The challenge of carrying out research in care homes: malnutrition

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With an ageing population that is set to increase significantly in the future, care homes will play an increasingly important role in the care and support of older people. A lack of evidence to support best practice, however, has led to the need for further research in these settings. There are a number of challenges and complexities involved in conducting research with care home residents, which has contributed to their under-representation in research studies and has restricted advances in understanding and management of this population.

This article discusses some of the issues and challenges of conducting research in care homes — in this case with a focus on malnutrition — and makes recommendations for future research.

BACKGROUND

Care homes serve one of the UK’s most vulnerable populations (Quince, 2013), most of whom have multiple physical and mental health and social care needs. This distinct group of over 400,000 people have very different mortality, health status, and healthcare needs from people of the same age living in their own homes (Petty and Scrivener, 1998; Sinclair et al, 2001; Nimmo et al, 2006). These differences are often so pronounced, that research outcomes established for older people living at home cannot be considered valid for care home residents nor used to guide best practice (Bugeja et al, 1997; Bayer and Tadd, 2000).

There is a tendency to avoid research in care homes, because of the challenges and methodological issues involved (Maas et al, 2002). Many research studies specifically exclude care home residents on the basis that their inclusion would present the research team with ethical and practical difficulties (Watts, 2012), including:
- Problems with recruitment due to physical and/or cognitive impairments (Maas et al, 2002; Hall et al, 2009)
- The consent process (Maas et al, 2002; Hall et al, 2009)

AGE-RELATED MALNUTRITION

Older adults are most at risk of malnutrition, with approximately 10% of those over the age of 65 years affected. People over 75 years are at even greater risk and this population is expected to double over the next 30 years.

Causes of malnutrition are often multifactorial and include one or more of the following:
- Taste changes due to disease or medication
- Physical difficulties such as difficulty with shopping, preparing food, chewing or swallowing
- Poverty and deprivation
- Depression, anxiety, apathy and self-neglect
- Poor quality and lack of variety in meals
- Dementia.

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Responding to concerns from family members or carers (Maas et al., 2002), higher attrition rates of older people from research studies (Maas et al., 2002; Ridda et al., 2008).

Trying to collect data around the busy schedule of a care home, along with poor staff compliance with interventions and data protection protocols (Maas et al., 2002), can pose additional issues for the researcher. A recent review revealed that the majority of epidemiological studies, either exclude care home residents at the outset, or fail to follow up participants when they move into institutional care (Collingridge Moore, 2013).

With the ageing population set to grow in the coming years, care homes will play an increasingly vital role in supporting older people, and the lack of evidence to support best practice has led to recommendations for more studies to be conducted in care homes (Royal College of Physicians, RCN, British Geriatrics Society, 2000).

At the time of writing the author was investigating the feasibility of a full-scale randomised trial comparing the efficacy of established dietary interventions for malnutrition within care homes. However, in the process of recruitment and baseline data collection, the author encountered methodological challenges in conducting this research. By highlighting some of these issues, this paper aims to help future researchers better plan research projects in the care home setting.

**METHOD**

A pilot study was proposed to assess the feasibility of comparing food-based interventions, prescribed oral nutritional supplements (ONS) and the standard care home diet used to treat protein-energy malnutrition (PEM), within care homes.

Following local ethical and research and development approval of the study protocol, six private care homes (three nursing homes and three residential homes) in Solihull, West Midlands were approached to participate.

The inclusion criteria for care home residents to receive one of the nutritional interventions required by the pilot study were:

- A malnutrition risk score of ‘1’ or more, as determined using the malnutrition universal screening tool (MUST) (Elia, 2003)
- Being able to eat and drink
- Being registered with a Solihull GP.

The exclusion criteria were:

- Any patient receiving tube or parenteral nutrition
- Any patient receiving dietetic-led nutritional support
- Any patient having a known eating disorder or illness requiring a therapeutic diet incompatible with fortification and/or supplementation
- Any patient on an end-of-life care pathway.

Eligible residents within each participating care home were identified using routine malnutrition screening, followed by a review of their records by care home staff. Of the 280 residents screened using the MUST tool, 110 were found to be at risk of malnutrition (39%). Of these, 14 were already receiving nutrition support (13%), two were in hospital (1.8%) and one was not registered with a Solihull GP (0.9%). The remaining 93 residents, seventy-six of whom were female, were deemed eligible to receive one of the nutritional interventions.

One objective of the pilot study was to review the feasibility of a range of dietetic outcome measures for use within the main trial. Outcome measures routinely used to monitor nutritional status such as changes in nutrient intake and physical parameters including weight, body mass index (BMI), hand-grip strength and mid-arm muscle circumference, were collected at baseline, in all eligible residents.

Additional outcome measures, including quality of life, health status, and appetite and dietary satisfaction were explored by questionnaires in those residents assessed by the care home staff as having capacity (17), and for whom written informed consent had been received (11). These 11 residents made up the pilot study population.

Following the collection of baseline outcome measures, the six care homes were stratified by the type of care provided (nursing...
or residential) and randomised to receive either food-based intervention, prescribed ONS, or to continue with the usual care for malnutrition.

**CHALLENGES**

Challenges identified by the author when trying to conduct the pilot included the recruitment and consent process, the measurement of baseline outcomes and data collection in the busy care home environment, and the involvement of care home staff. Ensuring residents’ privacy, and retention and mortality rates were also identified as challenges unique to the setting.

**Recruitment and consent**

**Recruitment**

The pilot study is cluster randomised at the level of the care home; therefore, consent was sought for each care home site from the manager. Collaborating with managers and staff is essential when conducting research in care homes, as identifying and gaining access to residents requires the continual involvement of everyone who works in the home.

However, gaining consent from the care home manager by letter is problematic as it is essential that they fully understand the research project, the implications for their residents and the involvement and time commitment required by their staff. A personal approach is required to achieve this level of understanding and a face-to-face meeting is usually helpful.

In this study, the researchers (a local dietitian and the author) had already spent three years in clinical roles establishing a good working relationship with local care homes, standardising nutritional screening and improving care planning for malnutrition. These existing relationships proved crucial to the recruitment of the six care homes participating in the pilot study and enabled the researchers to carry out the research in full partnership with the care homes (Luff et al, 2011).

**Consent**

It is also important to ascertain whether each resident who meets the inclusion criteria for a research study is able to give informed consent. In 2013, the Alzheimer’s Society estimated that 80% of residents in care homes have dementia or severe memory problems (Quince, 2013).

In this pilot study, 70 of the eligible 93 residents (75%) had diagnosed dementia at baseline, and just 17 residents (18.3%) were assessed as having capacity by trained staff. Informed consent was only sought from individual residents that were assessed by trained care home staff or a GP as having capacity to take part in additional participant-centric outcome measures, including quality of life, health state and dietary satisfaction.

The requirement for valid informed consent includes providing the individual with a written description of the research, followed by a face-to-face discussion including the opportunity for questions. The researcher needs to be satisfied that the subject understands what is being asked of them, before consent is signed.

‘Gaining consent from the care home manager by letter is problematic as it is essential that they fully understand the research project.’

Other studies of care home residents have noted that some who appeared to understand the research while it was being explained to them, had forgotten about it by the following day, or could not recall reading the information about the study (Zermansky et al, 2007; Hall et al, 2009). As a result, the resulting consent rate was lower than originally anticipated (Zermansky et al, 2007).

In this pilot study, the care home staff made the initial approach to the 17 residents that had capacity to consent to discuss their possible involvement in the collection of the additional outcome measures.

There was a risk that the care home staff would only suggest the more ‘compliant’ residents be involved, but it was hoped that the care home information sheet and associated consultation with the dietitian would enable care home staff to make an informed decision concerning who would be able to take part.

It was also felt that the wealth of staff knowledge about the prospective participants would be invaluable to this part of the study.

In practice, the care home staff approached all 17 residents and 11 consented to take part in the participant-reported outcome measures. Of the six residents who declined to participate, three simply declined, one was too unwell to be approached by the dietitian to receive further information and another one declined because of family influence.

**Data collection**

Finding the time to conduct the physical outcome measures (weight, BMI, hand-grip strength and mid-arm muscle circumference) used to monitor nutritional status was sometimes difficult.

In this pilot study, the dietitian visited each care home to measure handgrip strength, mid-arm muscle circumference and tricep skin fold thickness on all of the care home residents receiving the allocated nutritional intervention.

It was important to avoid busy times of the day, such as mealtimes, medication rounds or during regular visits by GPs and other healthcare professionals. The dietitian spent a great deal of time waiting for residents to finish other activities, or waiting for a member of staff to become available to make the initial approach to each resident and explain the physical measurements that needed to be carried out.

Several visits had to be arranged to take account of residents not feeling well, not being prepared for an unexpected visitor, or simply not being available during the visit.

Of the 93 residents approached to measure handgrip strength in...
the pilot study, 10 refused (11%) and 31 (34%) did not understand the instruction or were unable to undertake the measurement, due to physical limitations.

The acknowledged limitations of the handgrip strength technique, which provides an estimate of muscle mass and function, include the influence of debility, age and familiarity (Thomas and Bishop, 2007), potentially limiting its usefulness in an elderly dementia population.

A further eight residents (9%) refused to have their mid-arm circumference measured and 12 (13%) refused the tricep skin fold measurement. At the three-month data collection interval, the author planned to determine whether the same residents refused the physical measurements each time, or whether consent to allow these measurements was more variable.

Resident height, weight and BMI was obtained from care home records, while food records and fluid charts were collected from each care home site to determine average energy and protein intake for each resident.

In the pilot study, four food record charts (4%) and five fluid charts (5.5%) were unavailable or had not been completed and 15 food record charts (17%) and nine fluid charts (10%) were incomplete.

When designing a study in the care home setting, it is important to consider whether any data being collected retrospectively will be accessible to the researcher and whether it will be reliable and consistent.

There was variation across the care home sites in the measurement techniques used to obtain height — 60 residents had been measured using a stadiometer (67%); self-reported height had been recorded for two residents (2%); and height estimated from ulna length (the thinner and longer of the two bones in the forearm) for a further 28 residents (31%). If it is not possible to measure standing height, self-reported height is considered the superior secondary method (Thomas and Bishop, 2007). Ulna length can be used to estimate height, as these bones are relatively unaffected by ageing, however, they may not reflect actual height as this decreases with age due to vertebral changes (Hickson and Frost, 2003).

To enable the relationship between measured and estimated height (from ulna length) to be examined within this population, the author planned to measure ulna length for all of the residents enrolled in the study.

STAFF INVOLVEMENT

During the recruitment phase and the collection of baseline outcome measures, help and cooperation from care home staff was invaluable. However, the way in which care home staff introduced the dietitian could sometimes be problematic. They would often emphasise the ‘research’ element of the work, although for those residents involved only to the point of ‘usual dietetic care for malnutrition’, the outcome measures formed part of their usual assessment process.

Some residents or visiting family members became confused or worried by this, which subsequently required further explanation by the dietitian, who would have to remind them of the purpose of the visit.

The participant-reported outcomes were measured using questionnaires and self-reported scales, which were left with care home staff to present to participating residents at an appropriate time and to be collected by the dietitian within two weeks.

In practice, several return visits had to be made to each care home site and staff often had to be reminded to explain the questionnaires to the residents.

PRIVACY

Since not all of the residents at each care home were involved in the study, it was important that privacy be maintained while physical measurements were being taken.

However, on some occasions staff would take measurements in a hallway, communal activity room or dining room where there was little or no privacy. As the majority of residents enrolled in the study had mobility problems, moving them to somewhere with more privacy was time-consuming and usually involved the help of care home staff.

RETENTION AND MORTALITY

As this was a pilot study, data on withdrawals, changes to residents’ nutritional intervention plans, mortality rates and adverse events were to be collected later throughout the actual study itself.

This data would allow for a subsequent assessment of retention rates, reasons for withdrawal from the study or from the allocated nutritional interventions, and would inform aspects of feasibility and acceptability reporting.

CONCLUSION

Conducting research within the care home setting can be challenging and time-consuming, but remains vitally important in challenging discriminatory attitudes in research and to ensure that this under-represented group in society benefit from improved understanding and management.

To enable future researchers to plan effective care home research, the author has compiled a number of practical points to consider when conducting research in a care home (Table 1).

The experiences of the dietitian researcher and author show that care
homes residents and staff can be very enthusiastic about participating in research.

However, key lessons learned include the need for patience and allowing plenty of time, particularly when collecting data from care records and measuring outcomes with residents.

Researchers also need to consider the expected loss of potential participants between identification and consent or collection of baseline outcome measures, as well as the need to account for the high mortality in this patient group.

The time spent planning care home research and gaining knowledge of this unique setting is essential, both to ensure the effective collaboration needed for research and to improve the quality of care for care home residents. JCN

**REFERENCES**


**Table 1: Key advice for carrying out research in the care home**

<table>
<thead>
<tr>
<th>Advice</th>
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<tbody>
<tr>
<td>Care homes vary in size, type of care provided and management type: consider this when sampling to achieve a representative population</td>
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<tr>
<td>Take high mortality into account within sample size calculations</td>
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<tr>
<td>Obtaining consent or a declaration from a nominated consultee can be time-consuming. Models of advanced consent could be considered</td>
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<td>Obtain approval and support of key stakeholders, such as care home managers, relatives and GPs</td>
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<td>Take into account the prevalence of cognitive and communication difficulties with this population and the busy environment of the care home setting. Multiple visits are inevitable when collecting data and measuring outcomes with residents</td>
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<td>Data collected retrospectively from care home records may be difficult to access and may not always be readily available, reliable or consistent. Training with care home staff may be required before beginning a study</td>
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to the learning zone test:

**Reflect**

Do you understand some of the issues with malnutrition in the older population?

What are some of the main problems associated with research in care homes?

**Evaluate**

Do you appreciate how the patient can be negatively affected by malnutrition?

**Act**

Read the article when you have a spare few minutes in the day. Make some notes on what you have learned, then visit the online test (www.jcn.co.uk/learning-zone/) to complete this subject.

The whole test, which involves reading this article and answering the online questions, should take you 90 minutes to complete.

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