

Using Palliative Care Needs Rounds in the UK for care home staff and residents: an implementation science study

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Scientific summary

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Scientific summary

Background

Despite high levels of morbidity and mortality, care home (CH) residents do not always have adequate access to specialist palliative care (SPC). Residents can experience uncontrolled symptoms, poor-quality deaths and futile/burdensome hospitalisations. CH staff can feel unprepared and unsupported to look after residents at end of life. Although models exist for improving end-of-life care in CHs, these are primarily focused on education and do not adequately triage residents to focus on those most at risk of dying without a plan in place and rarely integrate clinical care. A clinical innovation in Australia called 'Palliative Care Needs Rounds' (hereafter 'Needs Rounds') combines triaging, with anticipatory person-centred planning, case-based learning and case conferencing. The approach has been synthesised into a checklist to provide guidance to clinicians running Needs Rounds. In Australia, Needs Rounds reduced length of stay in hospital and number of admissions, increased dying in preferred place, improved symptoms at end of life and normalised death/dying to CH staff. CH staff felt more confident looking after the residents. Preventing hospital admissions saved AUD\$1.7 million over a year (nearly £1 million).

Aim

To co-design and implement a scalable UK model of Needs Rounds, which takes account of the different policy/practice context in the UK.

Objectives

The *implementation objectives* were to:

1. co-design a UK version of Needs Rounds, which is responsive to different contextual characteristics of the UK CH sector (Phase 1)
2. implement the adapted model of care, assess feasibility, acceptability and effectiveness and ultimately propose how the model of care can be further refined and adopted in the UK context, to reap the benefits demonstrated in the Australian work (Phase 2).

The *intervention objectives* were to:

3. determine the transferability of the core elements of the Australian Needs Rounds intervention in the UK context (Phase 1 and 2)
4. delineate the mechanisms of action that enable more effective palliative and end-of-life care practices to be applied in UK CHs (Phase 2)
5. identify the relationships between (1) the mechanisms of action embedded in Needs Rounds, (2) how these mechanisms function in different CH contexts and (3) the outcomes arising for different stakeholders and parts of the care system (Phase 2).

The *process evaluation objectives* were to:

6. document the outcomes of UK Needs Rounds on hospitalisations (including costs), quality of death/dying and CH staff capability (Phase 2)
7. assess and report the perspectives of CH residents, relatives, CH staff and palliative care staff on using UK Needs Rounds (Phase 2).

Methods

A pragmatic critical-realist implementation study using the integrated Promoting Action on Research Implementation in Health Services (i-PARIHS) framework. We determined what works, for whom and in what circumstances for the UK Needs Rounds model. Implementation was conducted in six case studies, where a case is defined as a SPC service working with three to six CHs each.

Phase 1: development of an initial programme theory

Inclusion criteria: SPC or CH staff in one of the six sites; residents or relatives of someone residing in one of the CHs; worked in a role supporting CHs (acute care, the ambulance service or primary care); and had capacity to consent.

Participants and methods: stakeholder interviews ($n = 28$) across the six cases were used to develop an initial programme theory. Subsequently, we ran four online workshops to co-design UK Needs Rounds with key stakeholders ($n = 43$).

Analysis: Inductive thematic analysis was applied to the interview data, using NVivo for coding. Integrated Promoting Action on Research Implementation in Health Services informed subsequent deductive analysis, categorising the data into contexts, mechanisms, outcomes and innovation components. Chains of inference were identified, and context, mechanism, outcome configurations generated.

Outputs: Five theories and an initial programme theory to be tested during implementation.

Phase 2: implementing, adapting and evaluating United Kingdom Needs Rounds in the six case study sites

Inclusion criteria: interviews – SPC clinicians or a CH staff member in one of the sites; research team member for patient and public involvement and engagement (PPIE) evaluation. Capability to adopt a palliative approach (CAPA) – CH staff members in one of the six sites; Quality of Death and Dying Index (QODDI) for all CH-deceased residents; CANHELP Lite – relatives of someone discussed at Needs Rounds.

Participants and data: interviews, $n = 58$ CH and SPC staff; PPIE evaluation, $n = 11$; CANHELP Lite questionnaire, $n = 13$ relatives; CAPA, $n = 171$ CH staff; QODDI, $n = 81$ CH staff; fidelity, $n = 14$ Needs Rounds recordings. Interviewees in Phase 2 had not been interviewed in Phase 1, but participating hospices had staff involved in both Phase 1 and Phase 2 interviews.

Analysis: Qualitative data were analysed inductively using thematic analysis and coded using NVivo and organised in line with the five theories derived from Phase 1. Deductive and retroductive analysis were used to formulate the data into context, mechanism, outcomes and identify causal forces of generative causation. Data sources were triangulated in analysis to aid development of the theory. Chains of inference and connectors between and within the initial theories were subsequently refined and integrated to produce the final programme theory of implementation for the UK context.

Capability of adopting a palliative approach (CAPA) was analysed using generalised least squares random-effects models with robust standard errors; regressions were conducted for overall CAPA scores and for each individual CAPA item, and a paired t -test was conducted using the subset of CH staff members with multiple responses.

The QODDI analysis was conducted using QODDI10, a subset of the QODDI questionnaire, which included 10 items. Due to large numbers of missing data, QODDI10 was selected to preserve the largest proportion of the sample with complete responses (92.6%).

Family perceptions of care analysis used descriptive statistics for the family perceptions (CANHELP Lite) survey due to the small sample size.

Fidelity was assessed through a random sample of 20% of all audio-recorded Needs Rounds to determine adherence to the agreed approach developed in the workshop. A three-tier scoring system, of 1 (high adherence), 2 (moderate) and 3 (low), was adopted.

Estimating the treatment effect on health service outcomes was conducted using descriptive statistics for number of hospital admissions and number of hospital bed-days.

Estimating the cost effectiveness (cost-benefit analysis) was not possible due to insufficient data. Qualitative interview data were used to describe costs associated with Needs Rounds.

Outputs: A programme theory of what works for whom under what circumstances with Needs Rounds in the UK, an implementation translation package, and policy briefing.

Patient and public involvement: three lay people were coinvestigators and contributed to protocol development, ethics paperwork, topic guides for Phase 1 and 2 interviews, content development and participation/co-facilitation at the coproduction workshops, data analysis and dissemination outputs including newsletters, blogs, Twitter, journal articles, conference abstracts and this funder report. Training and support were provided to PPIE members.

Results

Phase 1: five theories were generated focusing on

(1) Confidence and competence, (2) reducing hospitalisations, (3) interagency working and collaboration, (4) better-quality lives and deaths and (5) supporting families. These were integrated to produce one initial overarching initial programme theory to be tested during implementation.

Phase 2: primary outcome

Needs Rounds resulted in increased CH staff confidence and competence to support residents in their last months of life. Sector-wide workforce issues and associated impacts on time and resources, however, shaped the scale of change, with CHs often being limited in the number and type of staff members being able to attend.

Improved relationships were forged between CH and SPC staff. The facilitation approach was a key mechanism for this and was based on developing collaborative, reciprocal relationships where complementary expertise was harnessed. Increased confidence improved communications between CH staff and general practitioners (GPs).

Better-quality death and dying resulted from proactive discussions and action plans regarding residents' physical, psychosocial and spiritual needs. CH staff reported that families felt more informed and secure in the care their relatives received.

Fidelity to the coproduced UK model of Needs Rounds was variable. An assessment of a random selection identified that many sites achieved low scores despite qualitative interviews providing evidence of managing to achieve important outcomes.

Facilitation approaches were collaborative and involved gentle work in determining people's current knowledge and areas for extending insights as well as which residents were appropriate to discuss. Managers were key facilitators in enabling staff to attend Needs Rounds, through rotas or paid overtime.

The programme theory of what works for whom under what circumstances is as follows:

While care homes experience workforce challenges, like high turnover and recruitment difficulties, exacerbated by poor pay and conditions, staff have variable skills and confidence and sometimes having insufficient support within the wider healthcare system. Needs Rounds can provide care home staff and specialist palliative care staff with the opportunity to collaborate during a protected time, to plan for residents' last months and weeks of life. Flexibly arranging Needs Rounds to suit care home needs, having manager buy-in and building collaborative relationships can help to encourage time to be protected. Needs Rounds augment existing practice by building care home staff confidence for those who attend and prompting anticipatory planning and care. A facilitation approach that is responsive to the difficult context in which care homes operate can improve collaboration. Needs Rounds can strengthen relationships and trust and shift power dynamics between care home and hospice services by harnessing complementary expertise. Integrating learning into Needs Rounds strengthens understandings of the dying process, symptom and pain management, advance/anticipatory care planning, and communication mechanisms between care home staff, families, specialist palliative care staff and primary care. This leads to high-quality resident-centred care, enabling residents to be cared for and die in their preferred place. Needs Rounds also benefit relatives by increasing their confidence in care quality and care home staff, by providing timely expert input.

Secondary outcomes

Capability of adopting a palliative approach: Questionnaires were returned by 171 CH staff members. Questionnaires completed later in the study achieved higher CAPA scores, indicating that CH staff increased their confidence as Needs Rounds progressed. Staff in not-for-profit homes had higher scores than those in private CHs; care staff and other staff had lower capability scores than managerial staff. Working in a larger CH (50 + beds) compared to a medium CH (11–49 beds) was associated with lower CAPA scores.

CANHELP Lite: Thirteen surveys were completed. Family members were largely satisfied with the care provided to their relatives and least satisfied with care provided by doctors.

Estimating the treatment effect and cost effectiveness: There was an increase in CH bed-days in hospital (from 1.6/1000 to 2.2/1000) and nights in hospital (from 9.9/1000 to 14.9) from baseline to follow-up. The small sample size ($n = 5$) and confounding nature of COVID-19 meant it was not possible to test for statistical significance. These factors also meant it was not possible to compute the cost effectiveness of Needs Rounds. Qualitative data indicate several costs including the opportunity costs of CH staff time spent in Needs Rounds meetings, travel costs for SPC staff and medicine costs.

Patient and public involvement and engagement: PPIE members were fully integrated into the team. They were meaningfully involved from the outset and made key contributions to the study. Relationship building was a core mechanism that made the PPIE members feel valued; this was facilitated through regular communications and monthly debriefs for support and a relationship dynamic based on equality and mutuality. Many of the academic team members also had lived experience of supporting relatives in CHs and/or receiving palliative and end-of-life care. This enriched the team dynamic without invalidating the contributions of the PPIE members.

Care home participation: Low data returns were observed for all quantitative measures. A range of factors impacted CH staff ability and desire to return data to the research team. Conducting complex data collection while CHs were in intermittent lockdowns, experiencing extreme staffing shortages, and being asked to complete bespoke tools all acted as barriers to high levels of data collection.

Limitations

Key contextual factors impacted implementation of Needs Rounds and data collection. Needs Rounds delivery took place during 2021–2 when COVID-19 lockdowns continued to occur both locally and

nationally, which significantly impaired implementation. This resulted in core parts of the intervention not working, namely the case conferences with family members and multidisciplinary team meetings. COVID-19 also reduced the amount of data returned for analysis; the resulting small sample sizes limited the power of claims we can draw from the data.

Conclusions

Needs Rounds improve palliative and end-of-life care for CH residents by enhancing staff skills and confidence, communication between CH staff and GPs and relationships with SPC clinicians. Needs Rounds result in more proactive support for residents and communications with families. These findings complement the robust evidence base on Needs Rounds in Australia.

The facilitation approach was central to implementation. Needs Rounds worked well when SPC clinicians and CH staff adopted a collaborative, partnership approach and recognised and used complementary expertise to improve the quality of lives and deaths of residents.

Implications for health care

1. Future work should focus on the sustainability of Needs Rounds to ensure equitable access to SPC for CH residents, engaging with commissioners and policy-makers to secure funding to integrate and embed Needs Rounds into CHs across the UK.
2. Increased CAPA scores demonstrate that Needs Rounds improve competence as the intervention progresses. CH managers should ensure that care staff are able to attend Needs Rounds to benefit from the intervention; larger CHs should include a range of staff to improve staff confidence and competence across the workforce.

Recommendations for future research

1. Enhancing the UK evidence for Needs Rounds would involve calculating the cost-benefit analysis and treatment effect.
2. Future research could examine how Needs Rounds run alongside primary care.
3. Semistructured interviews exploring families' and residents' perspectives of UK Needs Rounds would provide a fully rounded account of the impact of the approach to care, which was not possible given the limitations of COVID-19 during this study.
4. A follow-up study evaluating how much knowledge and learning is retained and applied by those attending Needs Rounds would provide evidence regarding the long-term impact on staff, including staff moving to different CH providers.

Study registration

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