview climate, the co-research approach may also have assisted with processes of identity transition and management for both participants

and co-researchers. Recent research with people with dementia has revealed the strategies and processes by which they manage their identities (MacRae, 2010; Phinney, 2008; Wolverston et al., 2010). The identity management strategy of narrating stories may be especially important for people with dementia whose lives have undergone significant change and who are at risk of being devalued (Killick & Allan, 2001). In analysing the published autobiographical accounts by people with dementia, Page and Keady (2010, p. 519) note the authors' efforts to resist the "enemy" of dementia by retaining their identity and presenting this positively to others. For co-researchers, the foregrounding of their dementia as an essential requirement for their research role afforded similar opportunities for "re-positioning and resistance". It enabled them to own and embrace a positive dementia identity and utilise this in a constructive way in their interactions with others via the presentation of positive identities, such as "survivor", "advisor" and "expert". The performance of their research roles enabled them to challenge their own internalised negative constructions of dementia as well as those held by participants and carers they encountered. It is likely that the research participants, more recently diagnosed, were experiencing tension between preservation of the former self and reappraisal and reconstruction of a new self (Clare et al., 2005; Pearce et al., 2002). Their encounters and sharing of stories with co-researchers, who were positively embracing a dementia identity, may have represented an important step in their own identity transition.

There were also social benefits of involvement for both co-researchers and participants. Killick and Allan (2001) argue that "symptoms" of dementia, such as social withdrawal and disrupted communication, may be a consequence of the dearth of opportunities for communication, rather than inevitable features of dementia itself. The project generated opportunities for the communication skills of people with dementia to be exercised and utilised for a specific, socially valued purpose. This challenges pervasive negative social stereotypes and internalised perceptions that dementia destroys communication skills and cognitive abilities, erodes selfhood and creates "zombies" (Behuniak, 2011).

Although it was extrinsic to the research relationship, participants valued the advice, encouragement and validation given by co-researchers. The importance of peer support to people with dementia and carers was similarly noted in research by Willis et al. (2009); they found that the opportunity to meet others with similar experiences "... subtly altered the experience from a catastrophic change in life and health to an experience which is shared by others. This made having dementia seem more 'normal'" (p. 32). The encounters with co-researchers who had been living with dementia for a longer period gave participants hope for their own future. Hope has been shown to be significant for sustaining the well-being in people with early stage dementia (Wolverston et al., 2010), so this is a potentially important by-product of the participatory approach.

Limitations of the co-research process

We were working with a very small number of participants and co-researchers. They were all "older people" and direct users of dementia services. Other than this, they were potentially as diverse as any other section of the population, and we could not assume "peerness" or "fellow feeling" on the basis of the two facets of identity (age and dementia) that we had elected to foreground in the research (McLaughlin, 2010). The co-research model relied on co-researchers and participants establishing shared understandings and common points of reference through their experience. While in some interviews, the personalities and characteristics of the co-researcher and participants connected well, this was not so for all interviews. For example, Brian, was quiet and reflective and enjoyed walking and

cycling. Harry, one of the participants he interviewed, was much more social in his personality and interests and enjoyed going to the pub with his ex-work mates. While Brian and Harry were able to share concerns, such as what it is like to have a poor memory and to have to rely heavily on partners, at other levels outside of the dementia experience, they had little in common. While this may not matter for more conventional interviews, for these interviews where the rapport and emotional connection between co-researcher and participant was a key research tool, greater scope to attempt to match the parties might have been helpful.

All of the co-researchers and participants had mild or moderate dementia. Although we are presenting our work as “co-research with people with dementia”, it is, rather, co-research with people at certain stages of dementia. We need to avoid creating “a new form of ventriloquism”, whereby selected individuals are seen to be speaking *for* others, whose experiences may be quite different (Frankham, 2009, p. 16). This applies particularly to people with more advanced dementia, who are not represented in our research. Also, both co-researchers and participants, by dint of agreeing to participate in the research, were willing to “own” their dementia identity. As Alan commented in one of the preparation sessions, “Different people have different attitudes to dementia ... some hide away and don’t want to talk about it”. Clare et al.’s (2005) research suggests that while some people with dementia tend to adopt self-adjusting responses in respect of their dementia, accepting the need for change, others seek self-maintaining stances that endeavour to preserve continuity with their previous selves. The co-research approach may be more conducive to research with those who favour self-adjusting responses.

Conclusion

Our research indicates that older people with dementia can make a valuable contribution to research as both co-researchers and participants. Their involvement in the project gave them a sense of purpose and value, countering the feelings of powerlessness more usually associated with dementia (Proctor, 2001). This form of research involvement is consistent with promoting the citizenship of people with dementia (Bartlett & O’Connor, 2007), since it recognises their capacity to exercise agency and exert influence.

Enhanced understanding of the potential benefits of involvement in research for people with dementia is relevant to decisions about the participation of people who lack the capacity to consent. The benefits that derive from feeling socially valued and personally validated may constitute part of the justification for their involvement (Sherratt et al., 2007). However, this is something of a circular argument, since further research is needed to establish the extent to which people with more advanced dementia can contribute meaningfully to research and benefit from involvement.

Ward et al.’s (2008) research with older people with dementia in a care home found that they “craved the opportunity to be socially engaged” (p. 637) and found creative ways to communicate meaningfully with others. Our research also indicates the capacity of older people with dementia to connect socially and/or emotionally with others and, furthermore, suggests the potential of these interactions to help people with dementia to manage their identity and preserve a sense of self. The side-stepping by our co-researchers from a narrow research role into broader realms of sharing experiences and strategies, giving emotional support and encouraging service use suggests the need to explore further the potential benefits of peer support and opportunities for facilitating and supporting relationships between people with dementia.

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Notes

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2. All co-researcher and participant names are pseudonyms.

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