

Care home residents' quality of life and its association with CQC ratings and workforce issues: the MiCareHQ mixed-methods study

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research, or similar, and contains language which may offend some readers.

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Scientific summary

The MiCareHQ mixed-methods study

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Scientific summary

Background

Over 425,000 older people in England live in care homes because they have significant long-term health problems. Many are living with dementia. The Care Act 2014 (Great Britain. *The Care Act 2014*. London: The Stationery Office; 2014) emphasises the importance of measuring and improving the well-being of social care users. However, there is no single, agreed minimum data set in the UK, making it difficult to measure and monitor the health and social care outcomes of residents as a quality indicator.

To ensure the quality of care provided and to inform public choice, care homes are regulated by the Care Quality Commission (CQC). Inspection reports and quality ratings are publicly available, with homes awarded a quality rating ('outstanding', 'good', 'requires improvement' or 'inadequate'). The most recent system rated around one-fifth of homes as 'inadequate' or 'requires improvement'. There is very little evidence concerning how well these ratings are associated with residents' quality of life and the characteristics and employment conditions of the workforce.

Care home quality varies for many reasons, but the nature and characteristics of the workforce, and the approaches of that workforce to care, are likely to be major determinants. Although a small body of literature exists on the impact of workforce characteristics (e.g. staff turnover) on care home quality, most of this literature is US based and focuses on clinical markers of quality or other process measures and not on residents' quality of life. Furthermore, there is very little statistical evidence in England linking skill mix and training levels with care quality outcomes.

Rigorous and reliable methods are needed to understand how well residents' needs are being met. The Adult Social Care Outcomes Toolkit (ASCOT) is a suite of tools for measuring the aspects of quality of life that may be supported by social care. We call this 'social care-related quality of life' (SCRQoL). ASCOT offers different modes of completion, including a mixed-methods approach to measuring SCRQoL in care homes [Adult Social Care Outcomes Toolkit Care Homes, four levels (ASCOT-CH4)]. This was designed to be used with residents who cannot self-report. Trained researchers collect evidence about SCRQoL through observations, conversations with residents and interviews with staff and family members.

ASCOT was designed to measure residents' current SCRQoL and also the impact of services (e.g. care homes) on residents' SCRQoL. However, it does not measure aspects of health, such as pain, anxiety or depression, that are reported to be under-recognised and undertreated in care homes.

The Measuring and Improving Care Home Quality (MiCareHQ) study focused on care home quality. It brought together three interlinked strands of work to examine the relationship between care home residents' health and quality of life, regulator quality ratings and the skill mix and employment conditions of the workforce.

Objectives

Specifically, the study aimed to:

1. develop and test measures of pain, anxiety and depression for residents unable to self-report
2. assess the extent to which the CQC's quality ratings are consistent with indicators of residents' quality of life
3. assess the relationship between aspects of the staffing of care homes and the quality of care homes.

Methods and results

The aims of the study were addressed through a mixed-methods design involving three interlinked work packages.

Ethics approval was required for the primary data collection undertaken in work packages 1 and 2. The study received ethics approval from the Health Research Authority, which governs research ethics in the UK (reference 18/LO/0657). As this was a social care study, approval was sought from and granted by the Association of Directors of Adult Social Services and each participating local authority.

Public involvement and engagement strategy

Public involvement and engagement was an integral part of the study and was delivered in the following ways:

1. Study Steering Group – two members of the public with experience of social care were recruited to the Study Steering Committee as lay representatives.
2. Co-researchers in work package 1 – we recruited three lay co-researchers to assist with the focus groups with staff and to contribute to the development of the new measures of pain, anxiety and depression. This is described in detail in *Chapter 3* of the main report.
3. Contributions to study outputs – lay advisors from the Study Steering Group contributed to the drafting of the *Plain English summary* of this report and reviewed it for quality and clarity of writing. The co-researchers from work package 1 co-authored *Chapter 7* of the main report.

Work package 1: measures

Methods

A rapid review of existing measures, with a particular focus on tools already incorporating observational methods, was undertaken to inform the development of items of pain, anxiety and depression to be used alongside the ASCOT-CH4. Three focus groups with care home staff were held to (1) identify how staff recognise when residents are in pain or are feeling anxious or depressed; (2) identify the words staff use to describe residents' anxiety, pain and depression; and (3) review draft questions on pain, anxiety and depression.

Following the focus groups, the measures were revised and cognitively tested with a sample of staff and family members of care home residents ($n = 37$) using a combination of verbal probing techniques and thinking aloud. Lay co-researchers were involved in the focus groups and subsequent revisions of the new measures.

Results

The rapid review, reported in *Chapter 2* of the main report, yielded 196 unique papers on pain tools and 166 unique papers on anxiety and depression tools after duplicates were removed. The titles and abstracts of all of these papers were then reviewed for relevance and adherence to inclusion criteria. In the final review, 26 papers were included for pain measures and 22 papers were included for measures of anxiety and depression, yielding 22 tools for each. The review revealed that most tools relied on a maximum of two modes of data collection (e.g. self-report, proxy or observation). Tools developed for people living with more severe dementia often rely on proxy and observation, thereby excluding the person's own voice. Very few anxiety and depression tools had been developed for people living with more severe dementia. None of the existing tools estimated the impact that care homes have on residents' pain, anxiety and depression. Informed by the review, the research team drafted questions and response options for each domain (pain, anxiety and depression), following the approach used in ASCOT.

Twenty-two care home staff took part in the three focus groups (see *Chapter 3* of the main report). Most of these were care workers ($n = 11$) or care home nurses ($n = 6$); two were managers and three had other roles in the home (e.g. activity co-ordinators). Staff were able to describe the verbal and non-verbal (behavioural) signs of pain, anxiety and depression among residents, which helped us conceptualise the observable indicators relevant to our tools. Staff felt that residents rarely used terms that had clinical connotations, such as 'depressed', and preferred more colloquial terms, such as 'low mood' or 'feeling sad or down'.

We conducted three iterative rounds of cognitive interviews with 21 care home staff and 16 family members. Cognitive testing led to two important changes: (1) the outcome states were no longer anchored to 'never' because staff and family members felt that everyone feels anxious or down or experiences pain some of the time; and (2) the depression domain was renamed as low mood, reflecting the emphasis on quality of life rather than on clinical or diagnostic criteria. The question wording, response options and observational guidance were finalised for the three new items of pain, anxiety and low mood, which were to be piloted alongside the ASCOT in work package 2.

Work package 2: psychometric testing

Methods

We undertook primary data collection to pilot and psychometrically test the new items and to explore the feasibility of the mixed-methods approach (see *Chapter 4* in the main report), recruiting 182 residents from 20 care homes for older adults (10 nursing and 10 residential) from four local authorities in South East England. To explore the construct validity of the new domains of pain, anxiety and low mood, questionnaires also contained staff-rated validated scales and items relating to these concepts so that we could explore the hypothetical relationships of these with the new attributes in the analysis.

Results

An examination of missing data revealed that the mixed-methods approach was necessary, and there was also tentative evidence of its feasibility. As expected, numbers of missing data were large for resident self-report interviews, with fewer than one-quarter of residents responding to any single item of the structured interview. However, data were still collected through qualitative interviews, observations and proxy interviews, which informed final researcher ratings, and so every resident had a rating for all items.

There was good evidence of the construct validity of the three new items for both 'current' and 'expected' ratings, meaning that they appeared to be capturing the constructs we intended. Psychometric testing revealed that, although the eight items of the ASCOT-CH4 formed a single unidimensional measurement scale, the three new items did not. This was expected, as the concepts captured by the new items (i.e. pain, low mood and anxiety) relate to aspects of health-related quality of life, which is distinct from the ASCOT construct of SCRQoL. Analysis also revealed that pain did not fit well into a measurement scale alongside low mood and anxiety. Taken together, these results indicate that the three items are better conceptualised as separate 'modules' that relate to the concepts of psychological health and pain, which may be added flexibly alongside ASCOT-CH4 (as a separate scale), with low mood and anxiety combined and pain standing alone.

Work package 3: care home quality

Methods

First, we combined data from two studies to examine the relationship between CQC quality ratings and residents' SCRQoL, controlling for confounding variables. The first study used data collected in work package 2 of MiCareHQ (see *Chapter 4* of the main report) and the second was a previous study, Measuring Outcomes Of Care Homes (MOOCH; see *Chapter 5* of the main report). Both studies had a cross-sectional design, in which researchers spent time in each care home and used the ASCOT-CH4 to

carry out observations of and interviews with staff and (where possible) residents and family members. Additional data about residents were collected from staff using questionnaires, including demographic information, health status and ability to complete activities of daily living.

Next, we conducted an analysis of secondary data of English care homes from 2016 to 2018 to model the relationship between CQC quality ratings and workforce characteristics. We focused on the effect that training provision for staff and staff terms and conditions (wages and turnover/vacancy rates) had on the quality of care homes. All of these variables, which can be affected by policy, are expected to be important determinants of quality. We used the following econometric methods to assess the relationship between quality and workforce characteristics: longitudinal panel data models, multiple imputation to address missing data, and an instrumental variable approach to control for potential endogeneity between quality and workforce characteristics, in particular staff wages.

Results

As described in *Chapter 5* of the main report, we found a significant positive association between residents' SCRQoL and CQC quality ratings. Everything else being equal, homes rated 'good' or 'outstanding' were associated with a 12% improvement in mean current SCRQoL among residents who had higher levels of dependency. Although care homes generally met the residents' needs in basic aspects of care, 'good' and 'outstanding' homes made a meaningful difference to those aspects of residents' lives that add quality to their days: feeling in control, being engaged in activities, being socially fulfilled and being treated with dignity.

Using the national sample of care homes ($n = 12,052$ observations of 5555 care homes), we found a significant positive association between wages and the prevalence of training in both dementia and dignity-/person-centred care and the likelihood of higher quality, whereas high staff turnover and job vacancy rates had a significant negative association. This was particularly true for wages, as we found that a 10% increase in the average care worker wage increased the likelihood of a 'good' or 'outstanding' rating by 7%. This is reported in *Chapter 6* of the main report.

These findings are of significant interest to the public, prospective residents, family members, care providers and the care regulator, the CQC.

Conclusions

Improving working conditions (e.g. wages and training) and reducing staff turnover is one way to increase care quality and outcomes for residents. This is particularly important for care home residents with the greatest needs, who gain the most from homes rated 'good' or 'outstanding', especially with respect to social participation and feeling in control of their daily lives. However, measuring their needs and outcomes is challenging, as many cannot self-report. We have presented a robust method of measuring the SCRQoL of care home residents, using the ASCOT-CH4. We found this methodology to be feasible and the eight ASCOT items formed a unidimensional scale of SCRQoL. We applied this methodology to new domains of pain, anxiety and low mood and found that the mixed-methods approach could be applied to these domains, while still capturing the underlying constructs. The three additional domains could be used alongside the ASCOT in future to capture the impact of care homes on these important health-related aspects of quality of life.

This study has demonstrated the need for the systematic and consistent collection of data on residents' outcomes (e.g. SCRQoL) as an important indicator of care quality. This important evidence gap is being addressed in the ongoing Developing resources And minimum data set for Care Homes' Adoption (DACHA) study (<http://dachastudy.com/>; NIHR127234), which aims to develop and pilot a prototype minimum data set of care homes in England.

Implications for social care

- Potential mechanisms for improving residents' outcomes are strong leadership, a focus on continued quality improvement and a culture of care that gives staff time to listen to residents and meet their needs with compassion.
- This study found a strong and positive relationship between staff training and wages and care quality ratings.
- There is a need for the systematic and consistent collection of data on care home resident outcomes to allow a robust quantitative analysis.
- It is important to use innovative methods to capture the views and experiences of those with the greatest needs.

Recommendations for research

Future research should:

1. consider using a mixed-methods approach to data collection in care homes that includes the voices and experiences of those unable to self-report
2. explore the relationship between pain, anxiety and low mood and other indicators of care home quality
3. explore the impact of bottom-rated ('inadequate') and top-rated ('outstanding') homes on residents' outcomes
4. assess the productivity of staff by examining the relationship between resident outcomes and staffing characteristics and employment conditions (e.g. wages and training) directly.

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