The development, implementation and evaluation of a collaborative end-of-life care intervention for care homes.

BACKGROUND

Improving end-of-life care (EoLC) for older people living in care homes is recognised as a priority for health and social care globally (Broad et al., 2013; World Health Organisation, 2011). Within England and Wales, more than a quarter of a million people 65 years of age and older are currently living in residential care (Office for National Statistics, 2014a). Increases in the age of the general population are reflected in care home residents, with greater numbers of residents aged 85 and over, many of whom are approaching end-of-life (EoL) with complex symptoms and multimorbidity (World Health Organisation, 2011). This presents additional challenges to care home staff who deliver EoLC. Whilst the current thrust of policy is towards choice regarding individuals’ preferred place of dying (Department of Health, 2008; Department of Health Social Services and Public Safety, 2010; NHS Scotland, 2008; Welsh Government, 2013), many care home staff lack training and confidence in EoLC and may choose to transfer their residents to hospital rather than trying to manage their needs within the care home (Livingston et al., 2012). This may be contrary to the wishes of older people and their family, may cause distress and compromise dignity, and could place an unnecessary burden on resources in the acute sector. The Palliative and end-of-life care Priority Setting Partnership (PeolcPSP) recently identified honouring choice regarding place of death, even outside working hours, as the top priority in palliative and EoLC research (Palliative and end of life care Priority Setting Partnership, 2015).
The End-of-Life Care Strategy (Department of Health, 2008) and subsequent EoLC initiatives have demonstrated the benefit of implementing palliative care interventions within care homes (Kinley et al., 2013). The most significant initiative within the UK is the gold standard framework for care homes (GSFCH) which has now been implemented internationally (Hall et al., 2011). Evaluations of the GSFCH have demonstrated an increase in staff knowledge and confidence and improvements in communication regarding EoL (Badger et al., 2012; Hall et al., 2011; Watson et al., 2010). Implementation of the GSFCH has also been shown to reduce the number of inappropriate hospital admissions (Badger et al., 2009; Finucane et al., 2013; Hockley et al., 2010); overall the number of residents dying within their care home in England and Wales has increased while the number of people dying in an acute setting has dropped (The National Council for Palliative Care, 2014). However, evidence suggests that overall quality of EoLC within care homes has not improved (Office for National Statistics, 2014b). The Neuberger review into the Liverpool Care Pathway (LCP), “More Care, Less Pathway” highlighted ‘considerable inconsistencies in the quality of care for the dying’ and recommended improved quality of EoLC as a priority for NHS England in the next Mandate (NHS England, 2013). The report states that adequate training and support are key to ensuring the workforce have the knowledge and skills to deliver good EoLC. A recent systematic review of literature regarding care home staff education and training underlined a need for care homes to receive support in order to ensure residents are able to receive EoLC in their place of choice (Means, 2016).

Staff within care homes report a strong commitment to improving care for their residents (Turner et al., 2009) but good EoLC is hindered by a lack of collaborative
working both within the home and with external agencies such as specialist palliative care teams (Badger et al., 2012; Livingston et al., 2012; Turner et al., 2009). Multidisciplinary communication and working has been highlighted as a fundamental feature of quality EoLC within care homes (Addicott, 2011). Following a “Refreshing the Strategy” conference in 2013, the National Council for Palliative Care published the overarching themes for improving future EoLC, which include a focus on ensuring ‘professionals feeling supported and able to learn and to care’ (The National Council for Palliative Care, 2014).

This study arose out of a wider local strategy between a large acute teaching hospital and a number of community providers to improve and support EoLC for patients. The study sought to develop a collaborative intervention with care homes and their local NHS Foundation Trust, with guidance from local hospices. The study design was guided by doctors and nurses from the acute hospital and local hospices, nursing home managers and a local higher education institution. The aim of the study was to (1) Increase the confidence and competence of care home staff in EoLC; and (2) Enable more residents the opportunity to experience EoLC in their care home rather than an acute setting.

METHOD

Sample

An audit within the NHS Foundation Trust identified care home residents who had died in the hospital between 1st October 2011 and 30th September 2012. The twelve care homes which had referred the greatest number of residents were identified. The managers at the six care homes who had referred the greatest number of residents -
two of which offered residential care with nursing support and four without nursing - were sent a letter inviting their care home to participate. The remaining six homes were not contacted but served as a comparison group in terms of audit data following the intervention. All six care home managers who were contacted expressed an interest in participating in the project. A researcher from the University of Surrey and a Senior Specialist Nurse in Palliative Care from the participating NHS Foundation Trust visited the care home to meet the manager, answer questions and gain approval for the project to be conducted within their care home. All the care homes had robust local hospice support available, though the extent of hospice input during the study was not collected.

**Design**

A two-phase Exploratory Mixed Methods Design (Cresswell et al., 2011) was employed. This design is characterized by an initial phase of qualitative data collection and analysis (the development and implementation of the intervention) followed by a phase of quantitative data collection and analysis (evaluation of the intervention).

**Phase 1: Development and implementation of the intervention**

Phase 1 entailed five discussion groups including 24 care home staff from two participating care homes; one which offered residential care with nursing support and one without nursing. Appreciative Inquiry (Watkins et al., 2000) was employed within the discussion groups, an approach that can be used within organisations to locate best practice and to bring about change, requiring a move from a problem-orientation to an appreciative stance. Care home staff were encouraged to reflect on what they felt they currently did well in terms of EoLC, to imagine how they could improve their
EoLC, to determine changes that need to be made in their practice and identify their training needs. Discussion groups were facilitated by a researcher and a palliative care specialist, were held within the care home and lasted for one hour. Each group was audio-recorded and transcribed. A framework analysis (Ritchie and Spencer, 1994, Ritchie, 2013) of discussion group data informed the development of an EoLC toolkit which covered five key areas where care workers had highlighted they could benefit from support this included –

1. Clarity about ‘end-of-life’ - How will I know if the person I am caring for is nearing the end of her/his life?
2. Communication - How can I talk to people in my care and their families and friends about end-of-life-care and their feelings and wishes?
3. Considering symptoms - How can I make sure that the person I am caring for is comfortable?
4. Coordination of care – Who do I work with and contact for advice and support when I am unsure how to respond?
5. Compassion and dignity - How do I give compassionate end-of-life-care?

Based on the discussion group data, the EoLC toolkit was designed by the project team and the expert steering group (two doctors working in local hospices, two geriatricians working within the participating NHS Foundation Trust, and an academic specialising in cancer and palliative care); and delivered by a Clinical Nurse Specialist in Palliative Care, with support from a researcher and senior lecturer with expertise in communication skills training (the toolkit can be found at http://www.surrey.ac.uk/fhms/research/centres/ICE/research/). Three training
sessions of one hour each were delivered within each care home: 1) An introduction to the toolkit, and a session on compassion; 2) A session on communication and EoLC; and 3) A session considering EoL symptoms. Eighteen training sessions were conducted within the six care homes during a 3-month period (14th August to 21st November 2013), these sessions involved a total of 54 staff (between 4 and 9 staff participated in each session).

**Phase 2: Evaluation of the intervention**

A pre- and post-intervention evaluation design was used. The intervention was evaluated in line with study aims: 1) The confidence and competence of care home staff in EoLC was measured using staff survey data pre- and 3-months post-intervention, and (2) The number of residents experiencing EoLC in an acute setting was determined by an audit of the number of residents who died in hospital from each participating care home over a five month period pre- and 3-months post-intervention.

The staff survey focused on areas of EoLC identified in the discussion groups or highlighted by the palliative care specialists within the research team and with permission from the authors, some questions were also adapted from a previous study of EoLC (McClelland et al., 2008). In addition to demographic information (position in care home, number of years’ experience, religion, country of origin, gender), the questionnaire asked staff to rate their confidence/competence in each listed area of EoLC including the management of 24 EoL symptoms (Table 3). The questionnaire offered multiple choice responses to reduce participation time and encourage a response. Respondents were asked to use a 4-point scale to indicate whether they ‘Agree Strongly’, ‘Agree’, ‘Disagree’ or ‘Disagree Strongly’ with each statement. When
evaluating the impact of the intervention, ‘Agree strongly’ was coded as ‘1’, ‘Agree’ was coded as ‘2’, ‘Disagree’ was coded as ‘3’ and ‘Disagree Strongly’ coded as ‘4’.

Questionnaires were distributed internally within participating care homes pre- and post-intervention. Post-intervention, the questionnaire was adapted to elicit which training sessions (if any) the respondent had attended as part of the project and whether they had completed the pre-intervention questionnaire. Due to the sensitive nature of the content, all questionnaires were completed anonymously.

Questionnaire and audit data were analysed with the aid of the Statistical package for the Social Sciences (SPSS) version 21. Analyses were primarily descriptive but the significance of pre- and post-intervention differences in questionnaire scores were explored using independent t-tests.

**Ethical considerations**

This study was carried out between 2011 and 2014. Ethical review and health and social care governance permissions were sought and received from the University of Surrey Ethics Committee (EC/2012/136/FHMS) and the Research and Development Department of the participating NHS Trust in the south of England.

**Results**

Data will be presented in two parts in response to study aims: 1) To increase the confidence and competence of care home staff in EoLC; and 2) To enable more residents the opportunity to receive EoLC in their care home rather than an acute setting.
To increase the confidence and competence of care home staff in EoLC

Pre-intervention (T1), 301 questionnaires were left for distribution within the 6 care homes receiving the intervention, 78 questionnaires were completed and returned. Therefore, the response rate at T1 was 26%; this ranges from 5% to 50% across the care homes. Of those respondents indicating their country of origin 67% (46/69) were British; of those respondents indicating their religion the majority (76%; 48/63) were Christian. Nearly all of the respondents (94%; 72/77) were female. Not every question was answered, explaining the variation in the numbers presented.

Post intervention (T2), 325 questionnaires were left within the six care homes receiving the intervention, 103 questionnaires were completed and returned. Therefore, the response rate was 32%; this ranges from 0% to 80% across the care homes. The majority of respondents recorded their country of origin as British (60%, 50/84), their religion as Christian (65%; 52/80), and their gender as female (89%; 81/91). Once again, not all questions were completed. Interestingly, 73% of respondents could not recall having completed a pre-intervention questionnaire (59/81). Table 1 indicates response rate by care home. A mean score was calculated for each question pre- and post-intervention, the lower the mean the higher the agreement with each statement. Table 2 indicates the pre- and post-intervention means for each statement regarding EoLC (Q1-Q14).

Following the intervention, there was a trend for staff to report feeling more supported both in terms of emotional and clinical support within the care home (Q8 & Q9) and feeling able to source external support (Q10 GP/DN; Q11 Hospice/PCN) even out of
hours (Q12). Staff confidence in managing each of the 24 EoL symptoms including pain management, addressing anxiety, nausea and vomiting and mouth care increased post intervention, however this trend did not reach statistical significance (Table 3). The results suggest that confidence in ability to discuss death and dying with residents was lower post intervention, although this change in confidence did not reach statistical significance ($t(173)=-1.95$, $P \geq 0.05$). Mean scores for questions 2 to 7 were reasonably stable suggesting that the intervention did not affect staff confidence in terms of discussing death and dying with the resident’s family, identifying EoL, or the creation of EoL care plans.

A brief evaluation form was distributed to staff following the final training session in each home; 86% (24/28) of responders indicated that they would like to complete more training sessions in this area.

**To enable more residents the opportunity to experience EoLC in their care home rather than an acute setting**

A comparison of a 5-month period before (December 2011 – April 2012) and after the intervention (December 2013 – April 2014) indicated a 59% reduction in the number of residents (from 22 to 9) who died in the local NHS hospital from the six participating care homes in comparison to a 21% reduction (from 19 to 15) from six comparison care homes who had not received the intervention. Table 4 gives details of the 12 care homes and the number of residents from each care home who died within the NHS hospital. The audit period is December to April at both time points in order to match for any seasonal affects in referral. No other variable was identified by the expert
steering group that could explain this reduction in hospital deaths from these homes. Figure 1 presents this information graphically.

Discussion

This study has demonstrated the feasibility of collaboration between care home staff and an NHS specialist palliative care team, with guidance from the acute hospital and local hospices, in developing and implementing an EoLC intervention which is targeted to the needs identified by care workers themselves. The aim of the study was to increase the confidence and competence of care home staff in EoLC and subsequently enable more residents the opportunity to experience EoLC in their care home rather than an acute setting.

Staff confidence in managing EoL symptoms increased post intervention. This finding is in line with an evaluation of the effectiveness of the Gold Standards Framework in Care Homes (GSFCH) and the Liverpool Care Pathway for the Dying patient (LCP) which also suggested improvements in symptom management following tool implementation (Watson et al., 2010). There is also a suggestion that care workers felt more supported both within the care home and in terms of accessing support externally following the intervention. Relational working between care home staff and with other healthcare professionals is important (Goodman et al., 2016), increased perceptions of support will hopefully enable the sustainment of any improvements in confidence and competence resulting from the intervention.

Confidence in ability to discuss death and dying did not improve following the intervention. Some staff will have had little previous exposure to death and dying and
it is understandable that they feel they lack confidence to discuss these issues with residents and relatives. A recent National Council for Palliative Care ‘Dying Matters’ survey of over 2,000 adults in the UK reported that 83% agreed that ‘People in Britain are uncomfortable discussing dying and death’ (National Council for Palliative Care, 2015). More than a fifth of the sample had ‘never heard of’ palliative care (22%), end-of-life-care (19%) or advance care planning (36%). Reduced confidence in discussing death and dying with residents post-intervention may indicate a greater awareness following training that EoLC is more complex than they may have first appreciated, or it may reflect an increase in more difficult conversations as a consequence of more residents remaining in the care home to receive EoLC post-intervention. Research suggests that while not all care home residents want to discuss their EoL preferences many of them do, yet these conversations are often missed (Towsley et al., 2015). Finucane et al’s study (Finucane et al., 2013) indicates that residents without a recorded preferred place of death were five times more likely to die in hospital. Care home staff require support to ensure they have the skills and confidence to initiate these discussions with residents and their families. The fact that 86% of participants in this study indicated that they would like to complete more training suggests that care home staff are receptive to interventions which improve their skills and knowledge in EoLC.

The result of this study demonstrate a greater reduction in the number of residents referred to hospital for EoL from care homes who received the intervention than from comparison care homes who did not receive the intervention. This is in line with the results of previous work which report a reduction in hospital admissions following interventions delivering educational sessions to care home staff on EoLC (Roberts,
2015) or facilitating geriatrician input into nursing homes (Lisk et al., 2012). Palliative care knowledge and practice within nursing homes is associated with a reduction in futile interventions/acute care use (Miller et al., 2015); targeting EoLC training and education to the needs of care home staff may reduce inappropriate admissions to hospital at the EoL. Such a reduction is important for many reasons:

- Preferred place of death should be sought and respected if possible for all individuals (Department of Health, 2008);
- There is evidence that satisfaction with EoLC is higher within care homes than in hospital (Office for National Statistics, 2014b);
- Survival rates following admission to hospital are low for people transferred from care homes (Ahearn et al., 2010);
- Residents commonly experience in-hospital complications (e.g. pressure ulcers and delirium) and invasive interventions (Dwyer et al., 2014); and
- There is an increasing pressure to reduce the costs associated with emergency hospital admissions (The King's Fund, 2010).

One of the challenges encountered during this study related to the ability to engage continually with care homes during times of leadership change. It is essential that care homes with changes in management or high turnover of staff are not excluded from research, interventions need to be flexible and facilitate inclusion where possible. It is necessary also to consider the sustainability of EoLC interventions, especially in a workforce which often has high turnover of staff. Finucane et al (Finucane et al., 2013) address the issue of sustainability and showed that even with reduced resources following their EoLC intervention, outcomes were largely sustained. The strength of
this study lies in the fact it engaged with care home staff from the outset to ensure that the intervention was designed to fit their needs and that it sought to build collaborations between care home staff and visiting health care professionals from the acute hospital and hospices, factors identified in a recent realist review as promoting effective healthcare for care home residents (Goodman et al., 2016).

**Limitations**

The reduction in hospital admissions for EoLC during the project has been interpreted as suggesting that more residents received EoLC within their care home as a result of the intervention, however it is possible, though unlikely, that there were simply fewer deaths during this period in participating care homes. Future studies should collect data on all deaths within participating care homes. It is important to note that not all hospital referrals for EoLC can be assumed to be inappropriate admissions, a review of each death would be required to determine this, which was not possible within the resources of the current study. These results do not report actual changes in EoLC as these are based on perceptions of the staff themselves. Future studies could use observations of EoLC and the experiences of the care home residents to measure the impact of EoLC interventions. This is a relatively small study including only one NHS Trust with only 6 care homes receiving the intervention, implementation across other trusts involving their local care homes would enable larger numbers of participants and subsequently more robust results.

**Conclusion**

The relational and ethical aspects of EoLC in care homes are of great significance and require reflection and support. The collaboration that resulted from this research
project enabled staff to identify areas requiring development in their knowledge and skills relating to EoLC. Raising staff awareness of key elements of EoLC in terms of symptom management, communication skills, the co-ordination of care and the values (for example, compassion and dignity) that underpin ethical EoLC are necessary precursors to advance care planning and communication with residents and relatives regarding EoL preferences. This study highlights the value of facilitating further collaborations between care home staff and specialist palliative care teams.

**Implications for practice**

- Evidence that regular themed meetings with care home staff, facilitated by palliative care experts from the acute sector provide a safe space to discuss difficult issues and build confidence in EoLC;
- The study suggests the need for sustained collaboration between care homes and the acute sector focusing on the preferences and best interests of residents; and
- Identification of the need for further research to explore additional strategies to ensure preferred place of dying is honoured as far as possible for residents of care homes.
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