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researchers and participants**

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Doing research in care homes: the experiences of researchers and participants

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Abstract

The UK Prime Minister's Challenge on Dementia 2020 includes a target for more research to be conducted in care homes, yet research in care homes can be complex, as they are both homes and workplaces.

We reflect on our experiences as researchers on a mixed methods study in six care homes over a year. We include the experiences of care home residents, their family and friends, and members of staff.

Care home staff turnover was high, funding was constrained and priorities often differed from those of the researchers. Negotiating ongoing access and data collection was therefore challenging at times. Most residents did not mind taking part, but those who preferred not to felt able to decline. Private space was limited.

Research in care homes needs to be adequately planned and resourced, including funding for staff time, if staff, residents and visitors are to participate in a meaningful way.

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Introduction

Older people in care homes, particularly those with dementia, are often excluded from research (Davies et al, 2014). The UK Prime Minister's Challenge on Dementia 2020 listed an explicit aim of 'more research being conducted in, and disseminated through, care homes' (Department of Health, 2015, p33), echoing calls made by researchers over the past decade (see, for example, Froggat et al, 2006; Froggat, Davies and Meyer, 2009; Katz, 2011). UK care homes have also expressed a desire for more research to give 'a better understanding of how best to provide care and what "good" care looks like, as well as obtaining evidence to support the good quality of care already provided' (National Institute for Health Research (NIHR), 2017, p7).

The ENRICH network of research-ready care homes was set up through the Dementia and Neurodegenerative Diseases Research Network (DeNDRoN) in 2012 to facilitate care homes research (Davies et al, 2014). ENRICH is funded by NIHR and now provides online resources for researchers, care home staff, residents and their families, and the public (see enrich.nihr.ac.uk). The Prime Minister's Challenge on Dementia 2020 included a target that most care homes would be signed up to the ENRICH network by 2020. As of July 2018 around 1750 were signed up¹ - 15.5% of the estimated 11,300 UK care homes (Competitions and Markets Authority, 2017).

In recent years, research in UK care homes has increased (Gordon et al, 2012). There have been several reviews of such work (Luff, Ferreira and Meyer, 2011; Luff et al, 2015; Davies et al, 2014), and NIHR has published its own review of research in care homes funded by its programmes (NIHR, 2017). Though this showed an increase in the number of studies designed to improve the lives of people living in care homes, NIHR acknowledged that 'the research base is still new and relatively underdeveloped' (NIHR, 2017, p29).

In this paper we draw on our NIHR-funded study exploring the feasibility of evaluating life story work with people with dementia². We have previously published a paper from this study about the importance of involving people with dementia (both those living in care homes and not) as advisers and participants in research (Brooks, Savitch and Gridley, 2017). In that paper we discussed how to approach some of the challenges that have led to people with dementia being excluded from research, such as issues around communication and assumptions about capacity to consent to take part in research.

¹ Email communication from Adam Smith, Programme Manager, Office of the National Director for Dementia Research, NIHR, (6th July 2018).

² Life story work involves both recording aspects of a person's past life, present interests, and future plans and wishes, and using that information to improve their care or for their pleasure.

This paper builds on our previous work, moving away from specific people to focus on the institutional context of the research - care homes. We focus on two factors particularly relevant to social researchers. First, care homes, and the UK social care sector as a whole, face considerable financial constraints, therefore their resources for supporting research are limited. Secondly, care homes are **homes** as well as **workplaces**. It is unusual for researchers to be present in a person's home without being invited by them. Researchers should be mindful of the power imbalance their presence in care homes can create.

There is little written from the perspective of participants in care homes research (Dewing, 2009), so this paper includes the views of residents, visitors and staff about their involvement.

This research was part of a wider project examining the feasibility of evaluating life story work in dementia care. We used qualitative and quantitative methods, including standardised outcome measures, interviews, and focus groups. We also gathered information from care records. Participants were residents, visitors and staff members. A full report of the study has been published elsewhere (Gridley et al, 2016).

In reflecting on our experiences, we are mindful of observations made by Luff et al (2015, p197) after their own study of care homes research:

'while many studies alluded to methodological weaknesses in the study, these were not often detailed and failed to provide future researchers with enough information to avoid repeating mistakes or identify more successful approaches where multiple approaches were used. In general, there was little discussion by authors reflecting on the process of undertaking research in a care home setting.'

We aim to give a detailed reflexive account of our methods and highlight learning and potential challenges so others may avoid these in their work.

Researchers' reflections

Several key issues arose during the fieldwork. First, despite all the included care homes having signed up to the research, it was sometimes difficult to negotiate access, particularly in care homes where (senior level) staff turnover was high. Secondly, even where access was granted, staff and research priorities were not aligned. While researchers were concerned that, for example, questionnaires should be filled in fully and on time, staff had care tasks to complete with little slack in their rotas to devote to the research. Finally, the physical and temporal environment sometimes made it practically difficult to execute the research. These issues are addressed in turn below.

The reflections in this section are drawn from researchers' contemporaneous field notes, made electronically on the day of fieldwork, or the day after.

Negotiating and arranging access is difficult when management turnover is high

The care homes provider organisation was involved in the initial funding bid, and access to individual care homes was negotiated by their dementia care consultant, a co-applicant on the project. We recognised at the start that taking part in the research could potentially be an onerous task for care homes, particularly as it required the delivery of a new intervention (life story work). Care homes were therefore only approached if their managers were positive about research and keen to implement life story work. However, turnover of management staff in the care homes sector can be high and the lead in to the research was lengthy. By the time fieldwork commenced the managers of two of the six care homes had left and their care homes withdrawn from the project. These were replaced by two new care homes, but turnover of staff (both managers and care workers) continued to pose a significant problem.

In two further cases, where managers left and their replacements had not been involved in the decision to take part, lack of interest or understanding in what had been signed up to made it difficult to arrange fieldwork visits. More than once we arrived to find our scheduled visit had not been prioritised, or had been entirely forgotten.

Staff priorities differ from researchers' priorities

Recruitment and retention of care staff as participants in the research was considerably lower in care homes with changes of management during fieldwork, than in homes with consistent management. This may in part have been due to reduced overall capacity, but also in each care home, the manager's approach influenced whether care staff felt able to spend work time taking part. Engagement was highest where managers demonstrated to staff that this was a legitimate part of their work:

'Did staff baseline [questionnaires] in the morning starting with the manager, who sat with us in the communal area so other staff could see it was part of the working day and not something that had to be done in their own time'

Field notes from Care Home 3

Nevertheless, care staff still sometimes struggled to complete questionnaires during shifts. We gave staff the option of completing later and returning by post (using prepaid, addressed envelopes), but did not receive any questionnaires this way. It was more effective to ask staff to complete questionnaires while we were at the care home, but staff were busy with daily care tasks, and sometimes other activities such as training sessions, activity groups, or day trips. We always tried to arrange visits so they did not clash with planned activities, but often arrived to discover staff and residents were engaged in activities we had not been told about. This lack of communication was perhaps a symptom both of staff turnover and of the research being a low priority compared with other activities.

Care homes have little private space

We spent full days at each care home, so it was useful to have a room away from the public lounge to keep bags and paperwork, to talk to potential participants privately about the research and to support them as they completed interviews and questionnaires. The space available varied between care homes. One care home had two dining rooms, so we could use the second one without disrupting meals (although we were occasionally joined by residents doing jigsaws or playing Scrabble). In one we had use of a conservatory, in another a sensory room. This meant other residents could not use them during our visits. One care home put us in the staff room, but we could not take carers or residents inside, and staff felt unable to use it for lunch.

We therefore found we were often depriving other residents or staff members of a resource for a day. Sometimes we supported residents to walk back to the privacy of their rooms, but moving anywhere took time and effort and in some cases residents were reluctant to move. We therefore sometimes had to ask people questions in communal rooms, which could be quiet and with many residents in, potentially compromising confidentiality.

Care homes are busy

Care homes' daily routines influenced our research plans. We were advised to time our arrival for 10.30am, after breakfast. Lunch was usually between 12pm and 1.30pm, allowing time for residents to be escorted to the dining room. By 4pm some residents were getting tired, and the care home staff preparing for evening meals. A whole day of fieldwork could therefore translate into just four hours of actual time with residents. It could take over an hour to complete the questionnaires with each resident and family member, and it was therefore important to have two researchers present on each day to maximise what could be achieved.

Sometimes participants were not available on the day of our visit because of impromptu day trips or admission to hospital, and it was quite common for people to be called away for a hairdressing appointment or routine medical visit (for example from the district nurse or chiropodist). On some occasions, we arrived to discover that few of the included residents were available.

A key lesson learned was how labour intensive research in care homes can be and thus the importance of properly resourcing the fieldwork, particularly when it involves people with dementia who may need more time to complete research tasks. Even short quantitative questionnaires can take some time to deliver when participants need support. Having researchers more locally based would have increased efficiency and may also have helped build better relationships with care home staff and residents.

Experiences of residents, visitors and staff

Very few academic articles discuss involvement in care homes research from the perspective of the participants (Luff et al, 2015). As we were assessing how feasible a full evaluation would be, it was important for us to understand the acceptability of the research to the participants. In this section we outline participants' views about taking part, drawn from interviews with care home residents and their family and friends, and focus groups with staff members.

Residents' experiences

Researchers in care homes are usually invited by staff, and it is therefore important that residents feel able to decline to talk to them. We gained informed consent from residents who could give it, and followed a process using consultees to include those without capacity (see Gridley et al, 2016 and Brooks, Savitch and Gridley, 2017 for further details). All participants were asked for assent each time we met, and we were reassured to find that several did not agree (citing being tired, or wanting to take part in a Scrabble game instead), even if they had on previous occasions. This gave us reasonable confidence that residents who were participating were happy to. Residents reported that they enjoyed talking to us, and 'didn't mind' answering questions.

Some residents did sometimes conflate doing the life story work with taking part in the research, for example responding to our questions about the questionnaires with answers about their life story book or photographs. This was an understandable confusion and one which was made by some staff members too.

Visitors' experiences

Carers' comments covered both the research and the life story work, but were often not specific to the care home setting. For example, carers expressed some dissatisfaction with the use of questionnaires, particularly proxy measures, noting that it was difficult to describe situations and to know how their relatives felt.

More positively, carers noted they were mostly happy to take part. Several commented that completing the questionnaires did not take long, and gave them something to do when visiting relatives. Many felt the research would not necessarily help their relative, but it might help others; this is consistent with the motivations both carers and patients have given for taking part in other research projects (Gysels, Shipman and Higginson, 2008).

Carers' perspectives included thoughts on how the research could have affected their relatives. A few noted their relative may have felt anxiety, perhaps feeling they might have done something wrong.

'It wasn't that he wasn't happy to talk to you but I think afterwards . . . he sort of gave me the impression that he felt, because he hadn't been expecting it, but I don't know that he would ever expect it even if you'd warned him, that he'd said things on the spur of the moment that perhaps if he'd had chance to think about it he wouldn't have said'

Carer, Care Home 4

'If I didn't do it [sit with the person while we went through the outcome measures] she would be very worried if you were asking her all these questions, and she worries when you write things down because she thinks you're recording everything'

Carer, Care Home 2

Many carers believed relatives would have been pleased the research was being done, even if presently unable to understand the reasons for it.

Staff members' experiences

Staff comments also covered both the life story work as an intervention and the research itself. Care home staff were generally positive about the research and the intervention, but some commented they felt pressured to have achieved something in terms of the life story work - something we did not, in fact, require. Several felt they should have had extra time in their workday to complete questionnaires, take part in focus groups, and do life story work:

'It's great they [care home provider] get involved in these kind of studies but I do think that they need to offer support to the staff. If we're going to be doing this study as we'd wanted to do it, and as we should, there should have been staffing arrangements made to free up time for people to do it properly'

Member of staff, Care Home 1

This supported our own observations that staff members often had little time either to deliver life story work intervention or take part in research. Research funding covered a payment to the care homes provider, but this had been used to fund training sessions, not to cover staff time to implement life story work (which was expected to be integrated into their existing work) or for taking part in research.

Some staff were simply not familiar with the idea of research. This was in contrast to members of NHS staff who, in a different stage of the same study, had little trouble understanding the nature and purpose of standardised outcome measures. Echoing the views of carers, staff found questionnaires repetitive and vague, found the tick-box nature of the measures constraining and commented that answers had nothing to do with life story work. We made our information as straightforward as possible, but there was still occasional confusion; for example one member of staff had completed a questionnaire about attitudes to dementia for a colleague, rationalising that they were just tick boxes, and she knew what the other person would say anyway.

Discussion and reflections

Preparation is essential for researchers planning to work in care homes. One literature review (Dewing, 2009) identified that much research in care homes is carried out by inexperienced researchers, and, aside from one study (Mentes and Tripp-Reimer, 2002), there was 'a notable omission of reflections on the researcher's experience and skills, and how this influences their preparedness' (Dewing, 2009, p227). Care homes themselves have identified the need for care homes research training for inexperienced researchers (Davies et al, 2014). We were experienced researchers, supported in our preparations by Innovations in Dementia (a community interest company supporting people with dementia to be involved in research), yet we still faced some of the same challenges as other researchers. We advise other researchers to ensure they are appropriately prepared.

Our access to care homes was not dependent on 'cold calling' managers, which Davies et al (2014) have identified as being very labour intensive. Instead, we worked with a provider before applying for funding for the research, and would recommend this to others where possible, as it gave the provider organisation some sense of ownership. The provider chose appropriate care homes to be involved in the study, and our role was to negotiate when and how.

Nevertheless, while we had built a relationship with the provider before the research began, we still had to develop relationships with individual care homes during the course of the project, and where relationships were underdeveloped or disrupted this seemed to affect the sense of ownership and commitment of care homes staff to the research. In common with other research projects, staff turnover and changes in management had a particularly detrimental effect on the practicalities of fieldwork in care homes (Luff et al, 2015).

We relied on care home staff to facilitate access to residents and families, but staff have professional responsibilities towards the people in their care (Dewing, 2009), and personal preferences about access (Bartlett and Martin, 2002). Thus this process was not always straightforward.

We also found some staff were unfamiliar with the research process. We should perhaps have made more effort to explain the importance of repeated measures to staff who felt they were repetitive, as much good quality evaluation relies on such tools. Given that education and even literacy can vary in care home staff (see, for example, Hussein et al, 2009), staff may have benefited from more support with explaining the study to potential participants, whether residents or their visitors.

The day to day routine of care homes has also been identified as a challenge for researchers (Higgins, 1998, Hall, Longhurst and Higginson, 2009), and we also found this. Privacy was sometimes an issue (Hall, Longhurst and Higginson, 2009), and some residents did prefer to participate in research in communal areas (Wilson, 2011). However even having researchers in communal areas may feel intrusive at times (Ellmers, 2009). Both care homes staff and residents have extensive demands on their time and it was therefore difficult to find opportunities for research tasks (Hall, Longhurst and Higgins, 2009).

Financial incentives are rarely offered or expected in care homes research (Davies et al, 2014). We covered the cost of the time for which the provider's dementia care consultant (a co-applicant) worked on the project (including delivering the life story work training), but did not provide payments to care homes. This may have contributed to difficulties we experienced. It is important to recognise the cost to care homes of taking part in research. Staff members who were research participants completed questionnaires and took part in interviews, but also spent time contacting families, and facilitating conversations with residents and access to care records.

Staff members were expected to deliver the intervention and take part in research during normal working hours, but time pressures meant these lower priority tasks were often not completed. We suggest that financial support for care homes to cover back-filling posts where staff members are involved in research would help facilitate research participation in these settings, perhaps in line with the way NHS support costs are apportioned (see Department of Health, 2012).

Future research in care homes might focus more on developing reciprocal relationships with individual care homes, and perhaps building the research into their activities schedule. It may not seem much, but we were always sure to provide refreshments (usually tea and cake) each time we visited and we shared this with anyone in the vicinity, not only those taking part. This was well received and we felt helped to embed us in the setting and put hosts at ease. At one care home, our last visit was made into a wider event where residents shared their life story work with others and visitors were invited to join in, which created a celebratory atmosphere and gave something back to those who had supported us.

Limitations

Researchers were only present during the day, meaning access to staff on night shifts was limited. We did leave information about the study for staff on other shifts to complete but none did.

Response rates for staff questionnaires overall were low, and it is possible we could have adopted further measures to improve this, for example by offering online completion. However, there is evidence to suggest that this does not necessarily increase response rates for fixed (rather than open-ended) questions (Denscombe, 2009), and it would likely have been impractical for this population (Cho et al, 2013, p393; Scott et al, 2011, p10). Care home staff do not routinely use email as part of their work, and do not often have staff email addresses, so we would have been reliant on providing a link on paper for staff to follow on their own devices, which they may not have been able to access during work hours anyway.

Without access to personal contact details for staff members, we were limited to sending reminders to care home managers and relying on them to remind staff to fill in the questionnaires if they had not done so during our visit, which was not very successful.

Visits were widely spaced, and while we did build relationships with some members of staff, and in some cases family carers, it was not possible to do this with all. Some staff members left the organisation during the study, and residents died or were taken ill. All residents in the study had dementia, in many cases severe, and did not recognise us on our return visits.

Older adults from minority ethnic groups were largely absent from our study, which reflects their under-representation in care homes compared to the general population (Banks et al, 2006).

Conclusions

The UK population is ageing, and increasing numbers of people live in long term care homes. The importance of hearing views from those living and working in and visiting care homes is recognised, and there is a push from government, researchers and care homes themselves to do more research. However, there are numerous challenges to be overcome. In this paper we have detailed the experiences of researchers working on a mixed methods study in six care homes over the course of a year. Even with experienced researchers and a well-resourced project we faced some of the same challenges experienced by other researchers.

Staff members were dedicated to residents and largely enthusiastic about the research. However, tight schedules made it difficult to take part and to contact family carers. Ensuring meaningful engagement for residents with dementia (and, to some extent, their family carers), meant we were often effectively using qualitative methods to collect quantitative data.

We make a number of recommendations based on our own experiences:

- Research teams and care homes should agree their commitment to each other early in the research process. Where possible, more than one member of senior staff at care homes should be involved in this to provide some continuity in the event of staff changes
- It may be appropriate to consider using local researchers to limit travel, improve the efficiency of the fieldwork and to help build relationships with more frequent visits
- Where appropriate, it can be useful for researchers to make their presence known generally in the care home, for example by talking to all staff members in team meetings, and providing posters with photographs for care homes to display for residents and visitors, so they know who and what to expect
- It would be best if some payment could be made to care homes to cover staff time for taking part in research. Where this is not possible (for example with smaller research projects), researchers should consider how they can give something back to the care home

Care homes are both homes and workplaces, and any attempt to increase or improve research in care homes must be mindful of this.

Article text ends

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