

Outcome measures in care homes: a review of the literature

Summary

Care homes gather many types of key information about residents to ensure that residents' needs are being met and that residents have a good quality of life. If this information is gathered in the same format across many different care homes, it can be compared and contrasted easily to inform quality improvement. To achieve consistency across care homes, researchers and people in working in or with care homes need to agree on how to collect and record resident information in the most appropriate and useful way. There are many different "outcome measures" – instruments that help to collect information and measure changes over time – that could be more widely adopted and used in care homes to capture resident information more consistently, but it is difficult to know which are most suitable to use. To inform our thinking, we looked at research in care homes completed previously (2015 – August 2022) to identify which outcome measures have already been used.

A rigorous process was followed to identify the outcome measures. Out of 732 outcome measures found, only 14 of them were found to have been used more than 20 times by researchers. These outcome measures typically measured functional status, mood and behaviour, and medications. Interestingly, only a fifth of research studies used information gathered routinely by the care home, which suggests that most research relies on researchers collecting new information directly from residents, staff or records. There is an urgent need to start using the best outcome measures consistently for research and to support improvements in practice, working with residents, family and friends and staff to ensure that what matters most is measured in the most efficient and least burdensome way.

Key-points

1. Care homes and researchers working together to decide the best ways to measure what matters to older people could be of mutual benefit and help to improve care home practice.
2. Outcome measures to measure quality (e.g., quality of life or quality of care) must be suitable not only for research but also for use in everyday practice in care homes.
3. We found that researchers internationally are not in agreement with each other about which are the best outcome measures to use.
4. Using different outcome measures to measure the same thing is wasteful as findings can't be easily compared and contrasted.
5. However, there is an urgent need to agree the most useful outcome measures for use in care homes that can help accurately show changes and trends over time.

Background

UK care homes provide a home and range of services for older people with complex care needs, including dementia. The COVID-19 pandemic identified the importance of finding better ways to collect information about residents and their needs. However, out of all the potential outcome measures (instruments) available that could be used to collect resident information, it isn't clear which would work the best in care homes. We wanted to identify the outcome measures that researchers tend to use, which ones are used most commonly and what these outcome measures are used to measure to see if these could be useful in everyday practice within care homes.

Methods

To identify the outcome measures that researchers use, we looked for and described all the research papers that reported using outcome measures. We defined 'care home' as being any long-term residential care setting where older adults received 24-hour care and support, with or without on-site registered nursing staff. Next, we identified, grouped, and described all the outcome measures that had been previously used in care home research. We also counted how often these outcome measures had been used.

The outcome measures were grouped in relation to:

- activities & interests (activities preferences and involvement, daytime sleep);
- cognition (including delirium and dementia);
- communication & vision;
- continence;
- disease & diagnoses;
- functional status (including activities of daily living, locomotion, physical function);
- health conditions (including falls, sleep, fatigue, pain);
- medications (including nutritional supplements);
- mood & behaviour;
- oral & nutritional status (including anthropometry, dehydration, dental/oral cavity issues);
- psychosocial wellbeing (social and unsettled relationships, sense of involvement, loneliness, major life stressors);
- skin condition (including pressure ulcers);
- treatments & procedures (including oral health outcomes, hospital/emergency department admissions/other transfers & restraint use).

Finally, we noted whether the outcome measures used were based on the findings from a scientific test, routine information being gathered by the care home, or represented new information collected by the researcher in either paper or digital format.

Emerging results of the review were shared with people working in care homes and with family members of care home residents, to gather feedback about how easy and useful it would be to adopt these types of outcome measures in care homes.

Findings

We based our findings on the analysis of 436 research papers. Interestingly, there was a growing number of papers on care homes over time.

The following countries accounted for most of the studies:

- USA, 66 in number (n=66) (16.7%),
- Australia n=50 (12.6%), UK n=43 (10.9%),
- Germany n=30 (7.6%)
- Canada n=26 (6.6%).

The studies used a variety of different methods. Most studies (n=318, 80.3%) were undertaken in homes with nursing staff, with n=43 (10.9%) in residential homes and n=35 (8.8%) including both settings.

A total of 12,167 homes and 836,842 residents were represented in the studies. The point at which the outcome measures were used in the studies varied.

The research was trying new ways of working – interventions – to try and improve various aspects of resident care. The interventions were trying to improve:

- medicines management and prescribing (n=56, 14.1%),
- physical function/performance/activity (n=21, 5.3%),
- cognition (n=20, 5.1%),
- hospital transfer/length of stay (n=19, 4.8%) and
- oral health (n=19, 4.8%).

The interventions used:

- exercise (n=41, 10.4%),
- education/training (n=38, 9.6%),
- technology (n=28, 7.1%)
- pharmacology (n=24, 6.1).
- multiple components (n=90, 22.7%)

The 2,030 resident outcomes measures focused on:

- functional status (n=304, 15.0%)
- mood and behaviour (n=272, 13.4%),
- medications (n=169, 8.3%),
- cognition (n=157, 7.7%),
- health conditions (n=154, 7.6%),
- treatments and procedures (n=142, 7.0%),
- quality of life (n=140, 6.9%)
- oral and nutritional status (n=138, 6.8%) (Figure 2).

A total of 732 outcome measures were used between 1-120 times, with 501 measures (68.4%) being used only once. Of all of these 732 outcome measures, only fourteen measures were used more than 20 times.

The most commonly used rating scales were:

- Neuropsychiatric Inventory (mood & behaviour),
- EQ-5D (quality of life),
- Mini Mental State Examination (cognition),
- Cohen Mansfield Agitation Inventory (mood and behaviour),
- Geriatric Depression Scale (mood and behaviour),
- Cornell Scale for Depression in Dementia (mood and behaviour),
- Barthel Index (functional status),
- Timed up and go test (functional status),
- Quality of Life in Late Stage Dementia (quality of life).

The information used to complete the outcome measures came from using scales (such as those listed above) (n=1,036, 51.0%), from existing records (n=430, 21.2%), from biological tests (e.g. blood tests) (n=293, 14.4%) new information collection for the study (n=190, 9.4%) or information derived from technology (n=58, 2.9%). For 23 measures (1.1%), the information source used was not reported.

Whether outcomes were collected using electronic or paper methods was poorly reported.

In decreasing order, information was provided by:

- care home staff (n=491, 24.2%),
- residents (n=351, 17.3%),
- researchers (n=289, 14.2%),
- healthcare professionals (n=232, 11.4%)

- others including relatives (n=114, 5.6%).

But in over a quarter of cases, it was not clear where the information came from (n=553, 27.2%).

Discussion

There is continued growth of care home research that uses measurements. Encouragingly for residents, in recent years, research studies have focused more on measuring quality of life. However, measurement linked to continence and communication and vision only accounted for 1.2% and 1.0% respectively, despite their use in everyday care.

Outcome measures used by researchers tend to have been developed in hospitals or other clinical settings and may not be appropriate for use in care homes, given the levels of frailty of residents. Of the nine outcome measures used in more than 20 studies two were used for depression, two for quality of life, one for neuropsychiatric symptoms, one for agitation, one for cognition, one for activities of daily living, and one for functional mobility. Of these, only the Neuropsychiatric Inventory has a version specifically designed for use in nursing homes. However, this version was only used in 20/53 instances (37.7%). Some of the outcome measures used were thought to be of limited value.

It was interesting to note how few of the outcome measures were tailored to social care and social-care-related quality of life. Instead, most measured clinical and health-orientated aspects of care.

There is a need for further research on the ability of the outcome measures to measure what they are meant to measure in the context of a care home. Having a central place (repository) to keep the information from outcome measurements from research studies so that they can be used again could help to work on improvements to outcome measurements.

Quality of life is important to care home residents, but it is hard to measure. Instruments may not be sensitive enough to detect differences over time or between care homes and self-reported outcomes from residents might not be reliable, especially for those with cognitive impairment. Therefore, it is essential that outcome measures are designed inclusively to enable participation and allow for both self-report by residents and, although not ideal, report by others on their behalf.

The variety in approaches to assessment undertaken by researchers is not helpful in practice, especially when so many outcome measures have only been used once in research and findings cannot be compared across studies.

Strengths and limitations

Strengths of this review include the systematic approach taken to studying measurement across a range of different studies and how findings were grouped.

Limitations include the fact that studies were mainly undertaken in higher income countries, and it is not clear whether they apply to lower income countries. Also, we cannot comment on the quality of the studies examined. We also only focused on resident outcome measures, not those related to the experiences of staff and residents. Of note, these findings focus on outcome measures reported in research papers and do not necessarily represent what matters to care home residents, relatives and staff in day-to-day care delivery in care homes.

What did people working in care homes think of our findings?

"Lots of the outcome measures chosen by researchers aren't routinely used in care homes and staff wouldn't be familiar with them. Were care home managers and staff consulted when researchers chose the outcome measures – and if not, why?"

"It seems like a lot of time and resources are wasted by using so many different outcome measures. If someone could decide which measures to use across the sector, we would use them and know that we were making everyone happy, including the Local Authority, the Department of Health and Social Care and researchers."

What did the family members of people living in care homes think?

"A lot of the domains and questions on some of these outcome measures don't seem connected to people living in care homes or older people. Are these the most suitable measures to capture changes over time for care home residents?"

Conclusions

Care home research is growing, but our findings highlight the wide range and inconsistent use of outcome measures by researchers. There is an urgent need to find outcome measures that are appropriate to use in care homes and can measure change over time, which are also valued by residents, relatives and staff. This requires a more collaborative approach to research.

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