OVERCOMING CHALLENGES OF CONDUCTING RESEARCH IN NURSING HOMES

Catharine Jenkins, Analisa Smythe and colleagues explore the processes, barriers and make recommendations for research in long-term care settings.

GLOBALLY, 13% OF PEOPLE over 60 years depend on others for support with personal care on a daily basis (Alzheimer’s Disease International (ADI) 2013). For those in high income countries, care is often provided by staff in care homes, while those in low and middle income countries are more likely to be cared for by relatives at home. This situation is changing rapidly due to demographic factors and increasing urbanisation (ADI 2013). In the UK, around one third of the 850,000 people with dementia live in care homes and approximately 80% of residents have dementia (Alzheimer’s Society 2015). While many residents are cared for well, there is a broad consensus that care provision for people living in nursing homes needs to be improved (Joseph Rowntree Foundation (JRF) 2012). An international taskforce identified similar concerns worldwide (Tolson et al 2011) and there is growing interest in carrying out research in care homes (National Institute for Health Research (NIHR) 2015).

Participation in research could improve standards of care and enhance quality of life for residents and promote professional development for staff. Additional education and networking with other care homes can be invaluable as homes can often be insular environments (Goodman et al 2011). Yet there is a wide range of barriers to conducting
research in care homes at every stage, including design, obtaining ethical approval, recruitment, retention, ethical dilemmas and time pressures on staff. In addition, financial crises in the care sector may affect the conduct of research.

In this article, we report on the process of carrying out research in nursing homes, identify barriers and enabling factors and make recommendations for future researchers. Our experiences derive from an ongoing study investigating the effect of educational interventions to promote and embed person-centred care, designed for nurses caring for the people with dementia in nursing homes.

Despite the potential difficulties, research in nursing homes is worthwhile because of the need to develop an evidence base relevant to the sector, as well as to improve quality of care (NIHR 2015).

Research design
A cluster, randomised controlled trial (RCT) design was suitable for our study. Nursing homes, rather than individual staff members, were assigned to either experimental or control groups. It would not have been appropriate to randomise individual staff members or residents in the same home to control and intervention groups as this would risk staff members who were receiving the intervention influencing those allocated to the control group.

Cluster designs require a higher sample size to be adequately powered, and the analysis needs to be adjusted for clustering effects, for example, nurses in the same home have to be assigned to the same intervention because otherwise they might influence each other and contaminate the data (Woods and Russell 2014).

In our study, we needed to recruit 30 nursing homes to have sufficient power to detect a significant change in staff for our primary outcome measure of ‘burnout’ as a result of the training intervention. Recruiting the required number of homes requires significant time and resources.

In a systematic review of studies conducted in nursing homes, Spector et al (2013) found that many studies did not adhere to recommended guidelines for the conduct of cluster RCTs. This design requirement may hinder studies in nursing homes, yet ignoring the care home unit as a fundamental variable will produce invalid results.

Having taken into account the possible confounding effect of the nursing home as a unit, an additional threat to the validity of the study results from differences in the size of homes (Garcia et al 2013), which in the UK can vary from fewer than ten places to more than 150 (Royal College of Nursing (RCN) 2012). Those that are small in size are likely to vary considerably in culture, regime and governance compared with those that are larger. This means that study designs need either to restrict their recruitment to homes in a certain size range, or balance for size in randomisation. In the study, we ensured that each group had a mixture of small, medium and large homes.

A further threat to validity is high rates of staff turnover leading to high attrition rates, resulting in missing data (Garcia et al 2013). Care homes may also have changes in management while the study takes place, which may lead to homes withdrawing part way through a study. In addition, there may be difficulties adhering to the study protocol, for example, poor concordance with study timelines, data collection and accommodating the intervention.

A systematic review conducted by McCabe et al (2007) identified systemic issues specific to conducting interventions in health and care home settings, such as difficulties in training all staff members, entrenched, task-focused rather than client-focused practices and the heterogeneity of facilities.

It is difficult for care homes to release staff for training, or to take part in research generally, as not only do they have inadequate staff numbers (RCN 2012) but, as largely private, profit-making businesses, releasing staff to engage in study and research costs them money. Perry et al (2011) commented that the methodological quality of studies in this setting was diverse, and common limitations were the large proportion of participants lost to follow up, poor compliance with the intervention, as well as differences at baseline.

Research ethics committees
Complex ethical issues arose from our study design, including concerns about releasing staff and aiming to ensure that they and the home were not put under additional pressure. A detailed description of the intervention was required to demonstrate how it would protect, and potentially benefit, participants.

It is important to ensure equity of access to participation in research; in this study, the control group was offered the opportunity to take part in the training. Clear procedures are required to address capacity and safeguarding issues.

There are ethical issues related to including residents living in nursing homes in research, as the researcher’s presence could be perceived as intrusive, and residents may lack capacity to consent to participation. In this study, personal consultees were recruited who were able to take on the role of...
advising the researcher on the wishes and feelings of the person who lacked capacity.

The process of obtaining approval for a study can be daunting, and the UK research ethics system has been subjected to repeated criticisms (Tolhurst 2014). These criticisms include the requirement for duplicate submissions; submission forms that are long and complex; lengthy delays before a decision is made; inconsistency across committees; interference in study design; and a preference for, and greater understanding of, quantitative studies (Munk and Murphy 2012, Paniagua 2012, Tolhurst 2014).

The following queries might be relevant for future researchers. Subsequent to our submission to the East of England Research Ethics Committee, specific queries to us as researchers included:

■ Would NHS indemnity be appropriate for research carried out in the nursing homes?
■ Would site-specific assessments for non-NHS sites, for example, each nursing home, be required?
■ Would the research involve adults who were unable to consent for themselves?
■ How would we address issues about consent if the study included adults who may lack capacity?
■ If the home was part of a larger organisation, would we be able to ensure care home managers notified homeowners?
■ How would we justify selection of participants, that is, ensuring care home managers did not only approach those staff or residents who they thought ‘deserved’ to participate?
■ Could we ensure that the home was not left understaffed while the staff were participating in the study?
■ Did we have appropriate procedures in place in the event of abuse and/or malpractice or negligence being discovered or disclosed by participants?
■ How could we ensure privacy and anonymity of research participants if the research was to be undertaken in public areas, for example, dementia care mapping and qualitative interviews?

Questions from the ethics committee proved useful, for example, in clarifying the research question, developing details of the intervention, responding to abuse in practice, and advice to simplify the research design.

Recruitment

Our approach to recruiting nursing homes was based on a practical online guide for researchers on how to conduct research in nursing homes (NIHR 2015). Recruitment was also facilitated by the researchers’ previous experience and familiarity with nursing home settings. Our experiences taught us that the barriers to nursing home recruitment were considerable and can risk undermining a study if not planned for.

Table 1 shows the stages in our recruitment process, the barriers that arose at each stage, and successful strategies to overcome them. The team needed to be flexible, patient and creative to overcome difficulties in recruitment. The process took much longer than anticipated; there were financial implications from recruiting more widely.

It became apparent that the recruitment challenge needed to be met by the use of multiple strategies that reflected the heterogeneity of the care home sector (Davies et al 2014). Fostering and sustaining relationships appeared to be essential to recruitment (Goodman et al 2011, Garcia et al 2013, Davies et al 2014).

For each step in recruitment we recommend extensive planning that builds in time, including time to develop relationships and to be flexible in the face of unexpected hurdles. Nursing homes are more highly regulated than other healthcare settings, and staff spend significantly more time making sure that homes meet quality requirements (Hanson et al 2010). This may be one of the reasons why some care providers are wary of the time demands of research participation (Garcia et al 2013, Davies et al 2014).

Nursing home staff may have little interest (Davies et al 2014) or limited experience in taking part in research (Goodman et al 2011) or may mistrust researchers’ motives, fearing intent to expose poor practice (Garcia et al 2013) rather than to improve care (Hanson et al 2010). The JRF (2012) identified that research focuses too often on poor practice and blame. Managers and staff members may not want their usual routines interrupted, or residents to be disturbed by the activities of a research study (Shin 2013).

In a busy home, it can be problematic for staff to find enough time to participate in research, which has to take second priority to care. These difficulties may be exacerbated as staff work shifts and weekends, and many homes have staff who work part-time or flexibly (RCN 2012). Therefore, it can be challenging to ensure that the research intervention is delivered and that data are collected on time.

Implementing the intervention

Implementation of the intervention had to take into account the pragmatics of working with staff in the constraints of the homes. This threatened implementation fidelity, which is the extent to which interventions are delivered as intended,
Table 1 | Recruitment strategies, barriers and strategies

<table>
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<th>Barriers and difficulties encountered</th>
<th>Problem-solving and strategies for success</th>
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<tr>
<td>Nursing homes were initially identified through the Care Quality Commission website</td>
<td>None</td>
<td>Not applicable</td>
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<td>Invitation letters with reply slips and stamped addressed envelopes were sent to Birmingham nursing homes</td>
<td>Only 10% of homes initially approached expressed an interest in the research, which meant there were not sufficient numbers interested in Birmingham</td>
<td>The steering committee, including a home manager, lay people and professionals, contributed to the design of an eye-catching leaflet, as recommended by a member of the steering group. The geographical area covered in the project was extended to the West Midlands.</td>
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<td>The newly designed, eye-catching leaflets were sent to all nursing homes in the West Midlands</td>
<td>Often there was no recollection of the leaflet or, when the leaflet was seen, staff had not found time to read it. The research team was often asked to resend the leaflet, with a reassurance that it would be read</td>
<td>The researchers were persistent and flexible and kept communication effective by making calls frequent but brief and demonstrated respect for the time demands and responsibilities of running the nursing home (Hanson et al. 2010).</td>
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<td>A follow-up phone call to the home manager was made two to four days later</td>
<td>It was often difficult to speak to home managers as many did not return calls from the research team. Some managers hesitated to take part in the study; they asked for more information or said they could not make a decision as the home was part of a chain.</td>
<td>Liaison with individual managers was more effective than trying to contact senior managers.</td>
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<td>For the larger chains, the researchers planned to approach the head office first to ask for agreement for the care home's participation.</td>
<td>Managers were sometimes reluctant for their homes to take part due to difficulty in releasing staff, training was seen as a low priority, and availability of short and free online training alternatives.</td>
<td>In speaking with managers about participation, it proved important to highlight the benefits of participation for the home and staff (Davies et al. 2014). For instance, sharing findings from previous research studies on training and the way these benefited staff, residents and the standard of care in the home.</td>
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<td>The team identified home managers, deputies, training co-ordinators and senior nurses</td>
<td>Leadership changes occurred frequently during the study recruitment period, noted by Davies et al. (2014).</td>
<td>Contact with new managers was established, and additional meetings were offered to discuss the study (Hanson et al. 2010).</td>
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<td>Once contact had been established, managers were asked to invite potential participants – qualified nurses – to discuss whether they would like to take part in the study</td>
<td>There was a high turnover of qualified nurses and it was difficult to recruit the required number per home. Sometimes managers did not invite staff to take part, at other times nurses were put forward but were unaware of the research. The team had previously worked with care homes, but initially lacked insight into the specific needs of nursing home working environments; for example, staffing levels, diversity of provision, and changing rotas.</td>
<td>Face-to-face contact through verbal presentations at the homes enabled researchers to build rapport. Staff members reported that clear explanations of the research project through written material, that is, information sheet, training timetable, map and leaflet, and verbal presentations, aided understanding of the study and recruitment process (Davies et al. 2014).</td>
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<td>Members of the research team attended staff meetings in the nursing home to ensure all staff were aware of the study and could volunteer to participate</td>
<td>It was difficult to organise meetings at convenient times.</td>
<td>If meetings were not in place, the manager was asked to set up a convenient time for the research team to visit the home (Goodman et al. 2011). Following Garcia et al.’s (2013) guidelines, it was suggested that the meeting took place at change of shift so that two sets of nurses could attend the information session and receive an information sheet.</td>
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Recruitment strategies

The information sheet was followed up by a telephone call, three to four days later, to ask if staff had any questions and whether any were interested in taking part or whether they would like longer to decide. This process took longer than anticipated. The research team’s approach was to avoid burdening or distracting staff in their clinical responsibilities as far as possible (Hanson et al 2010), for example, by being flexible and calling in the evening.

A mutually convenient time to answer further questions and gain informed, written consent was arranged to meet those nurses who were interested in participating in the study, at their workplace. Nurses were often not present at the agreed times due to sickness, forgetting and non-communication. Researchers had to adjust timeframes and be flexible and accommodating. The team realised it was essential to telephone in advance of every appointment to confirm.

Making the training intervention attractive to participants

Some difficulty releasing staff, training seen as a low priority, and availability of short and free online training alternatives. Benefits were explained. These included ‘notional credits’ (equivalent to formal credits for students wanting to take standard modules), access to university, and organisational and family-friendly timings. Taster versions were offered to demonstrate the approach. Feedback about benefits of previous similar training was used to promote the training.

Each home was randomised into one of three conditions

Some homes were disappointed at the long wait for the training or to be randomised to the control group, while others were relieved. Researchers explained the importance and process of randomisation in research.

Those allocated to training were invited to training days

Staffing shortages meant some homes could not afford to release staff members for training during their working hours, so staff who were expected to attend, did not turn up. The team adjusted the planned timetable for the training intervention to ensure that nurses’ participation did not affect management of the home (Davies et al 2014). Some nurses chose to attend on their days off, or before or after shifts, including night duty.

Table 1 Recruitment strategies, barriers and strategies (Continued)

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with adherence to specifications in intervention manuals (Lorencatto et al 2014).

In this study, it was difficult to follow the protocol, adhere to agreed timelines and deliver the intervention as planned due to changes in the rota, sickness, absenteeism, organisational factors, management style and care culture (Spector et al 2013).

When research is conducted at the workplace, nurses may be concerned about work disruption and increased demands on their time (Cleary 2004). Cleary also discussed how researchers may be viewed by personnel as working in ivory towers and out of touch with the realities of long-term care settings. This experience was shared by the research team, for example, one participant stated: ‘You’re from the NHS – fairy-tale world.’

The in situ intervention in our study demanded flexibility in its application, yet also carried credibility as it involved the trainers modelling aspects of the application of knowledge in the care environment. Positive experiences as research participants encouraged the nurses to further their education and recognise their own expertise.

However, due to high staff turnover it was difficult to ensure participants remained in the study. Reasons for drop-out included pregnancy, illness, long holidays, family difficulties and leaving for new jobs. Where possible, participants were followed up in a different nursing home, with the agreement of the home manager. This may have affected the validity of the study, however, it was important to take a pragmatic approach and preferable to losing participation altogether.

Raising concerns

In the course of our study we observed high-quality care delivered by committed, caring nurses and care staff. In two of 30 homes, we became aware of neglect and teasing of residents, illegal deprivation of liberty, inadequate fire escape provision, understaffing and fraudulent use of funding.
In each of these cases the researchers had an obligation to raise concerns with the appropriate regulator, which in England is the Care Quality Commission (CQC).

The team acted on the duty to escalate concerns promptly, guided by the need to prioritise care of residents, act as advocates and be open and candid (Nursing and Midwifery Council 2015), following the framework for adult safeguarding under the Care Act 2014 and our conditions of ethical approval.

However, reporting concerns to the CQC had a number of consequences for participants and for us as researchers. During implementation, it is important to support all members of the research team. It is therefore essential to have clear agreements with the homes and protocols for reporting any concerns. In one case, the home manager made allegations about research participants (nurses) that appeared to be retaliatory.

In most of the examples in our study, nurses moved on, which made it more difficult to keep them in the research and increased ‘churn’ which is damaging to residents (McGilton et al 2014).

For researchers, once a concern has been reported to regulators, the home may withdraw its co-operation with the study. This means that the researchers will no longer have any chance of changing practice in that home and subsequent studies may be refused access (Garcia et al 2013).

Unanticipated ethical consequences of the research included increased risk of job insecurity for participants and staff turnover for homes. Coping with ethical issues reduced study power and validity.

Recommendations
Our experiences lead us to make these recommendations for research in care homes:

■ Ensure sufficient time and financial resources.
■ Ethical approval requires justification of every aspect of the study; prepare to respond to the particular questions outlined previously.
■ Invest time in forming relationships with homes.
■ Empathise with nursing home staff who have challenging roles, work long hours and are often taken for granted: aim to work collaboratively.
■ Manage expectations: clarify timescales and the nature of interventions and advise on longer-term benefits of research.
■ Be prepared to be patient, flexible, understanding, resilient, to persevere and be mutually supportive.
■ Adopt protocols that have built-in flexibility to adapt the intervention to different circumstances.

References
Have structures in place where you can debate and devise strategies to cope with setbacks. Our steering group included a home manager and former carer whose ideas were invaluable.

Be aware of the possibility of poor practice and the need to respond appropriately.

Ensure participants have a good experience so as to minimise drop-outs and promote willingness to take part in future studies. Be punctual, polite, friendly and professional.

Hold regular meetings and provide supervision for the research team to allow time for reflection, help manage stress and ensure effective completion of the study.

Benefits
Research offers benefits for people living and working in nursing homes. For nurses, these include education, development of new skills, to have their voices heard and experiences validated, networking opportunities, profile raising, empowerment and the satisfaction of contributing to creation of knowledge. Benefits for residents also include the opportunity to have their voices heard, as well as improved standards of care and quality of life. Benefits for researchers include the chance to make a difference to care and insight into a different world. Committing to overcoming the barriers to conducting research in care homes can contribute to advancing care standards.

Conclusion
Well-designed research studies are essential to inform the development of high-quality, person-centred care. Nursing homes should be supported and encouraged to take part. Extensive planning and preparation for ethical approval and recruitment are essential steps in the process.

The pressures on nurses working in homes can make it difficult for them to prioritise research over their professional responsibilities. Understanding their perspectives, clear communication, building relationships and being flexible, patient and creative, can help researchers recruit and support participants throughout the research process in nursing homes.

The main issues were ethical concerns and gaining ethical approval, appropriate design and recruitment, and retention of participants.

Constraints included time pressures, staff turnover and organisational cultures. However, there are opportunities to change practice in this under-researched field and improve quality of care for residents.


